

California State Council on Developmental Disabilities Survey Monkey Results: 5-year State Plan Needs Assessment

| | Response Count |
|--------------------------|----------------|
| <i>answered question</i> | 697 |
| <i>skipped question</i> | 415 |

3: In the areas you checked, describe the services and supports you need but have not received.

| # | Response Text |
|---|---|
| 1 | Housing, respite, and quality assurance of people providing services totally inadequate, especially for clients with significant behavioral or medical needs. Lack of proper training for people providing services; inadequate pay for people providing services |
| 2 | Independent living skills training. Better transportation options. |
| 3 | Milestone transportation to Vine Village. As well as impact for work at licit. If not eligible , then ask for help paying of for the Vine-go as a method of payment. That's all for now. |
| 4 | So far I have good support. |
| 5 | not receiving any services |
| 6 | I have not personally experienced this problem but have been in the industry for 30 years and would like to see some relief for regular based child care to help families have a break and avoid history repeating history. In our population many folks need consistent child care scheduled into there weekly routine to become effective to reduce frustration in their homes. |
| 7 | Early intervention to assist with learning skills that will help someone maintain a life after school and into adulthood. Community supports to provide housing, transportation and employment. Functional transportation to all areas of the county so people can get to work. |
| 8 | Stronger relationships with businesses and industry to support our efforts in the employment of individuals with intellectual and developmental disabilities. There needs to be an emphasis on employment at the Regional Center level with education and training to RC staff on Employment First, employment resources in the community, etc. Families and youth with IDD also need information about what resources are available to them after completion of secondary education. This needs to occur prior to the development of an Individualized Transition Plan (ITP) at the age of 16. It should happen at middle school age. The community also needs more information on self-determination. |
| 9 | Employment support services and quality job coaching have been very difficult for my brother to receive in the community. |

Survey Monkey Results

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| 10 | People on SSI or low incomes need housing they can afford. There is a tremendous lack of housing resources. Also, resources that are currently available are not well known. Need more education about early intervention. Need more details on self determination. |
| 11 | No housing for me. That I can afford might be homeless in July. Very hard to get around do not drive |
| 12 | Self determination |
| 13 | respite: we receive the hours but am not able to use them because it must be out of bed respite and there are little to no beds available for this service or the homes never respond to our Regional Center coordinator. If we can not find a bed the hours are just lost and we are not able to take advantage of the few hours we are supposed to get for respite to recuperate or do whatever we need to do with those hours without our special needs child. THERE NEEDS TO BE MORE OPTIONS AVAILABLE TO US SO WE CAN UTILIZE OUR RESPITE HOURS THAT WE SO DESPERATELY NEED! Housing: In regards to group/private housing for minors, the choice is limited and what is out there is awful 90%. There needs to be tighter reigns on these homes to assure that our children when they can not be in our homes for whatever reason are receiving the best possible care & attention and that all the services we are told are being provided are actually provided. There is a huge problem in this area that needs to be addressed immediately! |
| 14 | Many parents faced with transition to adulthood have very few resources to turn to for housing and employment |
| 15 | No facility is qualify to take care of my child with aggressive behaviors towrd swlf or others, thier aren't options when it comes to recreational oppoutunities. And school does not believe that my child can learn so they just baby sit him all day |
| 16 | We receive respite hours, but for the last year they have gone unused. It is challenging to introduce strangers to my autistic child as I try and find a good fit! My daughter passed away this year and we really could've used the help from a trust friend or acquaintance. I prefer Parent Vendered. |
| 17 | More ABA support for older kids/ adults |
| 18 | Special needs childcare assistance, respite caregivers that are available. Real support that actually follows through and completes task. More than just talking. |
| 19 | professional individual advocacy (e.g. advocate/lawyer who can assist through hearing process and at meetings when needed) |
| 20 | Housing; is told nothing is available, had to fight all the way through school just to get school to provide services they said they'd provide on IEP, if you don't agree with IEP "team" (district vs parent), you are outnumbered and if you cannot afford a lawyer or advocate, your kids are screwed, Regional Center service coordinators are uninformed/have no knowledge of what services are available - |
| 21 | More help with bus training adult summer programs |
| 22 | There are no support from SARC nor community. Our 27yrs old autistic son needs self care skill training, job job training, housing, |

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| | transportation , recreation & therapeutic facility. |
| 23 | My son was abused by his teacher in the special education classroom. We need to stop the culture of seclusion for our students with disabilities. We need safeguards in place to protect these students. Video cameras in classrooms and substantially better training for staff members. |
| 24 | My son needs to be educated in a job skill to become a productive member of the society. That skill would require ongoing support through education to not bore him. Housing is quite difficult, and where he will live continues to be a conundrum. How will he be successful without job skills and without housing. |
| 25 | Assistance getting my child supervision in the community. Respite is now IN HOME, IHSS is IN HOME seems like we are now institutionalizing children in our own homes. We are not getting help getting our child out into the community. |
| 26 | quality psychological or psychiatric visits when necessary on a regular basis and quality training and supervision for group home staff. |
| 27 | quality research based ABA services are still not provided or funded by the public schools or many regional centers. Employment is very difficult to find and resources to support that being successful are waitlisted . Meaningful programs to stimulate the minds and bodies during the day and weekends are too few |
| 28 | The ability to choose interventions and supports that meet our child's unique needs, not just the ones vendored by Alta Regional Center. Funded recreational activities that would benefit our child's social needs with support (e.g. camps, social groups, classes) Education tailored to the learning style of a child with Autism, such as skilled teaching in Executive Functioning. Tutoring and targeted teaching for Foundational subjects. Community Supports: legal advice and individual advocacy when issues arise in school, with regional center. |
| 29 | support for paid employment, affordable rent, better quality day programs. |
| 30 | mobility training, computer with JAWS on it. |
| 31 | Need more support health |
| 32 | My son is a young adult and is "high functioning" therefore he falls in the cracks as most programs are not a match, but since he uses a wheelchair he is precluded from a lot. There is basically nothing. As for housing - what housing? What recreation? These are people with the same basic needs as everyone else. It does not take a rocket scientist to figure this out. Why is it so hard? What do people think happens to the cute children with disabilities? They don't lost the disability at age 18. |
| 33 | unknown |
| 34 | Assisting an over 22 year old with job support, training, skills and supervision to live on his own. |
| 35 | Didn't qualify for regional center services |
| 36 | Support from schools to address needs such as intensive therapeutic services, in home behavior support, residential care & educational services, respite and EDUCATION & TRAINING for school administrators. They don't know how to assess, support or educate kids with unique needs. |
| 37 | Transportation. I have to drive him to school, all appointments, therapies, functions.. |

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| 38 | <p>Difficult as a working parent to arrange child care. Recreational opportunities are vendedored by some Regional Centers but not here in Orange County.</p> |
| 39 | <p>Everyone who supports people with disabilities need to continue to push for real employment opportunities. Regional Centers, cities and other organizations need to work together to develop many more affordable housing options for individuals who want to live independently. Service providers need to be funded at a rate that enables them to hire great staff that will stick around for a long time.</p> |
| 40 | <p>I wish I could check more than 3 boxes. I deal with many parents and caregivers who are struggling to get services for their higher functioning DD/autism individuals that do not have regional center services because they were found not eligible. They may have had spec ed services but their transition plans were very ineffective and did not adequately prepare them for work or post secondary education. Then they try and fail to engage with the state systems. Many get turned down for SSI even with repeated appeals. Many have not been able to access Dept of Rehab services because they are found "not ready for competitive employment". They don't know they can appeal. The repeated failures to access meaningful services beats them and their caregivers down and make them reluctant to re-engage. They don't fit anywhere in the systems, their caregivers don't know how to help them and are scared for their own and their adult's future. They live with their families or relatives and isolate themselves and become less and less functionally able to help themselves due to depression and/or inability to self-regulate their emotional state and physical needs. There's very little evidence-based practices research that addresses their needs as adults.</p> |
| 41 | <p>REAL Employment Opportunities, Housing, Transportation (not public transportation) so people get robbed.</p> |
| 42 | <p>My son just turned 22 last year and finished school December 2014, "adult life" is very new to us. He is in a day program that seems to be working. I am interested in self determination for him. We know that he will need a place to live with support. I would like to see him contribute to his community in some way.</p> |
| 43 | <p>Quality assurance the reason why I picked it because honestly believe that I need to be able to receive services within jobs. Housing to be able to afford a house and along with the housing cost. Employment now I notice that outside of program that their are people who are struggling to get jobs and this would concern me because their are also people with disabilities who struggle with socializing with others in the public environment.</p> |
| 44 | <p>There is no housing here for youth who cannot be at home. My 18 year old son had to go back to Canada for housing and financial support because we couldn't find it for him here. If he had been a foster youth here, there are a few housing opportunities. If he would have stayed here, he would have had to live on the street.</p> |
| 45 | <p>My daughter attends a sdc the aids are gone way to often, the aids spend a lot of time talking and being in the room but not to involved. I am concerned as a parent about what will happen after my daughter is 18. She is now 12 going into 7th grade but learning is at 3rd grade what services are offered after age 18. Also what re recreational activities are thier for special needs kids?</p> |
| 46 | <p>Never received child care. My child is not potty trained and is in need of childcare but it's hard to find/expensive compared to what it would be for typical child of same age.</p> |
| 47 | <p>Many clients cannot afford private advocates, they need to be able to have advocates go to IEP's and when client disagrees with regional</p> |

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| | center |
| 48 | Over night respite services. We never know until the last few days before the trip if we are able to get respite services. We have lost opportunities because we were unable to get respite. |
| 49 | there needs to be more outreach in all the areas checked |
| 50 | help with medical on paying for my strips |
| 51 | safety/abuse prevention - my children were allegedly/reportedly sexually/physically abused. RCOC keeps saying they are payer of last resort but fail to coordinate nor make appropriate referrals for community based programs. Child day care and respite care for disabled/language impaired children |
| 52 | NA |
| 53 | Of particular interest is out of home respite care, we are authorized for up to two weeks per year. We used to send our daughter to a "camp" but now those services are not available. That would not be an issue except that there are literally no other respite services available in our county. Therefore, we have lost out on out of home respite every year since the legislators made that change. |
| 54 | My son attended the county preschool program. The program did not have a qualified Special Ed Teacher that had any long time training/schooling in special ed. The first year of the program, my son was not taught preschool basics on a regular/weekly/daily basis. The second year of the program my son had substitute teachers 3/4 of the school year. These substitute teachers did not have special ed certification/background nor did they have any speech and language training or had worked with special ed children. Also this 2nd preschool year my son was not taught preschool basics on a weekly or daily basis. A typical day in the preschool special ed program consisted of recess, snack time and play with a little bit of circle or reading time, more recess. My son is now at the Kindergarten age and will be transitioning out of the preschool program and he is at a preschool entry level due to the issues of not having a proper special ed program at our county. Also, my son received very little mainstreaming as there was no mainstreaming program for over 1/2 of the second school year at his school. The county program was completely out of compliance! |
| 55 | Employment has been the greatest challenge since the economy took a dive. We have not been able to carve out jobs for our clients as employers are looking for individual who can multi task and make quick judgement. Transportation continues to be an issue for our clients to be fully included in their community, especially in our rural setting. Life stops after 5 and not on weekends. Continue to educate our clients to speak up for themselves, be given choices and stay safe. |
| 56 | Currently my daughter has access through her school and the regional center; she receives speech therapy and social skills therapy my daughter has autism and the services she will probably need are probably all of them but the 3 I chose are of most concern I just want to know she will have help and a place to live to learn to be independent and be happy and thrive these are my nightmares what is in store for my precious girl when I am no longer here for her |
| 57 | Early identification and access to early intervention services for infant/toddlers with developmental disabilities is too often delayed during |

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| | critical periods of development when intervention is most effective. Regional Centers are not consistent in responding to family calls for eligibility assessment for services, increasing the waiting period that delays intervention. The transition from Early Start to public education at age 3 is often not facilitated by case coordinators and school staff, again creating delays in access to services for young children. Community supports such as transportation services, respite for families are difficult to access. |
| 58 | My daughter's doctor's are all far away. They are required by ccs but you have to qualify certain conditions for help with gas. The wear and tear on my car, the mileage and the gas is enormous. Also, she turns 18 I need a conservatorship but it's to ridiculous to do on my own and it's too expensive through a lawyer. Would be nice if there was a program that assisted families with the legal stuff. |
| 59 | ABA Behaviorist Counseling |
| 60 | I see my clients struggle with getting jobs in the community that pay a decent wage. I see my clients struggle to find affordable housing in decent areas. Some waiting lists are 3-5 years long. Additional services are needed for transportation. It is extremely difficult to get temporary extra hours with a client when situations like medical issues arise where the client might need some extra assistance. Other services are needed for rare situations like a bed bug infestation. |
| 61 | Tailored day services, Respite, self- advocacy. |
| 62 | Transportation to out of town Special Olympics Electronic assistance when beyond clients abilities Companion/ care giver that gains relationship enough to escort insecure clients to outside activities with the goal of getting them comfortable enough to join program. |
| 63 | These do not necessarily apply to my son. His needs are minimal. But, I see others who need 24 hour care, and they need to be the highest priority, then others as money is available. |
| 64 | I do not need these services but I work with children with special needs and I meet with parents with adult children with special needs and I here that they are very concerned for their adult children with special needs in these areas. |
| 65 | I would like to see more employment opportunities in the rural areas for RC clients. Housing/Residential is a severe need for the current generation, but more so for the young adult generation. Our clients suffer from abuse, such as emotional, physical, mental, and sexual, so I would like there to be more opportunities for clients to be taught safety awareness. |
| 66 | Adequate housing and quality SLS support to live safely and happily. Social recreation including camp. Health care delivered by people who understand I/DD. |
| 67 | AST. BIS Child care |
| 68 | I am a Service Provider. I do not need the supports, but I see people with intellectual or developmental disabilities who have children needs |

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| | <p>additional supports. I am suggesting classes on child development and parenting, educational supports and household management. Of course, there is a need for meaningful employment as well as full time employment opportunities. Quality assurance is needed throughout this sector. First and foremost people with intellectual or developmental disabilities need to be treated as equals. Service providers should not be allowed to determine what time someone goes to bed, turns off the TV, turns in their cell phone or goes out into the community. There are many people who face challenges and roadblocks from those who provide supports. This can improve by providing a quality assurance program, having investigators, and providing regular and consistent training. Quality assurance ensures self-determination in an environment regulated by humans.</p> |
| 69 | At the present time we have our son in a group home. they struggle monthly on being able to give him the services he needs. |
| 70 | Qualified medical child-care options |
| 71 | Limited employment opportunities for people with severe disabilities |
| 72 | Need greater advocacy, education and available of services for appropriate health care and MUCH greater advocacy, education and availability of employment opportunities |
| 73 | There is very low availability of health care providers. Housing choices for low income individuals is becoming fewer all the time. |
| 74 | Give me a break... we're still asking the same questions |
| 75 | Respite, community park and recoup area that is friendly to my daughter's needs |
| 76 | IHSS. Not eligible because my wife and I don't work. I retired and unemployed so both my wife and I can focus on our son. But we need help! |
| 77 | I think individuals need to be more aware of Self-Determination and the rights and responsibilities that come along with it. I think more material and information needs to be made available to individuals about Self-Determination. I think we need to do a better job of educating the community and future employers about the benefits of hiring an individual with a disability. We need to share more success stories with our community to show employers that individuals with disabilities can be a productive member of their team. |
| 78 | No funding for any programs. My brother is 26 and has been neglected as a citizen of our state. He has been in programs that are disgustingly useless and we have had to fight to get him in a semi-formal workability program. This took years of fighting the city. NEED FUNDING --- NO BUDGET CUTS |
| 79 | More Mental Health counseling for individuals with special needs. |
| 80 | The State of CA needs more employment and training opportunities for individuals with intellectual disabilities. Community Colleges do not have enough specialized programs/classes available and students who exit out of the public school system at 22 are often left with few options (beneficial and productive options). Students with ID need more tailored day services that will open doors for them that previously would be closed due to stereotypes, lack of resources, supports, etc. Students with ID often want to be more independent, but the programs and services available to them are so limited that they do have an opportunity to really continue strengthening their independent living skills. |

Survey Monkey Results

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| 81 | Its really hard to keep good staff with the funding we receive. |
| 82 | We need more transportation services for the disabled. Besides Access, there are no other transportation services offered to the developmentally disabled. |
| 83 | Need socialization activities to teach skills and provide recreation outside home and school. Continue early start programs and fund special Ed in schools |
| 84 | Out of home respite. After school day care for disabled children of all ages. |
| 85 | Employment and Housing support are the services that my child needs to help him become independent and increase his self-esteem. Transportation for this population is limited and expensive. |
| 86 | Inclusion does not always happen and is greatly needed. In some places we are still in the broken down dumpster in the back of the school. Special Education needs to be fully funded. |
| 87 | The programs in the area generally close at three therefore working parents have to figure out what to do with our adult children when we don't get off until five or six. |
| 88 | Have not reached out for support previously |
| 89 | Employment It is very hard for my son to get a job |
| 90 | Appropriate placement |
| 91 | Lack of support in counseling for my son in high school. |
| 92 | Each of these of these are well-provided. |
| 93 | Early intervention |
| 94 | Employment is a huge issue as the agencies providing job coaches do not have enough employers associated to help employment. My kids need to work to be more independent and to be part of the mainstream society. People with disabilities are still very much isolated from the mainstream and the services are not individualized enough to maximize the potential. |
| 95 | Our son requires courses that stimulates his mind and encourages possibilities in the job market. Cypress offers limited courses in Computers, none in trade, and concentrates on independent living courses too much....skills that should be learned basically at home. |
| 96 | We have had trouble finding Angela a part time job or full time. Angela would like to work. We could go into a supported employment program, but then she would not be able to finish her program at Wilshire. She wants to finish her program at the college. |
| 97 | We need to heighten awareness and better incentivize employment for folks with disabilities. We need to have more job coaches from agencies that don't also job develop. We need more services to increase socialization for pwd that may live independently and work independently but struggle maintaining social ties. |
| 98 | Community Supports, such as transportation and help with finding employment for people with disabilities. |
| 99 | My son is 22 years old and he is a high functioning autistic and needs housing accomodation but the referrals for apartments are few and far in |

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| | between. |
| 100 | Employment has been very difficult. Affordable housing in a safe neighborhood is almost impossible to find. |
| 101 | Need for job placement |
| 102 | We all need to work with the community to encourage more employment opportunities. Many people with disabilities want to work, but are excluded from jobs due to misconceptions. Online applications are barriers to many people with disabilities. |
| 103 | Healthcare |
| 104 | my son needs to be challenged in a general education classes with accommodations to support inclusion. The district is telling me that students with IEP goals are not allowed in general education!!! incorporate into education curriculum about acceptance, diversity and understanding of people that are different. Making it so the districts cannot ignore hired private consultants recommendations and always choosing the least expensive option but what is the right choice for the child. |
| 105 | Child is too young to receive employment and housing still. Very concerned about these issues for the future. |
| 106 | There are no summer camps for young adults with disabilities. |
| 107 | Transportation Social skill services. They are expensive behavior services |
| 108 | A typical daycare that accepts students with autism. A typical daycare that accepts a one on one ABA therapist. More autism inclusion programs like Alexa's Play C Rady Children's Hospital and UCLA program that are researched based. More social skills groups for children with autism. Easier access to and more trained professionals on Social thinking and Theory of Mind. Better early intervention service providers thru regional center. A consult model for OT and PT is not appropriate. It should be a direct service for OT, Speech and PT thru regional center funded Early intervention services. There should be more information about available resources for children with a disability. It should be mandated that each parent has to attend parent trainings, parent groups if there child has a developmental disability because parents are the best resources. |
| 109 | Respite, respite, respite. Child with ID and numerous disabilities requires constant supervision. Very difficult to find qualified caregiver/babysitters. |
| 110 | As a single working parent of a child with autism, balance is extremely difficult. Both balancing work and home, and balancing the needs of my children and myself. Additional respite and child care assistance is needed, both in terms of funding and in terms of finding qualified care givers who can handle a child with autism. |
| 111 | After a long battle, I having finally received the services I need for my daughter, but it was emotionally exhausting experience for my daughter and I. |
| 112 | After graduating from high school I've still have not been able to find employment. There's teachers who do not know how to work with |

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| | college students. | |
| 113 | Support for kids that don't have a severe disability, I am always told that my son doesn't qualify to get services because you have kids with bigger needs | |
| 114 | Child Care and Respite are extremely hard to find. The Regional Center in my area is now going through ARC and it is nearly impossible to get people who can jump through their hoopsto become workers. It used to be that we could hire and pay for our people directly. With budget cuts to Regional Centers there are less and less opportunities to enroll kids in programs like Handi-Riders. More funding for programs at places like the Boys and Girls Club for special needs children would be great. | |
| 115 | I have a partner who has a child with a hearing issue | |
| 116 | NONE OF THE ABOVE | |
| 117 | San Diego Unified's TRACE transition program covers all of the topics listed above. | |
| 118 | More opportunities for employment, supported or independent; community recreation opportunities that are accessible by public transportation. | |
| 119 | Transition services for young adults, employment opportunities. | |
| 120 | Employment--- Need more employment in the community Community Supports -- Need more community services tailored to needs of consumers Self-Determination -- Need more encouragement and assistance with this program. | |
| 121 | Housing limited, almost no choices Limited to companies who hire Unsure how to find a Facilitator | |
| 122 | We had difficulty getting early intervention - one child was diagnosed with PDNOS but never got any help. Were told she was too high scoring and that her learning disabilities did not qualify her for assistance. She also had mental health diagnosis that was not accepted for 504 plan. She had severe anxiety and lack of social skills. Needed social skills training and pragmatic language, help with auditory and math disability. Needed a 504 plan. Other child had speech and language in pre-school for delays but each year after had the very minimum speech intervention. Had 1 session of PE intervention. We found our own therapists, OT and PT. In 6th grade, ran away from school due to anxiety and bullying and then was placed in social cognition class for 3 years and then placed right back into regular classes in a huge high school with the same students who bullied him in past. Needed social skills, and ongoing support in classroom with peers and someone interfacing with the teachers who did not understood his needs. Needed his diagnosis (Autism) much earlier. Finally withdrew from public school. Needed assistance with transition - employment and training for both. | |
| 123 | Not found an employment situation with the right supports or trained staff for autism | |
| 124 | I need addition respite hours for my home living but I haven't been qualified | |
| 125 | there are not enough community college classes for the developmental disabilities. | |

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| 126 | consulting |
| 127 | My experience is that vendors exploit their clients. |
| 128 | Parents would benefit from more psycho- educational/support groups. Clients needs more services with appropriate level support to increase their ability to generalize skills. Agencies need more training on how to appropriately support clients. More job trainings and coaching programs for adults, with adequate support, specific to each client's identified challenges. |
| 129 | Community services |
| 130 | Better health insurance That covers everything my son needs and affordable housing in safer areas not just the ghetto. |
| 131 | Assistance in finding housing, more options closer to home for both day programs and recreational activities. |
| 132 | having schools provide the appropriate services, and have the resources in place, the professional development and the training to know how to include ALL children with disabilities within general education. People with disabilities need to be empowered to be able to decide for themselves with help how they what to live their lives and be able to decide who they want to employ. |
| 133 | We are receiving help via a day program, but it's understaffed, underfunded and not geared toward all disabilities. People who cannot speak or advocate for themselves are greatly underserved. Housing is a huge problem - there are waitlists with 10s of thousands of people on them. People with developmental disabilities are last on the list behind other people who can advocate for themselves, even though they are very much in desperate need of affordable and appropriate housing. Assisted living places would be ideal for many vulnerable people with neurodevelopmental issues. For some reason, there is a movement to separate people by disability, which makes housing and caregiving harder and more expensive. |
| 134 | My daughter does not have a Day Program since she has frequent seizures and there is no one on one support available in current programs. My daughter will soon need a new PCP since she is aging out of the Teen Program at UCSF and we do not know of a PCP who is accepting new MediCal/Medicare patients. There are very few recreation opportunities for my daughter. |
| 135 | My son needs 24/7 nursing in the home. Because the reimbursement rates are so low, it is nearly impossible to keep his nursing care filled and consistent. We will not be able to continue the level of care we provide for him just ourselves as parents. Secondly, there is no capable system in place to coordinate his care other than his parents. CCS is incompetent at best, the Regional Center is not funded enough to do a proper job. Lack of coordinated care for all the services required for our son equates to a waist of State \$ and significant gaps in the services required. |
| 136 | Housing in San Francisco. My daughter is not ready to move into her own apt, but we need to start planning where she will live, with whom, and how much it will cost. |
| 137 | Employment services have not resulted in employment Dignified, supportive housing is inadequate DD individuals are amongst those most marginalized by law enforcement |
| 138 | extreme shortage of affordable, accessible housing validated by long wait lists on those that exist |

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| | still many attitudinal barriers to employment for individuals with disabilities, if work centers close many will be left at home doing nothing. Not enough resources to provide sufficient transportation especially to and from a work site |
| 139 | The need for the State to fund vendors is paramount for us to continue to provide services. We are operating at 1990's rates . As a result, many of our employees are forced to live below the poverty level. |
| 140 | Respite care needs to be brought back for Early Start families. This can be the most critical time in a family's life when they are first adjusting to having a family member with a disability. Child care providers need more training on caring for children with special needs. All school busses and special education classrooms should have camera's installed. Our most vulnerable population may have no way to communicate when abuse is happening to them. |
| 141 | no child care , not enough dental care, |
| 142 | Able/willing respite workers. Able/willing physical therapy/therapists. Education! |
| 143 | Very hard to find child care for a disabled child, but I need to work for financial reasons. Makes it very difficult. Need more activities for these kids. Also it's very hard to find affordable housing. I have to live in an upstairs apartment, even though my child is in a wheelchair. |
| 144 | Have received all three but transportation could be improved especially at night./ weekends for emergency calls |
| 145 | Community supports to actively integrate into the community. Transportation to and from additional educational services/opportunities. IHSS services that work! |
| 146 | Need help getting wheel chair repair & replacement quicker. The wheelchair vendors need to have the skill to do seating systems that fit every clients needs. Dental services are in desperate need. We have to wait years in some cases to get extensive work done (impacted molars, etc). The staff are required to take their clients to 2 or 3 dentists to prove what is needed. |
| 147 | Recreational activities that allow children and adult of all ages to participate in exercise classes to promote better health. I am not a working parent now but for those of you must work it is extremely difficult when the programs are only 4 hours long. I have noted that programs like ARC Los Angeles/Orange County are now eliminating their program for those individuals who cannot keep up with their productivity percentage. Our children should be able to work at a pace that is according to their ability and not their disability. |
| 148 | Consumers need to have more training opportunities for employment as well as independent living. |
| 149 | As elderly parents (83 & 87) we are concern about elderly care for our daughter (age 60). What plans are there for people like her? More and more of(us) are living longer. |
| 150 | I have 2 disabled young adults, who have been unable to find employment--they both attend 2 different work-training programs. |
| 151 | PROPER LEGAL REPRESENTATION OF THE DESIRES AND HOPES OF THE I/DD INDIVIDUAL. |
| 152 | Higher coverage on durable medical equipment from Medi-Cal, more respite and available at higher rate to attract a better quality of respire worker. Coverage for more therapies (i.e. hippo therapy, water therapy, acupuncture) |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 153 | <p>Yes- those services are scarce or not available for individuals with autism</p> <p>Families are having a very difficult time accessing early intervention services--they are often told "oh you need to go through your insurance" before they are even evaluated by the Regional Center, when in fact, the RC is responsible for providing evaluation and then when appropriate they can guide a family through the process with their insurance. Also EI evals are too often narrowly focused, eg., only on a couple of areas of development such as speech, despite a child presenting with social/emotional/behavioral issues. Children at-risk for autism are often not identified, and thus receiving only 1-3hrs a week of intervention which is not near the amount needed per evidence-based practice recommendations. Rather than viewing the whole child, there seems to be a tendency to focus on one area of development and ignore the others, which then leads to lack of intervention to treat those deficits. This also leads to discrepancies for children who come from lower income, or non-English-speaking families, or families who are less savvy at navigating the service systems. More uniform evaluation in all areas of development is needed.</p> <p>Community supports are also very limited, and families have difficulty accessing them--they really have to fight to gain access.</p> <p>Mental health supports for individuals with autism and other developmental disabilities are also incredibly limited, and often say they don't have the expertise to treat this population. Training opportunities are available but there seems to be resistance to improvement/change.</p> |
| 154 | <p>A large population of our community is underserved, particularly our Spanish-speaking families. There are limited resources and many of these families don't have transportation and cannot afford to access public transportation to take their young children to/from therapy.</p> <p>Resources and service providers are often limited too. This is a systemic issue state-wide. The more economically-disadvantaged the family is, the higher likelihood that a child with a disability will be under-served.</p> <p>Employment during summer school. Everyone won't work my son until he is out of school or 22. He needs to do something over the summer!</p> <p>Housing with supports for lower functioning consumer. A LIST OF PROVIDERS FROM ALTA!. Other regional centers POST THEIR providers but ours does not. We need transparency and not pick and choose FOR US OUR OPTIONS! Let us decide! I would also like a list of subsidies that are available.</p> |
| 155 | <p>1) We provide employment services both training and placement. The rate cuts of the last decade were sever and crippling.</p> <p>2) The DC's are snake pits. the abuse of the citizens with IDD is documented and yet they still exist at \$500,000+/person/year. The abuse is criminal and yet those that are there are ignored. 3) We serve adults with IDD and as their family are getting older housing is critical. On One can but or rent even a studio apartment on their SSA/SSI check(s) and have enough money to pay their bills, groceries, utilities, etc....</p> <p>As a vendor, we are dying financially with no rate adjustments in years. The cost of doing business, supplies, utilities, gas, wages, etc. continues to grow every year, year in and year out, with no money to support these costs. Non-profits are going our of business and people are losing services they need and deserve and are entitled to though the Lanterman Act.</p> <p>Have to fight through committee rather than listening to sons choices; I thought cost wasn't suppose to be the determining factor; why do we have to fight through and generate negative behaviors which then follow him. He is not responsible the system is - how does this follow those in the system responsible.</p> |
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Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 160 | N/A | |
| 161 | Individuals with disabilities need continuous support for the transition from school to adult life. Higher connectivity between community support and adult transition programs. More businesses willing to higher and retain individuals with disabilities. | |
| 162 | housing, transportation | |
| 163 | ABA therapy in my son's language (ASL) not because he's autistic but has autistic behaviors do do dual sensory loss and nd he can't even access what he needs Also, IRC early intervention was provided, but bot in my son's primary launguage. The boy is deaf and u sent a speaking teacher for 3 yrs to my home? I had no clue I had a choise or how to advocate @ that tkme. 3 yrs lost. =(| |
| 164 | After day care services for parents of adult and respite that works and more hours then 30 a month. Not to penalties older retired parents of disabled adult to live in their home and receive ihss services. Help make life not so miserable. Single parents of adult disabled child like myself needs more help. | |
| 165 | Our adult children with special needs could greatly benefit most from housing benefits. Whether this be an stipend to remain in-home with parents, or their preference which is usually to try to live independently, this would be great. Also, employment is challenging for many, especially for those with psychological issues and emotionally volatile states that make them inappropriate for positions working closely with others or the public. | |
| 166 | My daughter st age 22 had to wait almost a year before she started a program. | |
| 167 | Transition services for a student that is entering into adulthood | |
| 168 | The types of service and supports are not easily accessible by families or self advocates. Alta Regional and agencies in general tend to withhold information, prolonging wait time and giving excuses like committees have to decide before limited information is released. | |
| 169 | Behavioral consultation by BCBA's or other QUALIFIED staff to assist SLS staff, group home staff, parents who are caring for behaviorally challenged adult children, and adult day program staff with developing and maintaining behavioral interventions for adults with autism who have challenging behaviors; individualized and person centered planned support to obtain employment for adult with autism;; adult day programs that are not just a day care and that are staffed by trained employees who speak english ;SLS programs that contain a behavioral intervention component, sensory integration consultants who can work with adults who have sensory needs; mental health counseling for people with ASD and provided by knowledgeable providers for those with dual diagnosis; 24 hour crisis team support that have the ability to make home visits on weekends, holidays and not just 8-5 (that is not a crisis support team) , competent SLS and IHSS staff who see caring for adults with special needs as not just a temporary position but are willing to see their work as a career; ;job coaches who understand autism; employment needs | |
| 170 | Ihss Regional center | |
| 171 | I personally don't need them. My clients very much need these services. All the services listed are needed. I do feel that most of the services fall | |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | under the Formal and Informal Community Supports. |
| 172 | 1) I want my young adult daughter to live in housing that is part of the community and managed by an on-going agency - not a private vendor with a few group homes whose business ends when he/she retires or sells the homes. 2) I want there to be well trained and knowledgeable long term social workers at the regional centers - I've had 3 inexperienced counselors within the last year. This is a huge problem for getting any reliable assistance. 3) I want wages high enough that college graduates with business degrees can afford to become job developers IF we truly want to implement EMPLOYMENT FIRST. |
| 173 | Help finding employment |
| 174 | There is a lack of housing options for young adults with developmental disabilities that are affordable and available in Santa Clara County where I live. |
| 175 | Currently looking for adult day programs with openings for 1-1 or 2-1 ratio. Lots of waiting list. Lots of places don't offer 1-1 services. |
| 176 | my son's housing has been provided, but rents are so expensive in the Bay Area that it takes all his SSI. |
| 177 | Lack follow-up in reference to self-advocacy and self-determination. |
| 178 | My biggest need, having a child who is 10, is making sure my daughter receives FAPE and assistance in interacting with the community (ABA). However, I feel now, and for her sake in the future, we must have supports in place to help people obtain employment and housing. Parents of people with DD will not be around to tend to children forever. |
| 179 | There needs to be a housing plan for the State of California. |
| 180 | Hard to find child care that is suitable for our son, who has a mild disability. He needs more support than "normal" kids his age BUT doesn't need a high level of care. After school daycare and summer programs that we've found just don't offer enough support for him to be able to attend. |
| 181 | WE tried originally to get our daughter in with Regional center and then turned us to the school district, although she is autistic. We struggled with the school district for many years and have now finally gotten our daughter into Regional center a few years ago. But with our income, we really don't qualify for anything except respite. They announced a month ago that they were going to have seminars on housing in the OC area but all of the slots were full so we didn't get to go; they also wouldn't provide the information that was going to be presented because they said that it may be incomplete. As it I got nothing, so even incomplete information would have been something. With regard to community support, I'd like to see some data base that we can access. My feeling is that there is very little where we live and things are concentrated more in some areas of OC but not in others (typically where we are). It makes it difficult to participate. |
| 182 | I have received no help because of the area I live in. My family has been alone in the education of our five year old sense day one. |
| 183 | As our population ages, I see programs for the more challenged, but not much for the moderate group and they often end up languishing at home. We need a set way to obtain some kind of employment for our students. Maybe programs that staff from their programs could implement...clean up park crews etc. |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 184 | no t very many opportunities for employment for students with ID. |
| 185 | Help finding a program or something for my 19 yr old son to do after he leaves the Irvine Adult Transition Program. The programs we have talked to so far, say he isn't independent enough. He has a developmental, but not intellectual disability. He is easily overwhelmed and needs to do things in small steps, with help when he gets stuck and doesn't know what to ask for help with. |
| 186 | My brother needs more hours allocated for him to become more self-sufficient. |
| 187 | Housing and tailored day service |
| 188 | We live in an outlying area. As a result of that, and low reimbursement rates for vendors, our options have been awful. We get what our daughter needs, but have to drive 600 miles per week to do it. We also were denied our services (even though all were covered by Lanterman) and went to mediation and fair hearing twice before our daughter was two years old. She is almost three now. |
| 189 | Child care when needed. Poor services in schools and therapies get cut.. Difficult to get needed dental services. |
| 190 | Livable wage for very important services rendered |
| 191 | I never had child care for my intellectual disable daughter |
| 192 | Housing Job development Job coaching |
| 193 | Access to a rental subsidy for people with developmental disabilities. Something approximating a Section 8 rental housing voucher. |
| 194 | There is a need for job development, specifically in supported employment, for individuals who need the constant presence of a job coach. There also need to be more choice for places to live. Individuals should be able to choose those they want to live with, the type of living situations/communities and supports. |
| 195 | We live in a rural area with very limited or non-existent resources for: Supportive job coaching and employment; lack of quality day, recreation or educational, activity programs for those who don't need extensive support; serious lack of child care for single DD parents on SSI; affordable legal help for those who need it; Adults need independent living and safety instruction skills for personal (sex) development issues. Counseling for single mothers, or those going through a divorce, would be nice as well. |
| 196 | satisfied |
| 197 | My adult child has developmental disabilities (socially and emotionally severely delayed) though she tests as intellectually average. Most programs seem to be for those intellectually impaired only and so they reach out to and include just those most obviously intellectually impaired and "developmentally disabled" has become a politically correct way of saying "intellectually retarded". What about those who are truly developmentally disabled but intelligent like many with FASD (Fetal Alcohol SPECTRUM Disorder) who desperately need the same help, but may need to have a different approach? They are ignored, though with the right support, they might become workers and taxpayers. Housing, ongoing job support, ongoing social worker or case manager support[ie life skills support] so they don't end up as victims, single parents, or jail prisoners--all costing the taxpayers more money in the long run than preventable ongoing support would cost. |
| 198 | I get very limited help with child care and health coverage. He qualifies for Medicaid, but it does not cover any of his doctors or medications, |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | because we have insurance. However, I have to have a much better plan than I would normally so that our insurance will cover his medical needs. Therefore, I have much more medical expense due to his condition. |
| 199 | More therapy providers (physical, occupational, speech) to serve the 0-3 year old population; lower caseloads for early intervention service coordinators to better serve the families and children in the Early Start Program and get them the services that they need in order to prevent future disabilities and maximize developmental potential; more daycare assistance for low income families |
| 200 | DDS needs to provide capital and operating subsidies to ensure there are adequate, affordable, independent housing options available for everyone with a developmental disability living in the community. |
| 201 | Housing : my daughter & 16 year old grandson who has autism and ADHD live in a one bedroom small house, we asked for accommodation to section 8 for a two bedroom for many reasons having to do with his autism, accommodations were denied :-) |
| 202 | For my clients, they need housing for high functioning autism and ADHD. Although they look like they can be self-sufficient, they often lose their first four jobs or so in the first 6 months of being hired. They lack self care and self awareness skills. |
| 203 | As a case manager through the Orangewood Children's Foundation, a non-profit organization that serves transitional-aged foster youth, there is a clear gap of services for foster youth who also have a disability, especially when it comes to transitional services and housing. So many of these youth end up homeless and on the streets and there is a dire need for support as they work to transition out of the system. |
| 204 | Employment, Health and Housing are critical to facilitate independent living, but sadly are often lacking for this population. |
| 205 | Regional Center services denied for Autism. Summer services difficult without school ESY. Social leisure activities for teens. |
| 206 | I work in Early Intervention. Finding childcare for children with developmental disabilities is nearly impossible, especially if the child presents with significant behaviors or simply requires constant supervision. The daycare stipend offered by the Regional Center, in addition to the \$5/hr parents are expected to pay is not high enough for a daycare provider to be able to hire an additional staff member to provide the necessary support for many of our clients. There are times when Regional Center is able to provide additional supports in the daycare setting (behavior services, developmental supports, etc.), but there are many daycare providers that refuse to let any specialists come into that setting. In some instances that results in the child not receiving services because their parents work full-time or in them being kicked out of the childcare. In Sonoma County we are lacking Spanish speaking specialists (speech, OT, PT, etc.), which can result in a child waiting for services or not receiving the appropriate service (home teacher instead of a speech therapist). Housing is also very significant issue for low income families with children with disabilities, particularly when it is a single parent. Parents want to work, but without appropriate/affordable childcare and a permanent place to live that is nearly impossible. Many parents make the difficult decision to quit working. We need more services/supports/advocacy related to accessing childcare and housing targeted toward parents of minors with developmental disabilities. |
| 207 | Affordable housing for our folks who are living with aging parents and transition aged young adults |
| 208 | In my experience with clients, their housing needs often take a long time to accomplish. |

Survey Monkey Results

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| 209 | safety/abuse prevention My daughter is too young for housing but I know that she will need in the future and I am worried that with her physical and developmental delays there will not be a place for her. She should be able to have a choice of jobs not just some companies that have opened their doors to help, it should be any company. There needs to be more community and government involvement to help educate the public about the abilities that people have and not the disabilities. Physical activity- no gym will take a child evenwith my being there. She is over weight and only getting worse and no help for her |
| 210 | Inclusion classroom for my 3 year old son. Services he will need to be successful with school |
| 211 | There are virtually no resources for families to find day care for their children with developmental disabilities. Many if not most parents are unable to work because of this. There need to be places/websites where providers can sign up to be providers and families can look for providers. Most families find care by word of mouth and often this is not successful. Housing is terribly expensive for anyone let alone someone living on social security and/or low wage employment. Even with a housing voucher housing is difficult to locate. |
| 212 | 1. Housing: As an example, in El Dorado County, which is home to nearly 1000 consumers, there are no children's residential facilities, no level 4 residential facilities, and only one 3-bed level 3 residential facility. This gap in housing eliminates out-of-home respite options for minor consumers and many adults in the county. For most level 3 or level 4 adult consumers in El Dorado County, the only permanent housing option is SLS. At the same time, El Dorado County has not issued any Section 8 housing vouchers in nearly 15 years, meaning that there is no public assistance to IDD residents for housing costs. This means that only financially secure families who can afford to finance housing and living costs for their IDD relatives have a housing option in El Dorado County. While we have requested, and have received authorization for SLS services, many more families have no affordable housing option for their IDD relatives in this county at all. IDD housing should not be an option solely for the wealthy. |
| 213 | 2. Self-Determination: it is incredibly important to move this forward as quickly as possible. Consumers in ACRC's catchment area no longer have a voice in service decisions: these decisions are made in committee meetings which the consumer is not allowed to attend, populated by regional center managers who have never met the consumer. IPP meetings at ACRC are now meetings in which requests for services are made, but not determined. This is the essence of institutional decision making, and self-determination is needed now to save person-centered planning. |
| 214 | Special accommodations for people with disabilities in housing and housing assistance to help pay rent. In home supportive services to assist those with special needs to accomplish daily tasks. |
| 215 | Online services can reach the most people, can be reviewed and are accessible (for the most part). These tools need click definitions, paragraph summaries, scaffolding of information for multi-step processes, and links to information clearly written for this population. |
| 216 | Transportion-- Regional centers cut off transportation services and vendors are made (forced) to provide these services. Although we get paid, it's not even enough to cover gas, maintenance, insurance. We do not have choice. |
| 217 | We are not in need yet, but we are entering Adult Transition. It would be nice to be able to have a list of adult day programs with a compare |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | and contrast. I assume Regional Center must have something like that, but it should be introduced before we get to that stage so families can start to research what they need and maybe get on a waiting list. |
| 218 | Recreation. I believe there should be more recreational options for people living on a low income budget. |
| 219 | 1. Affordable housing and vouchers. 2. Timely review, response, and closure of services/funding requests through RCOG and SCDD health and safety waivers. Waiting over 14 months for closure is draining on our finances in order to keep quality trained staff that is critical to our son's care. |
| 220 | Not yet ready for employment, but few options are available for people with similar disabilities, funding for programs that make sense and would be therapeutic but are not ABA: DIR, RDI, Socialization Training, inclusion aides for community activities. My child's disability is too severe for him to participate in even disability focused recreation and community activities without additional support. |
| 221 | Transportation Agencies to work together to get the consumer to their destination in the safest and most cost effective way possible. Our problem stems from being right on the border between 2 counties and agencies not wanting to cross the border of the counties. Therefore 1 agency will pick them up and drop them at the border to wait for the 2nd agency to pick them up and deliver them to their destination. |
| 222 | School districts refuse to provide services tailored to individual needs. They prefer to group all students together, make them attend their "special education" schools regardless of what the students parents or medical treating team has to say. |
| 223 | Ensure school districts do what they are legally required to do and have legal support to ensure positive results. |
| 224 | Help with elopement issues at school and home |
| 225 | Affordable housing in decent areas is sorely needed if we are to care for the exploding population of Baby Boomers. |
| 226 | All of the above |
| 227 | Very interested in Self Determination however have not received any details of how to apply and still waiting to hear back from our case worker. |
| 228 | If we didn't maintain an independent, expense, and excellent health policy on our son, he is a 37 year old adult he would not receive the average health benefits an American receives with only medical. Housing is judged the same for these individuals on Section 8 as any other disabled person, but they are frequently unable to hold jobs for long periods. The jobs count against their housing in section 8 and they have to pay more for housing. My son only receives \$4.50 an hour for his supported job, not even minimum wage. More needs to be available for higher functioning persons. They don't fit in the severally disabled group for recreation, but are not accepted and don't fit with normal functioning individuals as well, who rarely accept them as friend. They are really left alone and lonely as they don't go to day programs, etc. |
| 229 | None |
| 230 | Did not qualify for Early intervention |
| 231 | My child is not of age for work but I would like more attention to be given to students and prepare them for jobs they might actually have the skills to be employed |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 232 | My son has high functioning autism and is graduating from high school and it seems all the support and services disappear for the older kids. He needs training/apprenticeships, interviewing skills, college support. Otherwise these kids just give up. |
| 233 | Speech therapy - it was not even discussed until 18 months & we are still waiting at 22 months to get a speech evaluation. |
| 234 | The employment does not apply to us yet but is a big concern. It's the formal and informal community support that is what will help our children mainstream become functional |
| 235 | Community supports |
| 236 | More assisted living housing options, more accessibility to mental health services, more emolument opportunities with commensurate pay. |
| 237 | Funding to provide a quality life for our clients who have disabilities. ICFDDH facilities had their rates frozen in 2008. It has been a struggle ever since just the meet client needs. |
| 238 | Inclusion , or for the schools not to dedicate one school for all kids with disabilities, we should have to drive 15 min or have my child take a bus because the school next to us doesn't have a special Ed program |
| 239 | My brother is placed at Fairview DDC and has had the best possible care for someone with my brothers needs |
| 240 | I have to kids with disabilities and only one has received care and help. With his education and I feel that it is totally unfair to him. He has the same right like any other child would too. Quality assurance would be another one so many of the times you feel like you are fighting to get care and services because no one out there truly cares for your concerns! |
| 241 | It is hard to find a child care providers |
| 242 | There are no services my child has not received. |
| 243 | Employment beyond job training |
| 244 | I am not getting support in any of those areas. |
| 245 | Orange County gave us what exceeds our dreams |
| 246 | Employment is hard for many of them to get job on their own and under vendor services they aren't given advancement or raises like others . In fact they usually get reduce wage and work hours change after time being there because they can't produce for what is expected. For those who can are then often overlooked at promotions. Then there's those who supervisors change and can't except them in their position and let's them go even though they are doing their job |
| 247 | Transition plan from school sites Overall education plan weighing all options for future education i.e College bound or tradesman |
| 248 | adult day care so I could remain working while my daughter returned home from school and now day program. There is a gap between my work hours and day program hours and she can not be left alone. |
| 249 | Adults with autism have a desperate need for jobs, housing and employment. |
| 250 | In service training to learn about the medical aspects of various intellectual/developmental disabilities such as autism, down syndrome, etc. |

Survey Monkey Results

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| | What does research-based findings say about the vocational need of these individuals? |
| 251 | direct legal representation, audit of County and State programs to determine the extent that the disabled are NOT being correctly identified for programs, informed staff of agencies that are supposed to HELP disabled adults. |
| 252 | Very little educational support, no help or call back from regional centers, support services. |
| 253 | Vendored or reimbursed camps and other recreational opportunities, transportation, transportation reimbursement |
| 254 | I answered generically as heavily involved in 2015 revised budget for Developmentally Disabled. Education: the 2009 workability law is a disaster as consumers do not want to stay in the educational system for 4 more years until 22 yet cannot get regional center support; community based services need funding or the Lanterman Act will collapse; housing resources so DD individuals can live in the community |
| 255 | Education and Intervention- My child is desperately in need of a social skills group. He is 14 and has limited skills in this area. Child Care- Keegan is not yet able to stay by himself safely, yet IHSS doesn't want to provide protective services. I have 2 other children with therapies and services due to disabilities and I need someone in the home with Keegan so he can be safe. Employment- we don't yet have a need in this area since Keegan is 14 at this time. |
| 256 | To make the available services known. |
| 257 | Individuals with intellectual disabilities need more opportunities to attend college in appropriate supported programs, a wider variety of semi-independent to independent living options and stronger advocacy for choosing the life they want for themselves. |
| 258 | Employment services, independent living and community support and housing. |
| 259 | My son receives tailored day services which have greatly improved his quality of life, but he needs more assistance, especially speech therapy. My wife receives some respite hours but it is not enough. Our case workers from the regional center do the best they can, but they are terribly overworked. The entire development services system needs more funding. |
| 260 | Better, efficient, comprehensive health care, Family wrap-around comprehensive resources (One-stop shop), Recreation services Recreation |
| 261 | Dental insurance for more than just extractions. |
| 262 | Need better support for mental illness. That can make all the other forms of support useless. Not much use getting a job when you are too paranoid to keep going there, for example |
| 263 | more incentives for hiring disabled, shorter waitlists for housing assistance and better support for self determination |
| 264 | We need more funds to be able to give the best care we can. We are very under funded which leaves these vulnerable clients in jeopardy. |
| 265 | We receive respite, but many in our very rural county do not because there is a shortage of qualified respite workers. Health care is hard to find because Healthy Families folded into Medical and many providers will not take medical patients and the few who do are far away and overbooked with patients so getting timely care is a problem. |
| 266 | The dental is very low wage and increase Bed rest |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 267 | Advocacy | |
| 268 | | Housing opportunities are practically non-existent or way too expensive. And, people with dev disabilities (who can't be employed at a high wage) can't afford what's available. We want to work! But finding a job that is sympathetic or geared to mitigate the developmental drawbacks is also impossible to find or retain. And having the freedom to utilize the funding available by contracting with vendors of my choice is imperative - The RCOC should not determine who the best provider is for my needs. |
| 269 | | Quality assurance (do not need housing yet but that is a big problem for many) and have not received the formal and informal community supports do not know what is out there except respite |
| 270 | | Quality assurance - I really hope somebody from the government office or position really cares to check the quality of services that our government providing for disable or special needs kids/people. Our school is sadly have poor quality of teaching, it sad to see how some teachers & assistant teacher seem uneducated to handle a stressful situation & so a special need person suffer & no way to talk for themselves. The school or classroom itself is unbelievable underfunded resulting to classroom with mold, playground that almost no activity for them & toys, bikes that are too old & unsafe. |
| 271 | | have been turned down by regional center, dont' have money to hire a lawyer to get in, appalled that they simply turn down most people hoping they'll go away, even though services are needed and person meets criteria. |
| 272 | | There is an ongoing need for those with DD to be HEARD, from using supported typing and augmentative-alternative communication devices when they cannot speak, to visiting a counselor when they need help to work through the frustrations that occur in their daily living, all requiring funding not easily available. |
| 273 | | Sex Education, life skills, social skills. |
| 274 | | Intentional housing developments for individuals w/diabilities that have full support services: health services, behavioral support, transportation, and recreation. |
| 275 | | my son has sec 8 but in SF there are few housing options available for sec 8 even with 2 bedroom voucher. There are few jobs available for the few hrs (3 hrs 2-3 X week that would be able to accomadate his abilities. Some of the staff that help with supportive living services are not trained/or paid enough to give the quality support that is necessary. |
| 276 | | We received very limited respite during our son's early years and we received intensive ABA and similar support from ages 2.5-6 but at age 6 he was moved off of the autism spectrum and we lost almost all services. From age 6 to 12, he made no significant gains. In the last 6 months, we have been forced to pay for a therapeutic day school and have seen quite a big of progress as a result. |
| 277 | | Housing support |
| 278 | | We need more state run facilities for parents who have to work after the their child turns age of 12. Daycare centers do not take children over the age of 12. My daughter is almost 21 and I had to quit my well paying job because I had no daycare for her after she turned 18. Luckily I had a daycare that kept her until she turned 18. |

Survey Monkey Results

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| 279 | School district does not want to provide further special education service due to child testing was not low enough. Current school district testing must reflect extremely low scores to have any services. Therefore many children can not qualify to be in the program. Even if they have problems which are reported by families. We have this to be true for multiple counties. |
| 280 | I wish my son can receive some musical training to help him stabilize his mood. I have always told that there is no funding or service for him on this. |
| 281 | People find it difficult to find affordable housing, so they can have spending money for food and clothing, etc. To find effective healthcare providers, people must travel 2 or more hours and find the transportation to get there. It is difficult to find employers who are willing to customize a position. |
| 282 | Actually true full inclusion in the school district!!! |
| 283 | standard residential rates and poor oversight have contributed to the lack of quality services available in our communities. As long as the state hospital system has almost three times the rate of reimbursement as community providers and they are allowed to keep running the developmental centers even through DHS has decertified these hospitals, we won't see a shift in better services in our communities. |
| 284 | Water safety, aide for community events and summer camp, specialized tutoring for my child's literacy. |
| 285 | Housing - quality and affordable housing |
| 286 | We thankfully have pretty good services, but we have had to fight every step of the way. |
| 287 | I have a brother that has disabilities and after leaving the public school system, the services that were and are available to him are next to none. There are many local "Day Program" providers but do to continued budget cuts and restrictions his community access within these programs is minimal. There is simply no money to retain quality staff, provide adequate transportation or even to maintain existing programs. Please restore funding and stop with the budget cuts. My brother and many others like him want only what every other person has the right and ability to do, to access their community, to give back and be a part of the community. |
| 288 | Respite care is very difficult to secure. I receive respite for my child through RCOC, but the service providers are unreliable and difficult to schedule regularly. I am also a mentor for families of kids with special needs and I know that many of them have issues with transportation - it is expensive and difficult to secure handicapped access vehicles. Many of our community partners are "resource" givers not resource "providers", for example, you can call organizations and receive referrals to agencies or organizations and because those groups aren't well funded, they no longer exist - can't use them. There are very few housing options for long term care. Very upsetting. |
| 289 | Eligibility to receive employment due to my disability.i am very disappointed the service provided by disability service. |
| 290 | All my clients are deaf with intellectual disabilities and there are very few to no services for the deaf intellectually delayed. |
| 291 | System is comfortable with intellectually impaired individuals. My daughter is socially impaired. Thus, a computer job where she does not have to deal with people would be ideal. Computer jobs are a new idea and made the DOR case manager wince. There needs to be a plan/program for working with higher functioning autistic people who have areas of strength in their skills but also have behavior problems. |

Survey Monkey Results

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| 292 | All services are dying, being starved of resource support by the decisions of the Governor and Legislature |
| 293 | Day programs for adults with complex medical needs. |
| 294 | With the recent cuts to supported employment it is very hard to place our folks in a job and give them continuing education about how to do their job well. |
| 295 | community housing/residential group home with appropriate levels of support |
| 296 | I need help for my 22 year old daughter who has Williams Syndrome. She has a job 5 days week which is great but she needs more to do. I want her to have a passion, I want other options for adults with disabilities. A sport, drama, art class, I'm trying to help her find what are her interests. I'm sure they are out there but I'm not sure where to find them. |
| 297 | "Childcare" is needed for adults and medical fragile adults after program. It stops at age 22 and that is a challenge for many working families. Health care can be challenging for our adult clients to access and/or their parents to access on their behalf if they are not conserved. Recreation can be challenging for our clients, not enough places to go/often/regularly scheduled during the week, and the transportation to and from is on the family to provide. |
| 298 | Assistive Technology Services and supports |
| 299 | For students with Moderate - Severe developmental disabilities it would be helpful if they had more employment options. |
| 300 | Transportation is not available in some of the more rural areas of the state. There is the employment initiative but not any additional funding. Furthermore, despite all the education and mandates regarding abuse prevention, there still continues to be more individuals taking advantage of the dd population. The abuse prevention at this point needs to focus on educating the dd population about recognizing it when it happens to them or their peers. |
| 301 | Recreation and after school get together. |
| 302 | It is so difficult to find out what is available to help your child. |
| 303 | In the area or transportation I see a need to simplify bus schedules for people with disabilities and have them run more frequent and more direct routes. For example, the bus stops right out in front of my FLS classroom runs to a transfer station and then into the next town's transfer station. If I wanted to teach my students to ride public transportation to the local library, they'd have to go all the way into Chico AND TRANSFER onto another bus just to be transported back into Paradise to get to the public library. Para-transit is available but must be booked in advance and many of the parents aren't aware that this service is available to their child. Para-transit also has a lengthy application process which I'm sure keeps many from applying.) Also, some degree of supervision and help should be considered to help people with disabilities if they get confused or disorientated when trying to ride the bus. Remember many times this population cannot tell time or may not understand they've been waiting too long for a bus! MORE HOUSING OPTIONS!!! The rents are way overpriced for the income these individuals earn. Rents also need to include amenities that allow the folks to get outside and/or get some exercise. A par course, an on-site gym, etc. Supported living should be funded more like apartment complexes for young professionals with separate living quarters but opportunities for socialization as well. . |

Survey Monkey Results

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| | <p>Formal/Informal Community Supports: PLEASE, PLEASE, PLEASE!!!, start a 24 hour drop in type of program for these individuals. I cannot tell you how many times I have started my shopping excursion with two disabled children in tow and when I explain we have to stop at the fabric store (or some other spot they don't prefer), behavior intensifies. Most parents can say, I'll drop you off at the mall or something.. and get their small errands run. I would LOVE to see a drop in recreation / day care type of program started so that I can shop for fabric or try on clothes or even have a quick and quiet dinner with my husband without having to pre-arrange respite, interview the respite worker and then leave this stranger in my home while I go out. This addresses another problem: Respite. I rarely use it even though I have two children with autism at home. I just don't have the energy to screen respite applicants, interview them and provide a trial run in my home with my children. I live in a very rural area and most workers come up to my area from one of the more popular towns. The time they claim starts when they leave their home town and travel 30 to 45 minutes to my home, then my travel time is counted as well. All this before I even begin to shop. Please consider a drop in service where I can bring my kids into town, drop them off for a few hours and then pick them up and take them home. This service would be best if it were inexpensive for families and would not require advanced reservations or notification. This would greatly increase my use of respite services!!</p> |
| 304 | <p>N/A...we are a vendor and do not receive services.</p> |
| 305 | <p>We have children that have Autism. I fear for ALL children with Autism because we have nothing for them as adults. What is out there for young adulthood and beyond? We need life skills classes, junior and 4 yr. college programs dedicated to their needs. We need job training for individual skill level.</p> |
| 306 | <p>My adult son with Autism is not functioning in his job programs and in his supported living program as well as he did in school and when he was living at home. We have narrowed the reason down to his sensory integration needs not being met. We have to pay out of pocket for an OT eval (prescribed by his GP) and any services and equipment they recommend as a result. MediCal will not recognize the provider, nor fund the services. This is essential for his well being, just as it was while he was growing up. Also, the home cannot afford the specialized foods and supplements on his medically prescribed special diet, so we are kicking in another \$350 a month, just for him to get the food he needs. There should be extra funding provided to homes that serve people on medically prescribed special diets. They are getting all the SSI funds, so this money we pay for his food and supplements is taking goods and services away from the rest of our family, which includes another minor child with a disability.</p> |
| 307 | <p>Getting around is a great problem. The Regional Center does not have help with this. Dial A Ride does not work. You just wait and wait for them and then take a circuitous route to where you need to go. Bus service and transferring is difficult.</p> |
| 308 | <p>It is extremely difficult to find meaningful and appropriate employment. Housing is very expensive and out of reach of most who are on SSI. It is difficult to find appropriate health care as Medi-cal is very limited in what services it will fund and most physicians do not have the training to work with people with developmental disabilities. They do not take the time it may take to do a full exam as it often takes longer for a person with certain disabilities to explain or discuss their issues. Also most doctors do not take the time to look for alternative forms of</p> |

Survey Monkey Results

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| | communication in those who have limited or no verbal skills. |
| 309 | Real Jobs! Opportunities to have fun in the community and not be isolated and the ability to use funds on what WE believe is BEST for our child! Not what the system says is available. |
| 310 | Nobody is hiring my son even with a certificate of achievement |
| 311 | More life coaches to help my daughter get to a employment. |
| 312 | everything |
| 313 | Better programs /teaching manuals that help students learn . Students are only given a few choices. Have teachers receive more training on disabilities and help w/ others ways of teaching and a better understanding of how the student w/disabilities feels. |
| 314 | Very little community inclusion. The supported living model offers freedom but also isolation. Staff becomes my son's only contact. He has very few social opportunities. He also has very limited opportunities to have a job. He wants a job and to be part of a community. |
| 315 | Cannot go to school provided childcare because need an aide. Theatre class after school also said he needs an aide. |
| 316 | Respite care givers who are not qualified, trained, or willing to do the personal and medical care needed. We have to do our own recruiting to find the help, convince them to go through the process of becoming authorized, then do the rest of the training on the job for our severely handicapped son. |
| 317 | ABA Emergency services when in dyad NEED More RESPITE hrs. SPEECH Insurance for lower income |
| 318 | Occupational and-physical therapy |
| 319 | provide more information about school. how to access loan for a family with a member with disabilities. |
| 320 | Employment for individuals with intellectual disabilities that would not affect any SSI payments. Training in day programs that teach better life skills for independence eg cooking, healthy grocery shopping. |
| 321 | More oversight of the residential/independent-living homes by independent monitors. |
| 322 | My son is transitioning to adult services soon. (He is 19), and there needs to be in place where they can have employment, to be independent and be able to contribute to the society |
| 323 | A plan for adult housing |
| 324 | Education and assistance with sexual issues. Ability to go to another school better equipped to handle instructing and assisting with behaviors without the school districts approval. (my son's education went down when entering certain schools) Dental assistance. job assistance training (my son can do more than clean up behind others and learn the word janitor) |
| 325 | My son will need intensive support with job search and employee-ability. He is currently at school, so we don't need help yet. |
| 326 | My son now age 49 has not yet been trained to hold a simple private sector, self-supporting job. His supervised work under Far Northern Regional Center has provided good quality training but not specifically job targeted, and being very high on the autism scale, he could hold such a job if taught on-the-job training in the private sector. |

Survey Monkey Results

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| 327 | <p>My son is turning 20 this year, and I'm very concerned when he finished school, and how I'm going to keep him busy and feel productive in the community , and I feel it would be safe for him.</p> <p>Child care is up to age 12 and licensed providers only take up to age 12, and assistance with funding stops at age 12. We need more day program for our disabled children, teens and adults like the YMCA or boys and girls club that ensure safety, supervision, and keep them active and included in the community.</p> <p>School districts don't treat our children with the services and respect they deserve. They have learned to manipulate psych-edu Evals and speech assessment results by using it against our children in order to not provide additional services, and then make us go through a lengthy appeal process.</p> <p>There needs to be more education and awareness regarding the safety of our children, or laws to prevent our children from being victimized while in the care of service providers, school, work, or in the community. Most community businesses don't make accommodations for our disabled children.</p> |
| 329 | Information to be accessible in English, Spanish, and Farsi. |
| 330 | Inclusion services, puberty education and occupational programs. |
| 331 | We were denied services when our daughter was born and it put us behind 5 years in receiving services desperately needed as she is a multiple handicapped child. We were not told about IHSS and I quit my job without understanding IHSS was a available. |
| 332 | Quality programs for youths. |
| 333 | I live in a rural area of Riverside County & there are no recreational activities & very little support. |
| 334 | programs are not being evaluated any more. There is no quality assurance of day programs in our area, or licensed facilities. |
| 335 | There are no daycare or after school programs available for kids with special needs whose parents work full time. The schools are doing a poor job at providing adequate and high quality services (speech, OT, PT Etc) and fight you for every increase in service you request. Our special needs children are not ready to transition from Regional Center services at the age of 3, this was an extremely difficult and challenging transition for our daughter and family. We should have been able to keep in home Regional Center services until Kindergarten or beyond. We would like to have self determination |
| 336 | Safety / abuse prevention...this doesn't seem to exist where we live (San Diego County) |
| 337 | Vocational Training a must, need to have housing choices and have help accessing housing, Need greater community supports provide quality assurance. |
| 338 | Summer Camp and After school program with 1:1 aid Social group with 1:1 aid on weekend |
| 339 | Employment and recreation for a full life. Safe transportation. A safe and happy place to live. |
| 340 | Vocational Training, Understanding of Housing choices and how to access housing, There are few community supports that insure any quality |

Survey Monkey Results

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| | assurance. |
| 341 | Now that the Regional Centers do not fund social recreation, we have been unable to provide summer camp experiences or after school care for our son due to his disability. He needs extra staff support, and the programs that I thought had a responsibility to provide services (i.e., organizations that receive public funds) for the customary fees, do not want to take him without us sending someone with him. I am unable to work enough hours due to lack of after school child care. |
| 342 | Lack of affordable housing is biggest need. |
| 343 | Employment ,tailored services,quality assurance poise |
| 344 | Ability to choose service providers. |
| 345 | No housing. No help in being part if the community. Health benefits are very limited. Quality of services is, VERY limited. |
| 346 | Recreation |
| 347 | Support at IEP meetings outside of regional center and counseling on how to better advocate at IEPs. Housing vouchers for single mothers raising disabled children who can't work because of it or who had to cut back hours drastically. Knowing what community supports are available. |
| 348 | Appropriate job training & vocational skills for educated HFA & Aspergers individuals who do not choose to go to college because it is too overwhelming. |
| 349 | Alta is failing to provide the support they were created to help with. Unless your child has a dual diagnosis they provide minimal support. |
| 350 | A paying job, rather then volunteer work. They need to feel they are worthwhile citizens in spite of their disabilities. |
| 351 | Most people need more than Day Care: a variety of supports in evenings, weekends; flexible and responsive Affordable and supportive housing Control in the hands of the people served |
| 352 | Difficult to find health care provider that knows about the disability but covered by insurance or medi cal. |
| 353 | Regional has recently implemented testing standards for services that I think are flawed or needs further evaluation as it may not consider the functioning quality of the impaired client |
| 354 | The most challenged individuals in the RC system represent less than 5% of all the consumers served. They need licensed residential facilities and we have systematically underfunded these services for a number of years. |
| 355 | 1) Currently, there is little to no support for families with children with disabilities? 2) Early intervention for children with disabilities took a hige blow during the economic crisis and regional centers and other state organizations have not restore early intervention funding for early intervention program. This is crucial services. 3) Transportation services for people with developmental disabilities is joke and a huge disservice to this community. ACCESS is often in appropriate for people with severe disabilities and regional centers are denying transportation services all together. So what do families do |

Survey Monkey Results

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| | when they can transport their child with DD? They stay hope in isolation, with their only time out is when the schools provide this service. If you have an adult child this becomes event more problematic. |
| 356 | There are many individuals with developmental disabilities that need employment but there are no transition services that teach people skills, increase stamina, etc. A work type program (not Supported employment) should be required to have training programs that teach work skills, preferably on the job. |
| 357 | Housing continues to be a huge challenge for individuals on limited income(SSI). Waiting lists on housing assistance programs are ridiculous. |
| 358 | lack of transportation prevents families from getting access to generic services which we are supposed to tap into. Access does not work well, we need more and more reliable transportation system. |
| 359 | continued education passed the 22 years of age in an adult facility,mandatory p.e. to keep our love ones in good health and freedom to choose facility regardless of regional center on lives in. |
| 360 | The key is to get the clients to be more independent and integrate in the community. It starts with the clients going to school and receiving an education. Then these individuals need to be provided with a place to live (independent living, supported living, group home) and assistance with determining what to do during the day (adult day program, college, work, supported employment). |
| 361 | N/A |
| 362 | More jobs and more places for recreation |
| 363 | 1) Too often, when program participant is doing well in a Behavior Management program, regional center will quickly move them to a step-down program. We see that the program participant come back to our program because they where not successful in a work program (step-down). One of the reason why is because the step-down program or staff does not know how to work the individuals. it would be a good idea to have the program participant remain in the same program or stay with the same staff, but offer a step-down program within the current program. This will help the program participant increase their skill sets without having to transition to a new staff or day program services. 2) To often, good care providers (Mom and Pop's operation) leaves the field because they can't afford to run the program or looked at as criminals rather than a helper to the intellectual/development disabilities population. While, bigger operations grow and expand because they have investor who knows very little about the business and just wants to make money. If a situation rise, bigger operations can smooth the problem because they have the power and continue to growth. I would like the State Council to check on who are the owners of the big operations care providers and what kind of experience they have in this field and their true interest at heart. |
| 364 | Home placement |
| 365 | My son is 15 but I am very concerned he will not be able to find employment and to have transportation here in L.A. |
| 366 | Some information's is lacking if you do not know some one who knows what's out there. |
| 367 | We must make certain that in special education and Early Start intervention that there is seamless support and services between school districts and regional centers in the areas of transition that include employment and independent living options. Parents of disabled children should not |

Survey Monkey Results

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| | <p>be made to feel like they know nothing and have to submit to what an administrator wants to do. There needs to be more community living options. Housing options need to be tailored to the needs of the person with the disability(ies) but also be affordable. More must be done to create real world employment options in the community. We should reduce the emphasis on workshops to the greatest extent possible and place importance on supported employment with job coach support. This will be an especially hard thing to do in rural areas but it must be done. Clients also need good community retirement programs that they can go into when they get too old or too sick to continue working. The safety net programs of Social Security, MediCaid, and MediCare are critical to working and retirement age clients and need to be expanded not cut. These critical safety net programs are too important to be turned into vouchers or block grants or be significantly cut.</p> |
| 368 | An agency vended for Micro-enterprise. Also Regional Center funding for AAC/Facilitated Communication. |
| 369 | Employment- ASD adult community soon will be bigger all kids who where diagnosis when ASD was 1 in 100 at 3 or 4 year old soon will be 18 year old |
| 370 | Meaningful supported employment, access to mental health services including a counselor and a psychiatrist, assurances of safety and protection from abuse. |
| 371 | Because of the decreasing number of Dental and Psychological facilities willing to accept medical funding clients are having to wait months in pain for appointments. Sometimes they will go to facilities that are not vended by the R/C and are being sent exorbitant bills and threatening letters by debt collectors which they can never pay off. Some R/C are reducing the number of client's that can live in a CCF and therefore reducing the number of CCF's available. The increase in client's that are maturing, parent's unable to provide a safe and stable home as well as the client's being discharged from closing Development Centers has over taxed the system and we have no placement for client's in emergency situations. Regional Transit & Para transit are over burdened and at times are having to leave the non-ambulatory clients at the designated pick-up place because they don't have enough room. The current wait time is one hour or more and client's with seizures, diabetes and other ailments are expected to wait in areas with no cover/shade to help them combat the environment. IHSS staff are paid to drive client's to medical appointments but they are not paid to go into the appointment with the client. Doctor's are cancelling any further appointments with the client's because they are not able to communicate with the client to find out if the client is following the doctors orders as prescribed. Our client's need someone in the office with them that can relay message back and forth for the client to the planning team and back to the doctor. |
| 372 | Job Coaching and assisted placement so able to learn skills to maintain a job. |
| 373 | Transitional services for over 21 are abysmal. The Day Programs are for very low functioning clients while the Employment Programs are for the much higher functioning clients. There's no "in between." So both ends of the cognitive/behavioral/disability spectrum are covered, but there's a HUGE gap where clients are NOT -- they're unable to keep up with Employment Programs, yet are held back in the low-functioning Day Programs. |
| 374 | My child is not yet of age to need the items checked, but I often hear the need is there. |
| 375 | I believe that outside of day programs which occur M-F, clients need to be able to socialize, make plans and get where they want to go. These options should be available to them 7 days/week, or as they desire. |

Survey Monkey Results

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| 376 | There is absolutely no housing available for adults with disabilities, not enough employers engaged in employing people with disabilities, and due to state funding crisis recreational opportunities are extremely scarce |
| 377 | Coverage for interventions, eg speech therapy, occupational and physical therapy. These services are inadequately covered by private insurance and would make a large impact on future outcomes if guaranteed by the state to the disabled person. |
| 378 | Housing |
| 379 | Independent living skill training, self advocate skill training, |
| 380 | Employment opportunities are needed but not adequately presented by RCOC. Support Groups for adult disabled are very hard to find. Help in setting up Special Needs Trusts and information on how to use family home as living option when parents are no longer available. RCOC is NOT helping, instead is putting up hurdles whenever possible. |
| 381 | Many of our clients and their parents have no resources to turn to once their children age out of the system. |
| 382 | Struggling with academics for my delayed 9 year old, currently. |
| 383 | We need to ensure the quality of the programs that are provided. There is no true quality control. |
| 384 | School is trying to change placement and take away services that our child needs. |
| 385 | affordable housing options of all types. Recreational opportunities that are community based and age appropriate. Expanded service system with all supports. |
| 386 | Supported living Employment Recreation/community activities |
| 387 | Housing for young adult w/ 24/7 nursing care needs Knowledgeable, seasoned, effective NBRC worker! |
| 388 | Adult Day programs are both underfunded and not widely available due to the lack of facilities in the Sacramento and Elk Grove area. |
| 389 | Employment: My son is non verbal, has auditory processing issues and because a solid communication strategy was never in place in the school environment, he can not get a job. If Regional Center had done a better job at informing parents what ALL the supports & services in our communities were instead of hand picking them per service coordinator, then maybe some of our kids/adults would have been better served. All the agencies should have been brought together during adult transition time so ALL options for an individual could have been made not just the ones a particular school district was offering. |
| 390 | help with recreational activities available for disabled adults. |
| 391 | More Job Developers to assist students with disabilities find employment!!! |
| 392 | Job Development for adult son in Supported Employment Program. They can do better. Lots of sitting around. |
| 393 | 1) Adequate sex/relationship education tailored to children with intellectual/developmental disabilities and family members or caregivers. 2) |

Survey Monkey Results

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| | Adequate job training and access to adequate employment. 3) Access to adequate health services paid for by Medical - There are not enough health facilities taking patients with intellectual/developmental disabilities and with Medical. |
| 394 | A kind of "one-stop" shop/website that takes advocates/the disabled through the process. Here's how you apply for disability, seek out an IEP at a public school, get skills training, get daily services, basically a go-to site instead of skipping around through the school system, the healthcare system, the state/municipal system and the private system. |
| 395 | Housing options for those who need supervision but also need to live independently of their families home. Increased vocational training options and incentives for employers to put clients on payroll once sufficient mastery in areas of training have been achieved. My clients do not and would not like to hear "baby sitting" when in fact they do require close supervision, maybe more on the level of "mentoring". Recreation is also important as it allows for socialization to take place within the client's community and supports physical and mental health. |
| 396 | Adequate services at school |
| 397 | Housing- my son does not want to live in a segregated environment, living only with others with disabilities. As he chooses this housing, he does not receive any assistance from the regional center financially to help pay for his rent, whereas if he lived in a segregated setting, they would help pay for it. Also, the employment opportunities that are offered to him are sub-standard or non-existent. All of his employment has come from work he did, making connections, and letting people know his abilities. No one seems to be able to support him as he works really hard to be an independent adult. |
| 398 | More services when these babies need them and the supports of respite and childcare would much improve the outcomes of this population, especially children who may not have a disability who are at high risk. |
| 399 | Wider variety of work day programs for persons with extensive daily care and behavioral needs. |
| 400 | teaching my son how to ride a bicycle with self-balancing aids. |
| 401 | Employment-diverse employment opportunities, training prior to job developing(resume writing, role play job interviews and rate how the person did so they understand where they are at with interviewing. Housing is a blanket statement of need in Ventura Co. The housing market is horrible to locate section 8 affordable homes. Health is overall health education due to obesity, diabetes, etc. |
| 402 | getting a chance to meet people in charge of hands-on programs to learn and then pass the information on to my students, or even giving them the chance weekly or monthly to be able to make money, so they can see that they can be independents. |
| 403 | As a day-program director for individuals seeking job-training skills and independent living skills to later make further steps towards independence in Central California—I experienced an annual waitlist of approx 10 prospective participants, hoping to enter our program when a space opened up. There aren't enough incentives (budget allowances given staff-individual ratios) for additional day programs to open for folks who have the ability and desire to develop greater vocation &/or independence. |
| 404 | At times quality of services is not what it should be and increased support or oversight from regional centers may assist with this. I have not personally experienced challenges in the areas of employment or housing, but I believe that there are major concerns in these areas as individuals desire employment to be meaningful participants in their community and lack of appropriate and affordable housing is a challenge. |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 405 | <p>I work with people who want to get out and be a part of life and who want jobs. My people want to know what they can do and how they can get there. There are agencies that can provide these services but there are waiting lists (people try for years to get to work) and wait times (people wait hours at a bus stop watching full buses pass by).</p> |
| 406 | <p>At the elementary school level, assistance with my sons needs as far as restroom usage. The ability to use a restroom after school and safety during the school day while using a restroom on campus. The staff and aids have not been assisting my son into the restroom during the school day. He is an 11 year old severely disabled boy with the mental capacity of a 2 year old along with Epilepsy and balance issues. In addition, he was denied use of a restroom after school and consequently urinated in the car. The staff at this particular school has put restrictions on my sons access to a bathroom at the end of the school day. This is currently taking place in the Newport-Mesa school district.</p> |
| 407 | <p>The Regional Center is able to provide some early-intervention services such as in-home IBS. But not all Regional Centers think it is their responsibility to provide such services. I believe the cost to assist our clients will be far more if early intervention is not pursued, and the school districts cannot be responsible for all of it. Also, if we had training in how to access insurance company funding, it would help take some of the financial burden off of the Regional Centers.</p> <ol style="list-style-type: none"> 2. Community supports for our clients is needed. There are ways to provide community access, but there is a need to be able to provide more, especially in rural areas. Without social support, our clients become shut-ins, which is not right. 3. Housing is always in demand, and there just does not seem to be enough affordable housing for clients on SSI. There is always a need for affordable and safe and clean housing. |
| 408 | <p>I work with children who are transitioning from elementary to highschool. And from highschool to adult programs. The schools are sometimes unable to find appropriate community outlets for the students to learn real job skills. Forcing our residents to be more dependent on the care providers. Appropriate Housing options are limited. There is a need for additional support in behavioral homes or other options to push for independence</p> |
| 409 | <p>Having board and care facilities located in areas where there is minimal access to public transportation makes it very difficult for the adult to access services and keep themselves actively engaged in the community. As well, there are very limited employment supports/resources which has a huge impact.</p> |
| 410 | <p>behavior support services for people with intellectual disabilities but who do not have autism</p> |
| 411 | <p>We need better transportation provided by the Mendocino Transit authority. clients can not go to trainings when there is no bus service to training sites. I.E. Bus to Talmage area and Mendocino Office of Education.</p> |
| 412 | <p>In Home Supportive Services</p> |
| 413 | <p>These services were needed, but not received by my son from Regional Center. I provided them for my son, and was paid by regional centers to access them for other Regional Center consumers.</p> |
| 414 | <p>There needs to be more quality adult day programs. The best programs would have community experiences at least twice a day which train for</p> |

Survey Monkey Results

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| | possible vocational placement. Right now, there is one or t there needs to be more quality adult day programs. The best programs would have community experiences at least twice a day which train for possible vocational placement two programs of questionable quality. |
| 415 | Once you are able to get your child through high school, this is no place to go for help, who do you talk to find help. I've spent the last month, 5 days a week trying to find some who can refer me to someone who MAY be able to answer questions. What, or how does the state plan for these children to be financially independent? There is NO PLAN, just get them out of school.....and then what...a warehouse job???? Just because they have a disability does not mean that they are not smart, they have a problem...they may think differently or act differently but they are employable. Treat them like that and we will succeed. |
| 416 | It is very difficult to get enough/good quality respite. |
| 417 | We don't need housing yet because we can still care for our son, but there are too few options for him to transition outside he home as he needs 24hour supervision and full daily supports. |
| 418 | Education: Our child has apraxia of speech. He didn't receive appropriate speech therapy for years. Until he was 7 years-old, we began to pay for his therapy. Last year (when he was 9 years-old, school district began to fund for his private speech). He couldn't communicate, and needs a shadow (aide) to mainstream in school, we took us 2 years to dispeal to the school district to get a shadow for him. Community support/quality assurance: We have been experienced a very little or no support from communities such as amusement parts, airplane or other public places. |
| 419 | As the parent of a 16-year old developmentally disabled child, my response was made in anticipation of my child's future needs. I am also a public health nurse who has worked for Adult Protective Services, and I have seen too many developmentally disabled people living in filthy, unsafe poverty and experiencing exploitation such as "friends" who take their money or give them illegal drugs in exchange for sex. I want for my daughter to live in a safe home with work and recreation opportunities. |
| 420 | 1. Transp support for church. 2. Quality caregivers 3. Assist vs doing 4. Keeping belongs clean/orderly |
| 421 | I feel that families need a better support system that is clearly defined and publicized. an example would be, advertisements or flyers. |
| 422 | I work with large group of minority who speaks Spanish, Vietnamese and Korean. Access to community resources and services available to those communities are very challenging due to cultural and language barriers. |
| 423 | Educational Support such as IEP assistance. Social Security- assistance with appeals. |
| 424 | Cannot find a proper Undependable Living place |
| 425 | Service to young adults transition from services received ages 3-15 |

Survey Monkey Results

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| 426 | Self determination and employment |
| 427 | absolutely NO appropriate educational instruction for my child and others like her with an IEP. Students with special needs treated as a nuisance, delinquents and bullied repeatedly by teachers and students. Parents only recourse to hire advocate/attorney if they can afford one. Services denied all year long. It is criminal what is happening in our public and private schools to these kids. It is child abuse and its tearing families apart. Pulling my child out of school and paying for a private tutor out of my retirement fund to save my child and my family. |
| 428 | I see various individuals in need a housing options. Most can't afford where they live and/or are not able to have a choice in the matter. That ties into job opportunities. Some organizations are trying to provide opportunities but I think the efforts need to be increased. |
| 429 | I just believe funding needs to increase in these areas. |
| 430 | Financial, organizational and social supports to improve my quality of life. As well emotional supports to aid in recovery from childhood abuse issues. |
| 431 | housing, needed to be affordable, in a safe area and in good repair with needed services at the home. employment training needs to lead to a job not a shelterd work shop for life. |
| 432 | The assessment are useful tools but there needs to be a system that is more developed to determine the type of disabilities and the service needs. There are too many misdiagnosis from the medical/educational environments |
| 433 | My son is 12 and receiving good services through our school and health insurance. But we realize that after 21 there are few housing options, employment opportunities or other meaningful programs to support his quality of life. Also, our son is unique and we like to make the best choices for him. Many services are a one size fits all many times we are forced to do things that dont help just to access the things that do help. It is wasteful of resources and time to be required to do things that arent beneficial. |
| 434 | My brother is a regional center consumer. In the last few years, we have been trying to receive dental services for his extensive need of dental work through Denti-Cal. This system leaves a lot to be desired. It seems to me that the only service that is approved are extractions. Evidently, our intellectual/developmentally delayed do not need teeth and are not worthy of having teeth. It is very sad. This system needs to be revamped and have staff that really care and know what they are doing, which is not the case at this time. |
| 435 | More affordable therapy and social recreational activities for ages 12-35 |
| 436 | Housing financial support or access to safe, reduced-rent housing |
| 437 | Early Start NPA program does not allow for a truly individualized education plan giving a child's unique disabilities. We have a child with sensory processing challenges and a compromised immune system in the most restrictive classroom setting and he is making very little progress because he keeps getting sick and cannot concentrate when being taught preschool-ready skills due to being unable to filter out all the distractions in the classroom with his peers and therapist all working in the same room but in small groups. Our school district said that this setting is the best they can offer. However it is ultimately a denial of FAPE given our child's unique disabilities and learning needs. Our child has been diagnosed with moderate-severe ASD, is non-verbal and far behind in every developmental category for his age in comparison to his non-disabled peers. |

Survey Monkey Results

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| 438 | We are developing CPP Homes for persons with forensic needs. We have difficulty getting the RC to coordinate services and have medical and vocational/educational services in place in a timely manner. We have waited many months for day programs and often even after they are located the RC will deny the one on one component even though they know it is required to have the consumer start the program. We have also had to wait for months for transfer of MediCal for services such as psychiatric needs which jeopardizes placement for these dual diagnosed residents. |
| 439 | Recreation is a big one. |
| 440 | In help finding affordable housing |
| 441 | There are limited Vocational Training and job coaching opportunities for adults with disabilities; |
| 442 | We did not qualify for ihss because our home is a upscale condo. It belongs to a relative but the gift of free rent somehow disqualifies this support. Wife is sick and I cannot work caring for my son with autism. |
| 443 | As a provider of services dealing with sexual education and safety, I would like to receive a materials refund as we supply educational materials and samples and are not reimbursed nor allowed to charge the consumer or their families. |
| 444 | More advocacy in education for Employment-related training and independence, higher pay for vendors that provide supported employment, more housing opportunities for those with ID. |
| 445 | No appropriate day programs or recreation. No assistance with home modification to make home accessible. |
| 446 | Help with employment and housing |
| 447 | recreational services for our son as a child or adult |
| 448 | There seems to be a real lack in all of the areas that I've checked (Meaningful Employment, Adequate Housing and social and recreational opportunities). As a behaviorist that has worked with this population for over twenty years, it is my opinion that a great number of issues could be avoided if these three areas were given adequate attention. |
| 449 | In the past, a number of people that we support had paid employment. Now, there are none. Our agency has closed three of our residential homes in the past 14 months, and budget reductions in the state are a large reason for this. Supported Living services have also dried up due to the discontinuation of rental assistance. |
| 450 | 1) Employment: In spite of new law, we have not heard any promotion toward more employment for adults with intellectual/developmental disabilities. 2) Housing: in L.A. any housing improvement has shown as outcome. 3) Health issue: we need more support/help for people with DD who has medical issues |
| 451 | Since I'm an advocate, I don't need services |
| 452 | I am currently receiving all necessary services for my son, but I am very concerned about future day options for him when he turns 22. |
| 453 | My son has not yet transitioned out of the school system. We are planning for his future after his last year of school in the 2015/2016 school year. I want to be able to provide the most appropriate program for him. |

Survey Monkey Results

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| 454 | Employment services that are catered to developmental disabilities having do with physical disabilities being a separate issues instead of often being bundled together with intellectual disabilities |
| 455 | Financial assistance: when illegal aliens are getting health care for free and are also milking the system, the least you can do is make sure that disabled citizens and their families (many of whom are unable to devote themselves to their own jobs full time because they are caring for their disabled family members) are receiving an adequate amount of financial assistance. \$700 monthly doesn't cut it. It would cost the government much more money if families did not take care of their disabled members and we deserve to be compensated for our efforts. The government would rather pay several low-level employees who don't really care about the service they are providing instead of helping actual families. |
| 456 | High functioning individuals with minimal ID have many fewer resources than individuals with ID. Residential options need to be available to those who may not qualify for RC services. DOR needs to become more familiar with servicing these individuals and make available to them more appropriate kinds of employment options. Recreational and dating resources need to be more available to them as well, both inclusive and non-inclusive so they have a choice. |
| 457 | Respite care has been found to be imperative for family well being and is often difficult to obtain. |
| 458 | Area Board 3 used to provide direct advocacy services to help families get the services their child(ren) need from schools and other providers when reasonable requests are denied. Some idiot made the decision to discontinue these and now families have 3 expensive or ineffective options: (1) hire an attorney at a very high cost; (2) try to file due process on their own (which is impossible to succeed at when you're up against the agency's or school district's army of attorneys); or accept that your child cannot get the services they need. Direct advocacy kept schools and agencies in line, providing the services that children need. Now they're getting away with murder. Bring direct advocacy back! If it wasn't beneficial, the caseload the Area Board had would have been low and it was always high! |
| 459 | un able to afford the parent portion for day care, not many options on job, rent is expensive. |
| 460 | I have clients in need of all the above Service Areas. |
| 461 | Recreation programs. Kids with disabilities work harder in school and at home with all the therapies that they do. They need more things to do just for fun and socialize, some of these recreational activities can be calming and therapeutic to a child. |
| 462 | I work/live in San Diego where the cost of housing is very high. Our Regional Center used to provide rental assistance for those who qualify. The program was discontinued a year ago, citing abuses in the system. People cannot move out on their own without some rental assistance. Living on SSI alone is not doable. |
| 463 | My Son is mildly mentally retarded and a little autistic We have tried several programs offered by the Regional Center with no luck. My Son does not see himself as disabled and does not relate to the other participants in these programs. We need a program for higher functioning disabled people. He is not capable of holding a regular job but he is too high functioning for the regional center programs. He gets very depressed if I force him to participate in a program with people that are a lot less functional than him. |
| 464 | comprehensive mental health services, clinics close to my home and public transportation, quality care from clinics, doctors, and hospitals |
| 465 | Offsight services funded by SCUSD school district to help ADHD student with peers and relationships. Social skills for child. |

Survey Monkey Results

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| 466 | Independence, employment, housing and equality. |
| 467 | More direct care providers to better help to assist those who do have developmental services. |
| 468 | Many individuals with d.d. need an array of job opportunities within their communities. They are very limited to workshop day activity programs which is still segregation. Employers need education about individuals with d.d and learn how to tap into their individual strengths that will enhance not only their organization but to the individual him/herself. |
| 469 | Services should be collaborative and linked. Reason for checking "Formal and Informal Community Supports. For adults this should include 514 funds that are directed at education on community college campuses (not current educational settings) that are directed at career development for those with ID...housing through HUD and Dept. of Rehab. also directed towards this group (collaboratively) to provide a better foundation for life after high school. |
| 470 | Not a need for me, but what I hear from other parents. |
| 471 | We have an elementary school age child, and the SCDD has been tremendously important for my family to identify and access services. |
| 472 | Child care support for children with special needs. There are almost no faculties trained to work with challenged children in an after school program |
| 473 | Adequate funding to continue to provide quality services. Also as a family member of a person with DD, not enough info about services and transition from school to work services programs. |
| 474 | tailored and appropriate employment and education opportunities |
| 475 | My son has been working with an employment prep specialist for almost 3 years - still unable to find a job Self-determination hasn't started - yet Transportation is always an issue for people with disabilities - ParaTransit is too expensive at \$4 per trip for someone on SSI Efficiency evaluation of RC staff and administration. Sometimes, almost always the RC are more problem than help. Example..... At the last Fare Hearing - negotiation meeting where most situations get resolved, the officer stated " this issue did not have to come tothis". I agreed and stated " not for lack of trying". Again as for the last 40 years people are having to become adversarial with the samepeople who should be thefacilitators. And they act like they enjoy wearing us down. Unfortunatly time isnot on our side. |
| 476 | |
| 477 | affordable housing and/or rental assistance, self determination with an adequate budget |
| 478 | employment first opportunities- regional center coordinators understanding the complex needs of the individuals that want employment and to make a living wage |
| 479 | Timely residential placement for adolescents with severe needs. |
| 480 | In the areas of employment for young adults with Autism living in the lower SES communities, there is limited options. Where and how to access employment opportunities with sufficient support and facilitation? Housing - the wait list is forever long. The Autism generation who were diagnosed in the late 1990s are now young adults with aging parents. Quality assurance - the level of services keep getting thinner and |

Survey Monkey Results

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| | trimmer. FOr hte functional adults with Autism/disabilities who are willing and able to work as future taxpayers, if there is no opportunity now, how will they learn and obtain employment independence? |
| 481 | Help in the schools...my school district is currently trying to sue me because they removed my son's special education status and I challenged them. I have been harassed and mistreated by an organization that claims to help children. I am graduate-level educated and accomplished in my field (licensed psychotherapist) and yet I have been called names, laughed at, and told my opinion as a parent does not count. |
| 482 | I have been informed by parents of older children that there is very little support with assistance after high school getting them a job - specifically the writing of a resume, assistance with the interview process, and finding places to interview. After the job is obtained, the parents stated there were many supports available. |
| 483 | Education - I had to advocate for ethical treatment for my child in San Diego for 13 years. What a waste of time for me and my child |
| 484 | Housing section 8 and owl my owl home affordable condo for low incomes |
| 485 | Adequate funding to meet the needs of each person. |
| 486 | We need the funding to provide services. |
| 487 | Adults need more recreational activities and need to be motivated to participate in these activities. Employment is a main part of every adult's life. It creates purpose, encourages social interaction and is a place to broaden experiences and skills. |
| 488 | Needs to be more services offered |
| 489 | Clients need ABA services in rural counties. Housing is limited and expensive in rural counties. |
| 490 | Many of the services offered today did not exist when my daughter was born in 1967 and I think there have been great strides - especially in the area of early intervention which I had to seek on my own traveling all over the bay area. |
| 491 | Better transportation and help with getting medical equipment and help with putting furniture together like my platform bed |
| 492 | not enough reimbursement and too much bureaucracy |
| 493 | More and better post-22 years community-based classes and training. |
| 494 | I feel we have received very minimal services through the local school district to assist my son with ASD. He performs at below levels in language arts and math. But I feel the school is meeting the very basic and minimal requirements but do not seek improvements to help my son reach the next level of learning. |
| 495 | Housing is so important but the funds for housing are never sufficient. Federal government needs to provide more funds to housing authorities across the country to help our clients have good housing alternatives. |
| 496 | Affordable housing. Many community programs for our population are underfunded or have closed, waiting lists for programs are long with extensive wait times. Many of the good programs folded under budget cuts, limiting options. Safety of our population in the community continues to be a concern, with abuses and exploitation is still a problem. Community integration is a challenge, mainly due to transportation constraints and lack of appropriate options. |

Survey Monkey Results

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| 497 | Police need proper training to know how to handle individuals with dd |
| 498 | Recreation for my child, who is currently 12. See many opportunities for older teens but very little for 7-15 year-old. Recreation opportunities that can help build skills to enhance opportunities for community inclusion, with typical and I/DD peers; and later with opportunities for employment and contributions to community. |
| 499 | funding for supported employment, . Not un met needs in my professional experience but high priorities are: programs and support for early treatment of autism / asd's and programs to help maintain optimum physical, mental and dental health. |
| 500 | The special education staff needs to stop treating kids like they are not able to do things and believe in them |
| 501 | Regarding transportation, when a client lives in let's say Rancho Cordova, and has an appointment in Roseville, they cannot use any transportation because they will not cross over the city lines. This causes many many issues for our clients in regards to medical appointments and even a day program. With housing, it is beyond difficult because the majority of our clients are on a very limited income. Most places want double or triple the income which is not realistic for anyone, let alone our clients. They end up having to live in the worst parts of town because of this. |
| 502 | There has been a gap for students with behavioral challenges and gaining access to a Day Program. Spaces are limited most of the time. |
| 503 | I would like to see more funding to develop early intervention service resources in low economic areas. |
| 504 | Housing for my disabled adult son |
| 505 | I do need any myself |
| 506 | Community college educational supports. Denial of services because they aren't federally mandated (0-3). Reluctance on the part of the general population to accept and involve someone deemed "different." |
| 507 | Transportation is very inconsistent. |
| 508 | High Function Autistic son who is 22 - Autism doesn't stop at 22... DOR's success rate with Autistic individuals is 8% if one believes the statistics. So far I have seen little that a dedicated friend or family member couldn't provide -- yet they string the people they are helping out for months without success in helping them find or keep a job. |
| 509 | Health care providers who are adept at providing services to people with disabilities (e.g. physical challenges and behavioral issues). Tier system that supports people with disabilities as they transition from school system to day program to employment. Supported housing that allows people with disabilities to have affordable housing options whether living independently or with others. |
| 510 | I do not require services but the clients I work with are constantly being told and given inconsistent services. |
| 511 | Transportation in Solano/Napa County severely restricted due to bus schedules Regional Center making significant cuts in funding for door to door transportation. Serious affordable housing shortage. Lack of vendors providing employment opportunities. Regional restricting referrals to some work activity programs. |

Survey Monkey Results

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| 512 | Of our 60 residents only one has a job in the community. Transportation is challenging when new residents come in for services to their day program. |
| 513 | a lot of people are not getting the help they need because the worker think they know what they're doing but they don't they think nobody to fit in one group they don't see the person as one person |
| 514 | Better support for services in compliance with new federal HCBS regulations |
| 515 | We are a rural RC, thus at a most basic level, ready, easy access to good healthcare, especially mental -health services, affordable housing nad public transportation that is more accessible on nights and weekends, would all boost quality of live in many of those other areas in your list. |
| 516 | Vocational training and also job development for adults with intellectual disabilities to be able to work in various areas of employment - with opportunities for advancement - in non-segregated, mainstream jobs. |
| 517 | coherent transition plan from the school to employment |
| 518 | If DDS is closing all DC's, then more medically fragile housing needs to be developed to meet their needs. Also no Advance Behavior Model currently exists in community to meet DC clients needs. |
| 519 | Their is little offered in our area in the area of community support. Tailored Day services only exist for those that have parents that do a tremendous amount of advocacy and groundwork to provide an adequate program for their loved ones. Abuse in all forms is still a major problem. Most families in our area are migrant and live in poverty and are not interested in Self-Determination nor are they aware of the existence of the service. |
| 520 | Employment: The Employment First concept is a valid concept, but competitive integrated employment is only achievable if adequate employment services are put in place. There needs to be a continuum of services and opportunities that range from Employment to Supported Employment to Community Integration. It is totally unreasonable to believe that every consumer wants to and is capable of achieving CIE. formal and informal community supports involves community mapping that starts with what is available for all and moving towards identifying where funding needs to support services that are not available anywhere else. Self Advocacy and Self Determination is the key to expressing hope and confidence- and the possibility of considering COE. Recreation - Life should be full- working, home and community are the life settings for everyone. Helping individuals achieve a balanced life style includes recreation/friendship/social outlets. |
| 521 | Special ed law and rights |
| 522 | We get 24 hours of respite. The respite organization we have is not flexible. They want a lengthy advance warning to schedule staff. This is not how the world works. When you have a disabled adult, things happen at the last minute and you need support. This is all wrong - it seems to be geared to the benefit of the staff. Adult care needs to be much better. I have a 21 year old who will likely need adult care his whole life. We plan for him to live with us and we have no extended family and the quality of care is hit or miss. For now, we have one wonderful worker but don't expect that to be so always. |

Survey Monkey Results

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| | We need more physical fitness opportunities. The OC RCOC should facilitate several sites where folks can access a gym. The disabled adults are some of the most overweight an unhealthy that I've seen. Sadly, that includes my son , in spite of our efforts. |
| 523 | Day supports to avoid isolation for family member who is fiercely independent and afraid any assistance means he will be candidate for institutionalization (which he experienced as a child) |
| 524 | There is no supported housing available. No work available in the day care program that works best for her. We received minimal early intervention & school services - it was like re-inventing the wheel. |
| 525 | There is a lack of qualified providers or providers who provide quality work. Behavioral support systems are lacking, being on a waiting list is not providing services. Continuity of delivery varies so drastically that my child may only get a small amount of services, but my child's friend receives what is in my opinion an over abundant amount. Yes in know each child is unique, but when the parent says its because in know someone, so I get the services, that's just wrong. |
| 526 | More resources which could be tailored to families needs and additional support from schools and community agencies. |
| 527 | 1) In the employment arena, a more comprehensive, coordinated effort regarding Employment First; blended funding when all three areas work together in an ore flexible fashion. 2) Informal/formal supports - we need to spend more time figuring out how to connect disconnected people to the community. 3) An honest and more comprehensive review of self-determination. there are many pros and these should be described, but there are some challenges and this has not been discussed. |
| 528 | transportation to post-secondary educational settings |
| 529 | Access to these services |
| 530 | I receive services in all 3 areas |
| 531 | Access to support - |
| 532 | Services for the others involved re: family members, community etc dealing with the disabled... |
| 533 | Early intervention |
| 534 | Many clients are unable to be employed even with supports. Housing waitlist limits the individuals ability to be independent. |
| 535 | we did not receive early intervention, but he is 8 now. we have aba, but are losing it. |
| 536 | As a service provider we need a rate increase in order to keep competent employees. |
| 537 | access quality, skilled affordable child care access to quality, skilled affordable health care |
| 538 | Need entry level job training. |
| 539 | Behavior help across the lifespan. Cutting intervention because someone hit their quota is unethical. Services should end based on accomplishment of goals, not on someone's ability to complete a program at a particular pace. |

Survey Monkey Results

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| 540 | <p>Haven't been able to find qualified respite workers for my son. There are no recreation activities available that can accommodate a one on one supervision need. The schools do not follow through with implementation of the IEP and have become very aggressive at denying services and even transfers to schools within their own district. The school district has refused to investigate school site when young girl age 6 with autism was sexually assaulted and infected with sexually transmitted disease. Parents pulled child and school district enrolled her at another school and are paying her nanny to be the one on one aide but they still haven't thoroughly investigated her previous school site to make sure it is safe for other children. There is inadequate housing for anyone with disabilities in our area there are no jobs for people with disabilities in our area.</p> |
| 541 | <p>Lack of employment opportunities and the training of skills to be employable. Respite services are lacking for those with medical and behavioral needs. Need better support in transitioning to adult services in health, community supports and employment.</p> |
| 542 | <p>More respite services</p> |
| 543 | <p>Proper funding from Regional Center to support SLS Services</p> |
| 544 | <p>Transportation</p> |
| 545 | <p>In our rural area we have a real lack of supports, both vendored and generic. It is expensive to live here, rents and property values are much higher than in Kern county. My client have a much harder time living on a limited income. Affordable housing is not available. Section 8 has not even been open for my clients to even get on the list in the almost 7 years I have been a service coordinator. Transportation is another big issue for my clients. The outlying areas, where they could possibly find affordable housing, there is no bus service to. There no weekend or evening bus service in many areas. How can my clients have access to even attend a movie or see friends if there is not bus service to get back home? Community Integration for social recreation was something taken away by the State - My clients are isolated and have no real opportunities for socialization other than the 1 day program in all of Inyo and Mono counties.</p> |
| 546 | <p>I am new to this community and am starting on services for my 6 year old son. In home support and school is a must</p> |
| 547 | <p>I have seen a lack of transportation for homes that may not be able to have their own wheelchair van and supported living wheelchair transportation. Currently there are not enough homes in community that are ADA compliant, especially in the NBRC catchment area. Many of the day programs are full as well and there is a need for more services for clients in community during the day.</p> |
| 548 | <p>Abuse-Schools should be taught about children with disabilities, make them a part of their school, engage with them not treat them as outsiders</p> |
| 549 | <p>There is a gap between the need for services, and the actual availability of services. Agencies, both public, and private, pass the buck. Getting early identification and intervention is difficult for children with invisible disabilities. Failure to identify, and lack of services have been our experience.</p> |
| 550 | <p>My son has been on a wait list for over a year for help with job placement. Housing options are limited and difficult to access, and wait lists are very long. Many individuals I know are not receiving the services they should be, or the services are inadequate to their needs.</p> |
| 551 | <p>1) New places or activities to take clients. 2) There needs to be a point of contact person who can follow up with questions that clients have. 3) It seems employers do not want to hire our consumers because its too difficult.</p> |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 552 | Advocacy |
| 553 | Available services for adults diagnosed with Autism is poor in California (i.e., employment options, vocational training options, etc.). Generic services are also lacking regarding the aforementioned dx. |
| 554 | My child needs to learn to be safe in the water however the school and regional center do not want to provide swimming instruction. We have paid for lessons privately, however due to limited resources, we are not able to provide them consistently for him to be able to acquire this skill. |
| 555 | There is an EXTREME shortage of work for our young adults that want to have living wages There is also an HUGE lack of housing for individuals who because of their disability cannot live in a group home...they prefer to be alone and have less activity in the house/apartment because they use all of their coping skills while they are at work |
| 556 | Transition Students ages 18 -22 need the support of a Mental Health Therapist, many of them have experienced trauma in their younger years and often have somewhat challenging family lives. Many of these students by the age of 20 are on their way to becoming pre Diabetic. Having a program to instill the importance of moderating sugar intake for these students would be great. |
| 557 | Early Intervention, IHSS, respite, Medi-Cal |
| 558 | Transition from school-aged services to adult services is abysmal. Meaningful work opportunities, independent living opportunities and the supports needed to allow people with disabilities to be meaningful participants in society are lacking at best and non existent at worst. |
| 559 | Early intervention in the home (0-3), and we are trying to get respite in the home since I can't leave her with anyone who is not trained so I only leave the house for Dr appointments. |
| 560 | The standards for the child to meet are very low. Once the delayed child meets this very low standard they are considered helped enough - graduated from services, but given nothing else to help them, but they're no where near being able to compete with their typical peers. |
| 561 | We need better special education supports for the general education teachers so that students with intellectual delays can be fully included in the general education classes. This should be a common practice not a fight with the district to receive inclusion. |
| 562 | It all starts with early education, that is a given, train when young. My other answers we have yet to experience, but I view them as our priorities as our now elementary age child grows up. |
| 563 | Speech therapy is not available for children under 3. |
| 564 | all are scarce |
| 565 | Very few recreational activities for people adults with autism and behavior issues. |
| 566 | Waiting for self determination to be implemented looking forward to housing to be more available |
| 567 | Lack of housing options, for persons who use wheelchairs |
| 568 | Support staff through community vendors are not paid enough to allow them to live in Santa Barbara. There is no longevity of support staff and therefore there is a deminishment of quality service. |

Survey Monkey Results

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| 569 | <p>Leaving the Public School system is the area of most concern. Parents are not being properly prepared for the TRUE opportunities for their consumer. They are lead to believe they'll get jobs and welcomed into the adult world. False...very few will actually be qualified for any work program. Work program, ADC and B-Mod program are the actual choices and they are limited on how many of those programs can full the need.</p> |
| 570 | <p>Help in the school setting</p> |
| 571 | <p>I have found that many individuals are not able to access services for their health. There is a lot of fear in the older population around going in for health concerns or problems the naturally arise with aging. Housing is an extreme area of need. The only solution is an increase in affordable housing options. Individuals with developmental disabilities are limited to part time employment, usually in a limited position. Greater partnership between local businesses and agencies may expand the options.</p> |
| 572 | <p>Affordable housing is very limited here. Meaningful employment options are also very limited. We seem to have plenty of sheltered employment opportunities, but I'd love to see more community partnerships that would allow our clients to have more opportunities in typical work settings (with appropriate support). And, since funding for social recreation programs was cut from our budget in 2008, there has been a need for recreational activities for our adults. Children have these needs too, but there are more resources for this age group. Our adult population is pretty much limited to Special Olympics (which is not suitable for or preferred by everybody).</p> |
| 573 | <p>Every week we receive multiple requests from families calling our office (we provide respite care) asking if we can refer them to someone who can help them with their daily childcare needs. Most have made multiple calls to licensed childcare providers in the community which cannot provide the level of supervision needed by their child. Compounding the problem is that TCRC only pays \$3/hr for childcare for kids under age 12, unless a health & safety waiver is requested. This low rate is supposed to account for the "supplemental supervision" required specific to the child's disability, and not meant to fully-fund the childcare cost that any parent would be expected to pay.</p> <p>The problem inherent here is that community childcare staff are paid \$10-\$14/hr to provide group care, and most families typically only pay \$3-\$5/hr for full-time childcare. Statewide advocacy is needed to remove the median rate mandate to RC's for childcare, and to raise the childcare funding rate to a practical level that will actually allow community childcare providers to accept our kids. This giving parents more options for both spouses to work and for siblings to be cared for at the same childcare.</p> <p>-Sharon Francis Channel Islands Social Services</p> |
| 574 | <p>The "threat" to ending supported employment will cost many people jobs as they will not be employable in regular jobs due to behaviors and lack of ability. SLS/ILS are valuable services that cannot survive due to low reimbursement rates and rising costs. Many landlords are refusing to accept section 8 vouchers and people wanting to live alone are challenged in finding 1 bedroom or studio apartments. Current rules that prevent providers from owning housing units and renting to clients has a negative effect to the overall housing picture.</p> |
| 575 | <p>Many of our older clients need supports to be able to work in our community. If we had somebody who could actively solicit job opportunities, I suspect more of our consumers/clients would be out in the workforce of our community.</p> |

Survey Monkey Results

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| | Our health care system is small, specialists come periodically. Many of our clients have to travel five hours or more to receive medical care beyond the everyday illness type of stuff. |
| 576 | Mostly families want babysitters. They like to call it ABA, but usually it's just to get free baby-sitting. Why not just offer it outright. |
| 577 | Areas of need transition from exiting high school age 22 to adult programs |
| 578 | There is a lack of funding and opportunities for recreation, people are lonely, isolated, and don't have the money or opportunity to participate in activities. It is difficult as a provider to offer more opportunities due to money constraints, lack of funding/reimbursement for activities, and increases liability. It is not worth the risk most of the time. Many of our folks have been victims of some sort of abuse or could be and again lack of reimbursement for this type of education/training in this area is not funded. The new bill having vendors partner with Dept. of Rehab. will not solve this issue due to companies needing to open a completely separate non-profit company, if not already established. This is a costly investment obtaining separate insurance, maintaining non-profit status, and addressing liability issues. |
| 579 | Transition information, recreation opportunities and specific self personal ADL growth opportunities. |
| 580 | ALL THREE ARE ALWAYS NEEDED AND I'M 63 YRS OLD. |
| 581 | Employment in sub minimum wage group working in a very large high tech company cafeteria, RC caregiver financial support in supported living leased home, local transportation, training. |
| 582 | Supplemental Composite Score Summary Table |
| 583 | There are NO support groups of any type in my county (Monterey), and I have to wonder "why?". The hospitals, the County Office of Education, SELPA, CHADD -- all seem to believe there is little support for parent-support groups, but statistically there MUST be a need here. |
| 584 | Health-1. Dental Care is a serious concern. Also sensitivity training for doctors. Recreation-Too many adults with dd sit all weekend and watch tv Community living in local communities or nearby to maintain family support/connection |
| 585 | There are very few day programs that are able or willing to support adults with autism who are on the low functioning side of the spectrum We know that early intervention results in better lives in the long run. Everyone deserves to work and to have their efforts valued. The push to eliminate commensurate wages, will result in loss of work opportunities for some people with greater support needs. |
| 586 | Safe, reliable and affordable Transportation is one of the biggest barriers to both work and recreation that people with disabilities face. A lot of entry level jobs have shifts that fall outside of regular public transit hours on central coast. Going on a normal evening date (dinner and movie) almost impossible unless they are willing to pay as much for taxi as they are for the dinner and movie....with no job, how's that gonna work? |
| 587 | I needed real help with an appeal of a regional center decision and it was difficult to get. I wish all parents got a primer on navigating Medi-Cal, IHSS, GGRC, CCS, and the local public school special ed dept. Each is a bureaucratic maze. |
| 588 | Our son is transitioning from full-time employment in a sheltered employment situation to minimum wage employment. We were concerned |

Survey Monkey Results

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| | that he was only working 4 hours a day. Then his employer decided to keep the crew engaged by supplementing the work time with community activities for 2 hours. I am worried that the changes will cause his employer to find this business model unprofitable and my son will be out of a job altogether. The waiting list for Section 8 housing availability is too long. |
| 589 | Advocacy |
| 590 | I have experienced a severe lack of real community jobs for people whom we serve, as well as a lack of great and appropriate healthcare and housing options. |
| 591 | Essential are employment that pays a living wage and is not dependent on higher education. Additionally, affordable housing and adequate public transit is needed for independence. |
| 592 | Not enough employment networking to build jobs, I have attended one abuse training in ten years in this field and it was about getting through the abuse not preventing the abuse, peoples choices are taken away without them even knowing they have choice |
| 593 | Self Advocacy President from 1999-2003 CAC President 2008- 20011 SCLARC Board member 2000- 2003 2006-2008 2008-20011 |
| 594 | Little to no transportation assistance to father, with limited mobility and being legally blind. Ramps are too far away from areas needed the most. Father fell downstairs. |
| 595 | From my own experience, I can say that early intervention is the key for our children to be successful in their lives, Child care is very important when we have a child with disabilities because it's hard to go back to work if you don't have a person who you can truly trust with your child. Employment, is a big issue since once they child gets out of the school system, it's very important for them to have a place where they can work and get a pay check also a place to call home is something the adults and their families need since it is hard for them to find an affordable one |
| 596 | Lack of Mental Health and awareness in Lake County, despite the repeated meetings with the Board of Supervisors, Need Peer Support Specialist trained to work one on one with clients/Behavioral Health / Regional Center of California, and the State Board. Lake County has to be the worst county for services, we are the third depressed and have a huge homeless population with a huge number of mental health issues. |
| 597 | All people want to be self determined, not just Regional Center clients. Housing and employment are 2 of the cornerstones of self determination. |
| 598 | Provision of services that allow someone with special needs to achieve their personal goals while being with their families and not being pushed to fill some "artificial quota" designed by people who do not know them or what they want in life. Having services that follow through on agreements made during team meetings. |
| 599 | Lack of places to include daycare for special needs kids qualified people. Enough educational support for kids 3-22 Not enough support for inclusion in general Ed |
| 600 | drivers training, job coach, |

Survey Monkey Results

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| 601 | As a Special Education Teacher, I have often been frustrated with trying to help students and families connect with social/community/employment opportunities for high school/college age groups. Most often the problem results from lack of or inadequate funding. |
| 602 | Schools provide many needed services. It is important that a good IEP is established and enforced. It is also imperative that the IEP is incorporated into the IPP so that the caseworker makes sure that the IEP is followed. |
| 603 | Housing is always a big issue with rental history, deposits, etc. |
| 604 | I think resources are so limited in our area that community supports employment in housing are critical for people with disabilities to be safe and independent. |
| 605 | We've not found something that fits our child (#1). All through his life special Olympics was not for him, he couldn't connect/relate. |
| 606 | It is often difficult to get the services mandated by state law in the more remote and rural parts of the state - there simply is not the expertise available. Perhaps someone can research alternatives for things like speech and behavioral therapy, occupational therapy, respite care and similar services. |
| 607 | lack of community education in schools and elsewhere that help the general population understand the differently abled and our societies prejudices that need to be overcome. |
| 608 | Responsive employees with Tri-Counties to go out and assess individuals and connect them with services and housing. |
| 609 | The provider community is being strangled by California's DDS budget cuts over the last several years (30). Rates have been frozen and the DDS budget has been cut by a billion dollars. This is causing a shortage in staffing and high turnover. This in turn is causing a poor quality of life for the people being served. Anything the State Council can do to encourage the state to increase the DDS budget is very needed. |
| 610 | People living in hotels or Convalescent Hospitals when they need a permanent home. Housing in this area is too expensive for SSI. No and limited transportation. Lack of real job opportunities. |
| 611 | day program and transportation |
| 612 | transition smooth from hs to adult agencies. collaboration |
| 613 | The schools have very little resources. Individuals with disabilities in my community do not have many options for their life post-school. Programs and resources are extremely limited or nonexistent. |
| 614 | 1. Because of tight school budgets it is difficult to get all the educational/counseling services these students need. Many students would benefit with having a SCIA (one-on-one aide) but budgets can't support that. There also needs to be a state mandated teacher/student ratio for Special Day Classes that will enable student success. Because I am a K-2 teacher most of my students are too young to understand quality assurance, but the families need education in their rights and classes on safety/abuse prevention. |
| 615 | Established Rates and reimbursement structure do not support employment first outcomes. |

Survey Monkey Results

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| | <p>There is not enough affordable housing available.</p> <p>Expansion of and supports for people to understand and benefit from self-determination is needed.</p> |
| 616 | <p>Social programs for young adults or rec classes would be helpful. More inclusivity</p> |
| 617 | <p>There are limited good resources in this county (Solano) for persons with developmental disabilities. There need to be more classes or certificated programs in Life Skills at the community colleges. Really do believe it's time the community colleges stepped up and offered educational/vocational programs or make life coaches available.</p> |
| 618 | <p>Difficulties with properly accessing FAPE and related services for my 3 developmentally disabled children; SVUSD's (and Moorpark College) "agreement"/Memorandum of Understanding TCRC which essentially serves as somewhat of a "gag order," stripping away an individual's right to seek advocacy from Regional Center during IEP meetings and other important meetings with the school district (within Ventura County); a lack of information/desire to work with us from TCRC service coordinator Cheri Lanier re: self-determination; difficulty accessing and/or being given information re: Formal and Informal Community Supports by TCRC.</p> |
| 619 | <p>I've seen huge success with early intervention and would love to see more in this area. I also work with high school students and I know that a lot of them struggle with employment and transportation, especially after graduation.</p> |
| 620 | <p>No support for the residents! Service coordinators have no feelings for the residents they are suppose to serve.</p> |
| 621 | <p>lack of jobs for individuals who have low skills and work very slowly. We need a lower min wage for individuals with intellectual disabilities so they are able to be employed and still provide value back to their employer</p> |
| 622 | <p>Getting early childhood service, and diagnosis in our area, was difficult</p> |
| 623 | <p>We have to fight for our daughters education. There should be a more streamlined system in place.</p> |
| 624 | <p>IEP support.</p> |
| 625 | <p>Children with combination disorders but not autism are overlooked. Sensory processing isn't on the spectrum, resources for this type of disorder are next to none and education and support are zero in humboldt county.</p> |
| 626 | <p>We've had issues with our daughters IEP and it's been nothing but a struggle and fight to get her the services she needs and deserves.</p> |
| 627 | <p>Health, housing, advocacy community support programs...</p> |
| 628 | <p>We have many individuals capable of working, but they are often not considered for employment opportunities; those that are offered opportunity are often given very few hours (10-15/wk) and many are expected to have support staff even if they may not need it. I feel that the most needed service is one that would provide a job coach to assist individuals in applying for employment and assisting them in being successful in that employment. Some may always need assistance, but others could easily fade the assistancne and likely perform very well on their own; I see many individuals with disabilities that are extremely capable and reliable, more so than those without disabilities in my opinion. Self-determination adn abuse prevention is key to creating safe independence and continuing to empower those with disabilities that historically have been given less power and have not been treated equally, with respect and dignity.</p> |

Survey Monkey Results

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| 629 | Young Adults with Special Needs have trouble finding appropriate employment & housing. I also feel that their safety is critical as they can become victimized (sp) . This population is very trusting of the general public. |
| 630 | The funding crisis for our system is resulting in a dire lack of housing, employment, and transportation options, and service providers who are skilled and quality-minded in these areas. This is especially the case in the Bay Area. |
| 631 | We need more affordable housing needed for low wage earners. Better transportation to get to jobs at odd hours. More opportunities for jobs. |
| 632 | Health: it is extremely difficult in our area to get medical support teams (doctors, nurses, medical office staff) to understand the needs of our clients. Housing: it's again difficult in our area to find housing for our clients. Transportation is a huge issue in our area because many of our clients need to go out of county to get good medical help. |
| 633 | At present, there is a conflict of interest - the agency that identifies a child's needs - must pay for the services. The funding is based on the organizations needs - not the child's. There is no developmental justification for ending services at 3yo. |
| 634 | Education. My son is in a preschool that He and I love. It is right next to his sister's elementary school and that is where we want him to go for K-5 BUT YCOE is saying that he will go to the school THEY choose, NOT the school I choose. Why is it that they can let him go to a preschool, make friends and then not let him move with them into Elementary? Why can't he go to the school I (who knows him better than anyone) know is the best fit? Why can't he get to go to the same school as his sister? Why is it okay for me to move my NT child but not my ASD child. It is Discrimination! |
| 635 | Working in a day program for 30 years, there have been no increase in the funding we receive for an extremely long time. Rents and utilities, gas and vehicle maintenance and utilities have increased exponentially. We have not been able to give out staff increases in salary for over 10 years. We cannot find jobs for out clients with programs like "Work-ability" working for free. Early intervention continues to be the best course for individuals to receive help early on. |
| 636 | Testing in school and learning support |
| 637 | Information on possibilities A DDS/RC Section 8 look-alike program until Section 8 rental assistance is available from PHA Ways to reduce the bureaucratic nonsense that goes on within regional centers |
| 638 | More access to dental services and transportation to get to dental providers. Need root canal and periodontal specialists |
| 639 | My daughter is 7 yrs old and we have NBRC. She did get early intervention and that was great. But we definitely need more supports in place. What happens to our kiddos when they age out of the system? |
| 640 | For self-determination I believe as a family member it is important for my family to be part of the process. Recently, I did not sign a IPP that indicated I was part of a meeting I which I was not. My point is include us it will make the system better. Respite needs that are not appropriate for family needs and then push families into considering outside placement. Does that cost the state more? |
| 641 | More workites are needed for supported employment both individual and group. |

Survey Monkey Results

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| 642 | <p>Lack of quality and adequate childcare for families, which includes care for adult clients</p> <p>Community supports for clients are extremely limited and many clients with significant behavioral issues are excluded from many of these programs.</p> <p>Quality Assurance: services for clients are not client-centered, but rather funding-centered/providers are paid a very low rate to serve clients with high needs</p> |
| 643 | <p>Housing is most crucial for my high functioning son who wants to work full time and does not get ssi and is making 9.30 an hour with no chance to move up. Housing is impossible.... So expensive.</p> |
| 644 | <p>Respite and some behavioral supports</p> |
| 645 | <p>In the N. Bay transportation is an issue and persons with disabilities can only find it during M-F, day hours. This has inhibited their employment search.</p> |
| 646 | <p>Early intervention</p> |
| 647 | <p>Would like to see programs at school continue into the late afternoon and/or have programs to help the teens be active and gave schedules during holiday/summer breaks from school. Most parents don't gave that time off, it's hard to find help for those hours as well because from 3 to 6 is such a short amount of time, it's not feasible to hire someone to help when it's mist needed.</p> |
| 648 | <p>Dept. of Rehabilitation is not coordinated with Regional Center. Question the interest of DOR identifying and finding jobs for Regional Center clients. Self Determination needs to be coordinated with development of housing subsidizing and with Sec. 8 vouchers that do not take 5 years or more to obtain.</p> |
| 649 | <p>There is a need in Alameda County for a Licensed Pediatric Day Health Center dedicated to providing nursing services in a day care setting along with and early intervention to children with special and medical needs. IN combination of comprehensive nursing care with invaluable childhood experiences of play and socialization. This would be in addition/ to supplement or an alternative to in-home nursing care. This will further support families in returning to the workforce to become contributing citizens and provide a sense of ease as their child' medical needs are handled by trained helath professionals WHILE the child socializes with others.</p> <p>More places for Respite: George Mark Children's Home changed their funding and some families are no longer able to recieve services.</p> |
| 650 | <p>Need more accessible, affordable housing. More transportation options. Employment training and supports.</p> |
| 651 | <p>In Mendocino County CA, it is very difficult to find housing for clients. Locals to Mendocino explain that this is due to a sour history between adults with disabilities and landlords which stemmed from when the institutions were shut down. Allegedly, there were a lot of squatters who had disabilities and landlords have been wary ever since of renting to this population.</p> <p>In terms of safety/abuse prevention, I think that vendors and agencies need to have mandatory training for mandated reporting. I have worked in an SLS company in the past that did not train staff on how to obtain, complete, and submit reports for Adult Protective Services (APS) or Child Protective Services (CPS). Staff for vendors need to be made aware that the phrase "Mandated Reporting" means that they are held legally responsible for reporting even SUSPECTED abuse of a dependent adult. Where I worked before in SLS, staff did not receive proper</p> |

Survey Monkey Results

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| | <p>training on what would necessitate an APS or CPS report. Instead, if we observed anything, we were to tell management, who would then file the APS report themselves. However, the problem with doing that is: what if the management abuses a client? Having Mandated Reporter trainings for vendors, and proof of such trainings submitted by the vendors might help workers feel empowered in the care of clients. Self-Determination is the third option that I selected because I feel that it is always a priority that those with disabilities understand their rights and responsibilities, that they make informed decisions, and take charge of their own lives as much as they possibly can. People with disabilities have goals, dreams, hobbies, likes and dislikes, political opinions, opinions about where and with whom they would like to live, where to shop, work, or go to school. At no point should any type of service provider, social worker, medical specialist, or anyone else infringe on the basic rights of people with disabilities. Clients should know that they can receive information about services or products that could assist them, and they should have those choices presented to them as options rather than as mandatory obligations. People in the support team have the responsibility of making sure that clients have as much information as possible to make the choices that are the best for them.</p> |
| 652 | <p>I work with transition age people. It has become more and more difficult to help individuals access work and/or day programs in our area. We just don't have enough programs available that address the individual needs and challenges of our clientele. There is a similar problem with housing, but not quite as much.</p> |
| 653 | <p>In our area there is a severe lack of services especially for clients who have graduated recently. Day programs, independent living skills services, transportation, transportation training, work programs, supported employment, and supported living are all needed.</p> |
| 654 | <p>As a Regional Center Service Coordinator, I feel that the community supports for our clients are limited and not easily accessible (this includes individual, family, and group therapies, parent support groups, psychiatric follow up and not just med reviews, and activities that make accommodations for children with special needs so that they can participate as well. Health-this goes back to therapies and psychiatric follow ups. Currently we have two psychiatrists in Ukiah and neither one is able to provide weekly, bi-weekly, or even monthly psychiatric follow up, rather it is a medication review every 6 months. Safety and Abuse Prevention - other than working with an RCRC funded behavior agency, there are not community resources available to parents and clients to increase safety awareness. Also, parent support groups. This is something parents ask me about on a regular basis. There is a need in our community for the parents to be able to come together and be supported.</p> |
| 655 | <p>Employment in our counties is difficult all around. Add that with lack of adequate transportation due to living in rural communities and employers who may not understand the benefits of hiring someone with a developmental/intellectual disability and gainful employment is hard to come by. If clients had gainful employment, they may be better equipped to increase their own education and/or afford adequate housing. Clients who are considered high functioning are finding it difficult to receive the supports they need in elementary, middle and high school settings, and even more difficult if they want to attend college as there is very limited college prep classes or instruction in our local schools. I also believe that Self Determination should be at the top of everyone's priorities.</p> |
| 656 | <p>Lack of affordable, safe housing continues to be a barrier to independence. Quality support services (SLS/ILS) are very difficult to acquire.</p> |
| 657 | <p>I work in resource development and these are the areas that come up the most often as requiring the most development, support and/or</p> |

Survey Monkey Results

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| | monitoring. |
| 658 | People with skills who cannot find appropriate work languish at the mall! I see way too many abuse reports. We have not addressed the issue of teaching people how not to be victims to have friends. I don't have the answers, but people have to value themselves and have access to healthy food, true friends, opportunities to truly "belong" to their communities. Maybe need more community education? |
| 659 | Mental Health- local Mental Health is in shambles and RC vendored psychiatrists are not taking referrals as they are booked solid. Employment - Dual diagnosis clients need specialized employment situations as present vocational training vendors cannot deal with behavior issues. Housing - Why the state refuses to raise rates for residential homes is beyond me. SLS uses up the biggest chunk of our operating budget. Many clients are best served in a residential home setting and they are slowly all closing as rates make it impossible for them to survive, Lack of affordable, safe housing for individuals with fixed lower incomes, this affects all citizens. Also, the lack of skilled, knowledgeable, local generic resources that can affectively work with, treat, support persons with complex needs - including medical and dental personnel, mental health resources, etc |
| 660 | The cost of housing in most areas of the state is completely unaffordable to individuals living on SSI/SSP, forcing them to continue living with family long after that is a truly positive situation, and long after other adults w/o disabilities would have moved out. As a broker for people in self-directed services I have personally seen what can happen when people w/ disabilities take back control of their lives - not just what services they get or what cost savings may occur for the state, but people's belief that they are competent and can make decisions that others will listen to, instead of the very paternalistic system that most people find themselves in - even if well intentioned and thoughtful. |
| 661 | Far too many people w/ disabilities are being hurt and abused -which is obviously a problem in and of itself, but I often wind up working with those who have taken that experience and then turned it on themselves or others, creating far bigger problems down the road. |
| 662 | No enough paid employment, not enough low income or wheelchair accessible housing, inadequate health care-especially dental needs |
| 663 | It is very difficult to find quality respite help. They pay very little next to minimum wage which attracts less qualified people. These sitters need to be ultra qualified when working with special needs individuals. Thus they need to pay more to attract qualified staff. |
| 664 | Limited employment opportunities. Need for safe affordable housing. Gaps in medi-cal funding and lack of medi-cal providers. |
| 665 | more opportunities for supported living, such as residential care facilities, and community day program opportunities that allow access to the community as well as opportunities to engage in meaningful work, whether through volunteer or paid employment |
| 666 | Inadequate educational staffing support. |
| 667 | As a new consumer, my daughter, with my assistance investigated vendored IL service providers before she had her first IPP meeting. I spoke by telephone to several agencies before we visited the one that seemed likely to be a good fit for her. She enjoyed interacting with the staff and they were very responsive to her. Since she has a dual diagnosis, her comfort was paramount. At the IPP meeting her service provider agreed to submit her request to the committee. The committee assigned her to a different service provider. There was no explanation from the |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | committee. I felt that our efforts to find a suitable service provider were disrespected. It was not a good start for my daughter. |
| 668 | With ILS my staff do an excellent job doing meal planning, cooking, and other things. I'm really happy with these services and they make a really big difference in my life and need them. With employment I need help to make sure I'm doing my job right so I can keep my job. With transportation/paracruz I've been frustrated and wondering why they keep having to rebook my pickup time to earlier times than what I choose and they make a lot of mistakes with booking. |
| 669 | I live in Davis. Pretty good services but I have begun to see few options. Folks having to travel to Sacramento to get more variety. Services not keeping up with the times; still old school in many ways. Employment seems very limited. I really wanted to say transition, as my biggest concern as an advocate is that folks are not exposed in the high school years to what is out there. Not even sure if parents know about services. Really don't feel the Regional Centers advocate for people. They don't share information, families have to do all the work! They have become too big!! Can't meet people's needs. |
| 670 | For many years I've been working with area board9 they been able to provide my family with efficacy and direction on where to go and what to do and how to do it I've been very pleased with the services of advocacy. |
| 671 | So far our he has only benefitted from respite services and supplies (I.e. Pull-ups) |
| 672 | Employment. Traditional working environments for competitive employment. Education can come later after working. Stopping the 18-21 funding, and just make it adult funding would get individuals that are 28-45 employment so they can contribute to society. Many times individuals that are 18-21 are not good cohorts for looking at this, the need is seasoned workers to get into employment. Housing, finding apartment type complexes that are receiving any types of subsidies w/residents of 200 or more units, requiring 10% of their residents be developmentally disabled, w/o it being solely restricted to veterans, so there is a chance for integration w/in traditional community settings and marrying up their hired staffing needs to reflect IHSS, ILS, SLS, personnel at the apartment complexes...similar to senior citizen apartment complexes. Some have suggested that senior apartment complexes take on singular 10% developmentally disabled individuals into them, because they are using the same support services. Also, there are communal events in these types of settings. |
| 673 | More housing in San Luis Obispo. City bus training for SLO. More jobs for the disabled. |
| 674 | There are not enough program options for adults with developmental disabilities, autism and behavior challenges. Programs do not meet the unique needs of the young adults that need appropriate services and options for work. |
| 675 | Advocacy for my sister. |
| 676 | Child care programs need training about appropriate services to parents with intellectual disabilities and their children. There needs to be better quality and monitored ILS services and more appropriate intervention for parents with intellectual disabilities and their children. Cost of transportation is a huge barrier to many services. |
| 677 | Community Supports - I am able to attend events from recreational programs if they are planned out well in advance. If I would like to go out on a weeknight (such as say the farmers market) I am unable to go because I am stuck at my group home because there is only one staff that works. |

Survey Monkey Results

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| | Housing - I live in a group home that I enjoy but my we continually lose staff. We completely lost all my staff (6 staff) in 2015 in my house Quality Assurance - If there are problems that I have and my homes staff is unable to help me I need to have a place I can go to help me get the answers I need |
| | Community Services - I have had trouble with my In home living services. It took me a year to find a new service because many companies have shut their ILS services down. No I have found a new company but they are having trouble finding staff for me. |
| 678 | Housing - I have been fortunate to live on my own for a while now but many of peers have not been able to and have asked me how I was able to live on my own. |
| | Quality Assurance - I have had problems where my direct support staff are unable to figure out how to solve my problems. I am able to go to the SCDD Central Coast Office and they are able to answer my questions everytime. I have refereed these services to my peers many times. |
| 679 | There is very little programs for children aging out of the education system. People have little choices as to what is available for special needs children as the age out of the educations system. |
| 680 | I don't feel the schools are equipping themselves with the right kind of information to assist some individuals |
| | I've experience a lot of bullying, abuse at home, and from people in the community. It's 2015 and people still aren't used to seeing an adult with a disability. I've gone on many outings in the community and from my experiences it has been uncomfortable and frustrating. |
| 681 | Uncomfortable when your getting stares from citizens in the community like were doing something wrong. Frustrating when business's in the community are not helpful and patient with adults with disabilities. My biggest issue would be transportation. Many times when taking the RT bus drivers have been rude and inconsiderate . |
| 682 | My son is quadriplegic (38 yrs old) and considered medically fragile - there are no groups homes for him here and I am trying to set up my home, but there are few supports. Casa de Vida is not an option. |
| 683 | My son got the early intervention from school I think that was great for him but wish they could of gave him more time than twice a week for 15min. |
| | There is not any out of home respite sites in our area. Camp does not qualify for this anymore. |
| 684 | We have had trouble finding dentists who accept MediCal. There is not a lot of recreation experiences for intellectually disabled children. We seem to fall in a gray area where our daughter is too advanced for some things, yet too mobile for others. |
| 685 | I was told from my regional center there were only four programs for me to chose from and of the four only one even came close to what my child would be content in. Two of the four she didn't even qualify for after I made the phone call to find out what the program was about. |
| 686 | I am a special ed teacher for severely and profound students in Kindergarten, 1st and 2nd grades. I have taught special ed for 34 years. Through my teaching I have interacted with all types of student services, especially speech ,APE, and OT and PT services. I have also helped the parents to try to get the correct health services. |
| 687 | Most individuals in my area with DD need more service providers that are familiar with the local area and Spanish culture or who can speak |

Survey Monkey Results

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| | Spanish. Families tend to not support their family members in service delivery because they themselves cant participate in meetings due to lack of transportation or conflicts per work schedules. |
| 688 | drtgere |
| 689 | If I needed a job I go to VTE- UC Davis for dishwashing/ If i get more other jobs I go to CES for Davis/ If I get more activities and work on my math and budget, I go to No Barriers in Woodland also I got from No Barriers helped me to go to get a volunteer job at computer concepts from the director of No Barriers Joseph Zavala. Get more job opportunities and experiences in goals and skills. |
| 690 | My son receives services through Maxim |
| 691 | Need services, opportunities, access and proximity to recreation for social and recreation resources, assistance. Employment - no opportunities - not ready. Too long with transportation, poor. schools not preparing. |
| 692 | None |
| 693 | education: early intervention is important, all services need to be continued to adult age. students continue to make progress even as they get older. services in education seem to fall away the older they get. Housing: many many families are in need of affordable housing. also more housing is needed for persons with disabilities who wish to live independently as adults with support. Self determination: these skill need to be reinforced with families and individuals. to often they comply with regional center requests rather then formulating their own ideas and needs and then getting the services they want. |
| 694 | We are concerned that the sheltered workshops will be shutting down. The Hope Services workshop in Gilroy has been an important part of our sons life and cannot be replaced with inclusion programs. Housing is also a large problem, we have yet to find an acceptable option and so continue to have our 26yo son live at home. |
| 695 | School related services are insufficient and it is horribly expensive to pay privately even when your insurance will help (due to copays) for what is needed. Also we could not get aba through regional center because we got our asd after 3. |
| 696 | Many clients are not involved with a job or day program. Many are wanting to feel valued and important and able to be independent |
| 697 | We desperately need housing for my sister-in-law who has Aspergers and lives with us. She needs independent living skills so she can learn how to clean up after herself and daily tasks such as putting clothes away. She drives and makes her own meals and is at PRIDE in Natomas, but she needs housing away from family and no one helps us with that. She needs ILS to learn to complete daily tasks. |
| 698 | Lack of transition services, difficulty even getting the regional center to respond to my three special needs children. Allowed out of home care and when one plans a vacation, even a year ahead of time, there is no coverage for vacation. There should be permanent vacation beds in which you can schedule your time up to a year in advance. |
| 699 | The services that I have experienced with help cleaning my own cottage, and learning how to learn who is safe and unsafe through friendship check lists has been wonderful. |
| 700 | Getting quality health care, dental care, equipment----e.g., wheelchairs, hearing aids, etc. |

Survey Monkey Results

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| | Living in poorly regulated homes----homes remaining open with substantial deficiencies. Waiting lists for community support services |
| 701 | When I was a child I received educational support for my teachers. I was involved in special needs classes, they helped me meet my educational requirements that I needed to progress in life. |
| 702 | In our area it is hard to find inclusive recreational experiences for our 10 yr old |
| 703 | With the help of Housing Choices Coalition, I have my son on the waitlists for multiple affordable housing 1 and 2 bedroom apartments in Santa Clara County. The wait time is long and in some cases his income (SSI only) is too low to qualify. He is also on the waitlist for " section 8 housing" |
| 704 | Advocacy for my sister by SCDD local agency there were able to help me. |
| 705 | Staff and teachers not following the Educational Plan or making excuses not to follow the educational plan. |
| 706 | Employment and Housing |
| 707 | I see families who care for a severely disabled child who have a difficult time with getting respite care and competent child care or activities for their child outside of the school day. |
| 708 | Employment: More training Self-Determination: I get to make my own choices. Housing: More affordable housing. |
| 709 | My mom has a bus service that picks her up but she has to pay 3.00 each way to use and i would say 5-10 times there late or a no show. |
| 710 | In remote areas the services are poor. We live in SOutH LAke Tahoe. Very few training opportunities.NO College welcome...Our Dis resource center is pathetic. They do almost nothing (one ILS CLASS twice a year) for people with DD. We have NO living arrangements being developed.. No SLS.... we are invisible here. |
| 711 | Regional center not willing to provide behavioral support without reducing my respite hours. My son's diagnosis has changed because of no one to help him transition in the classroom regional center refused Behavioral support For 3 years, so did the school. My son now had a diagnosis of emotional dangerous fm lack of behavioral services. |
| 712 | In Education, our family member has been incredibly lucky to be included in a number of pilot programs - Autism Spectrum Inclusion Program (ASIP) in Oakland Unified School District, and currently, College Link Program (CLP) at CSUEB. These programs have been a tremendous help and success for those people who were lucky enough to get into them. Pilots like these need to be copied in other education districts, and need to be expanded where they've already exist and made more affordable at the college level. Employment: my autistic college student is majoring in theater arts and wants to become a voice actor, working in computer and console games, apps, and cartoons/anime. There's no path to that, and we're trying to find a roadmap for him, help him get an agent, etc. He's done voices for one iPhone app "MotivateMe", which was a project of a computer science student, who "discovered" my son standing in line at an |

Survey Monkey Results

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| | <p>off-campus pizza parlor. We need to find ways to help nurture gifts, talents and interests, and get them paid for what they can do.</p> <p>Housing: He's still living at home, sharing a room with his high school aged brother. I've been trying to get him to live in the college dorms since he started attending in fall 2010. The CLP program has supports (life skills training) for their students who are living on campus. But somehow, we keep missing out. I'm not sure why.</p> |
| 713 | <p>My son with autism is 14. He is in the gap of not being old enough for some programs and too old for others. For any recreational activities we have to go to Thousand Oaks area and Conejo Recreation because there is nothing in Ventura /Oxnard area. Why is this? No summer activities especially! My other complaint is that my service coordinator at Tri Counties doesn't seem educated about resources and ideas about areas to help my son. Thank goodness he goes to Triton Academy for school.</p> |
| 714 | <p>Schools do not adhere to IDEA and use public money to fund attorneys to fight against the disabled child. Regional Centers do not adhere to the Lanterman Act.</p> |
| 715 | <p>Residential Care that is fraudulently lacking. Very poor oversight by CCL and the Regional Centers. Lack of understanding and execution agreed to and funded services and supports regarding the needs of the Autism population in Residential Care. Lack of choices in Residential Care, no real ABA models and no real structure in the homes. 6 in a house is too many and sharing rooms is unnatural past the very young ages as well as the lack of individual privacy in shared rooms. Providers exit clients when parents insist on adherence to law, IPP's and the program designs agreed to by CCL and Regional Centers. Complaints ignored unless parent is willing to stay on it throughout process and insist on completion and result. Often it is the parent that has to do the investigative work.</p> |
| 716 | <p>People who have intellectual and other developmental disabilities tend to be low-income therefore need jobs and vendors to assist with finding jobs as well as affordable housing.</p> |
| 717 | <p>Employment with job coach through DOR (department Of Rehabilitation).</p> |
| 718 | <p>help with becoming more independent accessing the proper support services available help with finding a job</p> |
| 719 | <p>My son is presently 28 and living in a group home. He was in the Simi Valley early intervention program and I am convinced that without this program, he would be more severely disabled. Employment is limited; I think it is horrendous that companies are allowed to pay disabled people less than minimum wage. My son will never drive so it is frustrating that transportation is limited; especially when one has to transfer from one bus to another and there is no coordination so he needs to wait an excessive amount of time for the next bus.</p> |
| 720 | <p>Resources are scarce and difficult to access</p> |
| 721 | <p>My daughter lives with her family in our home. She attends post-secondary during the day. I have a very hard time finding someone to take care of her when she is not in school and I am at work. This is early mornings and late afternoons. I cannot find a nurse who wants to do shift care due to the low pay. Finding dental care is another issue.</p> |
| 722 | <p>Need individual help for the family.</p> |
| 723 | <p>Research demonstrates the critical impact of big investments in early intervention on outcomes throughout the life span. QA is needed to ensure highest possible quality of supports throughout the system. Self-determination must be the foundation of all supports so that people are</p> |

Survey Monkey Results

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| | empowered rather than dependent. |
| 724 | With all the recent changes in regulations. It is becoming increasing difficult to find employment and to offer work training programs for people with intellectual/developmental disabilities. |
| 725 | There is poor accountability for results in SpED and thus too many kids are in "separate but unequal" school settings rather than fully mainstreamed. The related services in schools are very subpar (PT, OT, SPL) and this needs to be augmented to not lose these children. How are we actively looking to influence and solve the 80% unemployment rate by people with ID/DD locally? Do we have enough job coaches, are community members aware? Do we have companies that are partnering to give internships and jobs? |
| 726 | Our son lives in a Community Options Home but has also been in a number of group homes. He uses Ride On to get to his adult day program. We have developed a non profit that provides sports & recreation free to athletes with intellectual, developmental and physical challenges. There was not a local program that provided this; our son is very active and needed such a program desprately. |
| 727 | I have received help from Goodwill and they have been great at Job placement and community integration |
| 728 | Our daughter lives in a Housing Authority subsidized supported living home. There is always a possibility that the landlord will sell, and our area of Santa Barbara has very few rentals that are available. To move her out of her community would upset her life greatly so we are always concerned. In the health area she needs good dental work frequently under anesthesia to keep her mouth and her whole body healthy. This is hard to find and fund. As parent vendors we provide lots of support to get our daughter into the community in ways that she can participate. What happens when we can no longer do this? |
| 729 | occupational therapy, early childhood education, employments opportunities, housing in rural areas |
| 730 | More education to get employment. More bus service and education/support to use the bus more. |
| 731 | Residential Program for children ages 13-17 |
| 732 | Tremendous need for supports for adults with autism, including Aspergers. Housing, daily living support, job support. |
| 733 | As a support staff I would like to see some focus on the wages paid to support staff across the board. A wage that allows more people to chose this work and/or continue in it long term would provide stability to individuals receiving these services. |
| 734 | Due to trailer bills back in 2009 (?), recreation, social, camp etc. were taking away. Need to bring back these services to help w/social program and be included. |
| 735 | We are constantly faced with providers leaving due to rate issues. |
| 736 | Housing scarcity for DD adults. Job training challenges. |
| 737 | First responders report that they don't always feel comfortable or sure of themselves when dealing with people with disabilities. My pediatrician didn't know where to refer me when she diagnosed my baby with a developmental disability. Transportation systems don't appear to collaborate with one another to ensure consistent regional coverage or scheduling - there is no one-stop shop for getting anywhere. Educators |

Survey Monkey Results

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| | and doctors don't feel comfortable being honest about assessments and diagnoses - which doesn't help parents deal with grief or coping or finding and using available tools. |
| 738 | Lack of programming and employment for high functioning people with autism and Asperger's. Housing, in general, for people with disabilities, especially people with behavioral challenges. |
| 739 | Just to continue to offer in all areas the information so each individual can be a supportive part of our community and become as independent as possible. |
| 740 | Intense child care and support needs for the past 16 years; housing needs as they transition to adulthood |
| 741 | There is an extreme lack of supported housing options with viable supportive services for a range of adults with intellectual and developmental disabilities. The number of adults with ID/DD will triple in the next ten years. What is California doing to prepare for this?? |
| 742 | Housing is the #1 problem that needs to be addressed. Second is programs/options after HS. Few exist for the moderately disabled. |
| 743 | My daughter is 27 years old and still lives with me. She needs to be able to live safely with friends in the community. There is no housing available for her because of the high cost. Funds are needed to assist with housing and the supports she would require. She is in a good day program, but transportation is difficult because of the low pay - they can't get drivers. Both the day program and the regional center pay for staff is lower than what people can get elsewhere and so they have a difficult time filling positions with good candidates. And more training is needed for people like my daughter to learn to be independent before the housing and services are available, rather than waiting until they area. That's too late for them. |
| 744 | Throughout her school years, we had to fight for everything she received, even though she was entitled to it by law. Services for integration into the community were very limited. Now that she is "graduating" at age 22, there are again limited services as far as work & being with her peer group. The Sonoma County Office of Educations Special Ed program has been the best & I wish these services continued throughout her lifespan. |
| 745 | MY CLIENTS LACK HOUSING OPTIONS AND WELL TRAINED, STABLE SUPPORTS STAFF BOTH FOR DAY PROGRAMS AND SUPPORTED LIVING. THE INTENSIVE MANAGEMENT ISSUES ARE HANDLED PRIMARILY BY AGING PARENTS. THERE IS NO PLAN B WHEN THESE PARENTS ARE UNABLE TO CONTINUE IN THIS ROLE. |
| 746 | My son is a dual diagnosis guy and these new 15 bed delayed egress facilities around the state frighten me. I am afraid when he gets ejected from his community setting due to his mental illness he will end up in one or essentially be locked up. |
| 747 | dental services for student's that require anasthesia. Adequate mental health professional to monitor medications. |
| 748 | Need for appropriately trained one-on-one support. Need for accommodated employment. Need for state funding agency personnel to think outside the box and help figure out a way to make it work. |
| 749 | we have private health insurance, so that has not been a problem. Our greatest need is assisting our adult dtr. with transportation needs to and from appts, since my husband and I work full-time. I usually exhaust all my sick leave, vacation to tend to the needs of my adult dtr. who has |

Survey Monkey Results

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| | these special needs. |
| 750 | Unfamiliar with Early Intervention - but it makes sense, especially for people with autism. Carved and custom employment opportunities seem like a win/win for people with I/DD and employers. Know of too many examples of sub-standard or unavailable health care resources for people with I/DD. Mental and dental health care should really be called crisis intervention at this point. Serious need in these two areas. |
| 751 | Arc of San Francisco is a great help with project search and. more fund should be provide for that, Please do not cut any funds. |
| 752 | Limited housing availability. The principles of Self Determination need greater acceptance, not just a "program". |
| 753 | People with developmental disabilities are ridiculously under-employed and are in desperate need of housing and self-determination options. |
| 754 | Transportation is hard for individuals to get around and it makes employment opportunities more challenging. Affordable housing is difficult to come by and makes it hard for people to live alone if that's preferred. |
| 755 | Regional center says my 18 year old homeschooled son must have a certificate or high school diploma before they provide a job coach, even though he is not going to get that for some years yet, and wants to start working part time, but needs a coach. The school district they refer to as funding source does not have these programs and they know it. |
| 756 | My son is 19 with autism. I have been looking for adult day service for him. Found one that I really like. wait list is #65, maximum occupancy is around 130. When will he be able to get in? What would he be doing in the meantime? Employment: they need a meaningful life. Not sure how to get employment for them. Housing: with Silicon Valley's housing cost, how are they going to afford housing? what will happen when I and my husband die? who will take care of them? all these issues.... these children are growing up fast. There is not enough services available in the adult population. Reduction in services due to budget constraints as well as difficulty in recruiting and maintaining qualified staff at all levels. There are more needs at all levels, an ever increasing # of persons with autism and severe multiple needs, fewer appropriate adult vocational and housing opportunities for a growing adult population |
| 757 | self advocate |
| 758 | Case Referral Run-around has deteriorated. While funding reform is underway, families need an engaged advocacy committed&funded to close the gaps where all good efforts fizzle to NBE - No Beneficial Effect for clients. For instance - incentives promoting Section 8 vouchers are essential to prevent homelessness &/or institutionalization of people like my son. Instead, a game of hot-potato helpless reflex spends much time and resources, whereas a cheaper, simpler and more effective method is a simple, direct insurance premium to cover the perceived&actual risks landlords experience from Housing Choice Voucher tenants who are developmentally disabled and receive Supportive Living Services from a Regional Center. |
| 759 | Health- lack of doctors and other health care professionals trained in the specific needs of DD adults and children |
| 760 | Total lack of affordable housing for adult population. Upends families. |
| 761 | Affordable housing for care providers. Trained individuals to provide support services. |

Survey Monkey Results

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| 763 | There is a lack of options for transportation to after-school services for special needs youth which then means they don't get to access them. In the educational setting, Project Cornerstone ends at Elementary level and there is a huge failure to incorporate those youth in an inclusive way at a time with friendships and peer support means the most to them. |
| 764 | Not being able to provide support and referrals to children with disabilities to appropriate agencies due to wait list or not meeting certain criteria |
| 765 | A good Education goes a long way towards more appropriate work. Safety from abuse of all types of mistreatp |
| 766 | Adult Day Programs, THAT PAY MORE, FOR BETTER TRAINED JOB COACHES. I have a severely developmentally delayed adult, with some difficult behavior, due to seizure meds. My son could do more, if he had more experienced/trained job coaches. |
| 767 | 0-3yrs Hope Infant program. Physical/occupational Therapy Regional Center Social Workers |
| 768 | "But what of the generation who were born before 1980, who may have had Asperger Syndrome but for whom there was no diagnosis available? No specialist clinical teams, not even the concept of AS. How did they fare? The answer is that they were overlooked, and struggled through their school years. " and still struggle... http://iancommunity.org/cs/articles/very_late_diagnosis_of_asperger_syndrome |
| 769 | We are hoping to get help with a summer camp for our autistic boy |
| 770 | crisis supports for individual with aggressive behavior when family can no longer handle it but there are no appropriate placements; housing for individual with potential aggressive behavior but who is helped by being much more active than group homes, programs that serve individuals with behaviors in ways that interest them and so help them become more engaged with others in constructive ways; assistance with developing housing options for our adult children by supporting the development of scattered housing sites with supported living or other forms of individualized supports so that people can truly live and be involved in their local community |
| 771 | The DDS adult autism population is exploding. In the state, it will double in the next five years and triple in the next ten, to 42,000. |
| 772 | ABA therapy for home based children. Speech and occupational therapy. |
| 773 | Transportation services to and from DAP have negatively impacted the day programs ability to support all folks getting into the community due to delayed arrival and staff have no time to perform other necessary duties/trainings due to arrivals that exceed program hours by almost 2 hours. |
| 774 | Limited options for adults with disabilities, both in housing and employment. |
| 775 | education and early intervention- my brother received less than adequate services in Pennsylvania, the state where he grew up. Very few choices as far as education and schooling. Health- my brother received adequate health services as a child and continues to as an adult |

Survey Monkey Results

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| | <p>Employment- very limited opportunity for dd adults. my brother has worked in sheltered workshops, outside employment, training programs, day activity programs. His best experience was probably in workshops- he felt as if he was contributing to his community by working. That being said, these workshops seem so.....20th century. We need to do much better, not just nuts and bolts in a bag. Although nuts and bolts in a bag is definitely much better than the day programs he has been involved with. These day programs are basically day care services, and if i see one more group off dd adults waiting at a bus stop, drinking coffee at a Starbucks, wandering through a mall, hanging out in a library...well you get the picture.</p> <p>Unfortunately, my brother was unsuccessful at working in the community. While it certainly sounds like a great idea to work independently in the community, the reality was that my brother needed too much support.</p> <p>Can't there be a vibrant training center with a work component. A training center that has really great programs for independent living, arts and creativity, real work training and also some work. I think we need to try new innovative programs</p> <p>Persons with disabilities are always in need of adequate housing depending on the specific disability, health care that specifically addresses their respective needs, and transportation. Though transportation is better, access and reduced wait time needs to be addressed</p> <p>Will experience a need for support for a somewhat independent adult</p> <p>I have been trying to find after school programs that my grade 3-5 M/M students can participate in such as art, music, sports, etc.</p> <p>Young adults need more advocates to find and secure employment. We have limited resources for jobs in our area.</p> <p>Child care</p> <p>When my son was below 3 yr old.He received early start services and showed lot of improvement.These early start services are very important for people with disabilities.</p> <p>Hope these disability kids get some small jobs and live their own life.</p> <p>Education needs to be tailored to the need of the individual - my son was mentally gifted, however, his district had a one size fits all approach. After filing for due process requesting regular classroom placement with appropriate support, they gave in and created a class for him with 10 sighted students and him. This was still inappropriate because it was conducted in the same room with other VI students with only a low bookshelf between the two groups. After lobbying in Sacramento and the US Congress, the people I was with were advocating for a full range of program options depending on need. I was astounded at the number of elected officials who believed students with disabilities should be either in regular classes or special ed. classes, but not both. As an educator, I quickly learned that even students with disabilities do not learn in the same way, nor at same time. To be a good teacher, I had to adjust for the need of my students, ie. have my auditory learner read their lesson into a tape recorder and then play it back as she visually read. her assignment. She went from an F student to a A student in all of her classes. PS my oldest son graduated from Stanford and is trying to pass the Bar. My youngest son graduated from USC and is a working musician and gives individual music lessons.</p> <p>1) Many clients with intellectual disability appear to have difficulty acquiring medical (MediCal) support as needed because their parents are not made aware that thie child need state MediCal, rather than the HMO for which the rest of the family was signed up.</p> |
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Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | 2) Regional Center (parts B & C) in San Diego is not assigning early intervention clients to the services they need; for example even when a child lives in the SDUSD and an evaluation is performed by RC, they child will receive a "Home Educator" and ABA although in fact they need OT or PT or ST. Then by the time the child is assessed by the ECSE team, they are over three and had lost at last one year of good input. Now why can't there be a dual intervention? Schools don't have funding for ABA, but they have credentialed teachers, so can't the child be in SDUSD Infant Program and have ABA from another agency? Why can't there be collaboration and one agency supplementing another rather than isolation of services.? |
| 784 | Respite Services shlb be made available to Family Member inorder for the person to maintain sanity .Parents need breaks so respite services will be good.Also DayCare for Special Need kids. |
| 785 | The earlier we help these clients the less they need help in the future, We need to empower and educate parents and caregivers to promote independence from the start. |
| 786 | More job skill training for students. |
| 787 | Education - parents need advocacy support to get appropriate services and resolve problems Employment - direct service staff and regional center staff need training on customized employment, providers need rates restructured. Self determination - info for individuals and families, ensure regional centers follow the spirit of self determination |
| 788 | There is a large disconnect between the educational system and transitioning people with disabilities to the adult world and helping them be ready to lead productive lives. There are few opportunities for more disabled people to earn money as adults. Lack of transportation for those who can travel via van or bus is lacking outside of public school. Summer break nothing to do without transportation. Afternoon, weekend activities need transportation. Employment: public schools and Regional Center do not coordinate to establish jobs. DOR should come in the establish a job (paid or not) before the end of the Transition program. Young adults are stranded in day programs without a job. Families really, really, really need childcare. The cost is staggering. People need to manage their families and work and community needs along with raising a child with special needs. Families are struggling. |
| 790 | There is lack of support in all the areas discussed. |
| 791 | Respite hours, Medi-Cal services, SMSC, special olympics, Sports 4 Exceptional Athletes |
| 792 | Direct representation |
| 793 | Teachers that are not capable or have the capacity to teach children who have disabilities. Many times these teachers don't know how to teach or communicate with children with disabilities makes it very frustrating and detrimental for a child or student with disabilities or is a special needs child. |
| 794 | Employment- support employment, sheltered workshops, competitive employment and entrepreneurship Formal and informal supports- same as listed Safety/Abuse Prevention- SEEDS, Serra High (one of my schools) developed a student specific sexual and community safety program |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 795 | Not enough preschool classrooms, not enough specialized programs to address functional skills needs and skills that can be transferrable to employment |
| 796 | Early Intervention is critical to long term outcomes for all students with disabilities. The research shows that the amount of intervention a child receives decreases the intensity of need later in life. Currently, there are more children with special needs than there are resources. |
| 797 | As a parent and advocate for other parents, childcare is a huge issue. A parent working 9-5 in the summer is desperate for childcare - childcare from someone capable of taking care of their child, and their particular disability. Respite does NOT cover this. Not enough hrs. |
| 798 | To ride the bus to Jackson to meet my worker to grocery shopping. |
| 799 | There are not sufficient and quality housing or employment opportunities for developmentally disabled adults in Orange County. For example, the waiting list for HUD Section 8 vouchers is 7 to 10 years. This is unacceptable. Also, there needs to be more employment geared training programs at all Community Colleges in Orange County that emulate the success of the programs for the developmentally disabled at Cypress College. |
| 800 | Transportation |
| 801 | N/A |
| 802 | I am the conservator/advocate for my sister with CP. After aging into adult services, the only option for employment that has been made available to her has been supported employment. This option did not last long as my sister was truly demoralized by the unfair pay rate and the lack of challenge. The paucity of employment options and fair pay is a huge issue. |
| 803 | More work a bility programs, job opportunities, training and life skills. |
| 804 | I get calls frequently from the parents of individuals with developmental disabilities looking for supervised housing in the Santa Cruz area but there is really no place to refer them to. |
| 805 | Most of our clients are seeking employment in the community, but have great difficulty securing sustainable employment. We also receive several requests for assistance with housing, as many clients cannot rent a place on their own on their SSI payments alone. Lastly, most of our clients live in North County San Diego, which has a limited public transportation system that is very time consuming for consumers to utilize. |
| 806 | need for transport,housing,education,proper diagnosis for health plan,early intervention for proper transition into appropriate area of need. |
| 807 | People with developmental disabilities have the right to self-determination. The current changes in the Lanterman Act have eroded those rights. The limited supply of accessible/affordable needs to be addressed. Employment services needs to be restored. Agencies providing this service are disappearing due low reimbursement rates. |
| 808 | Lack of affordable housing |
| 809 | Self Determination is where it all starts. Without self determination, a person with intellectual/developmental disabilities will not have the drive to better themselves and seek employment. The lack of self determination often times stems from abuse sustained while growing up. If we can stop the abuse and boost self determination then persons with developmental disabilities will be more empowered and will inevitably seek |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | employment and careers. |
| 810 | A lot of apartments are not accepting section 8. There's not a lot of help with housing. |
| 811 | Housing and services for African American males. The number of homeless AA citizens living on the streets with NO HELP and NO HOPE. The number of AA citizens in jail and prison rather than getting mental health services. |
| 812 | Early Intervention/Education from 6 months (diagnosis). Having support was vital to learning how to care for and advocate for our child with special needs. Respite is a must! We were fortunate to find someone who fit with our families needs about 10 years ago & she is now like a member of the family. She is truly amazing! |
| 813 | We have not had much experience with good services being provided for folks who need SLS. The companies do not operate with an individualized person-centered model despite claims to te contrary. Additionally, there are VERY limited job supports available unless folks want to work in a sheltered workshop. DOR will not provide services, and the only services available in our area are through the company running the sheltered workshop so in our experience folks are not given much choice or control in where they work. |
| 814 | Transportation, independent living and respite |
| 815 | we are hearing disable |
| 816 | I don't understand his ? |
| 817 | Disimination of information regarding available services. Affordable, accessible housing. Financial assistance. Reliable transportation. Employment training and opportunities. Support for families & caregivers. |
| 818 | Education: There are MAJOR problems with k-12 "special education" system that need to be addressed. These problems include stereotypes, discrimination, restraining, wrong aggressive tactics as punishments, suspensions, lack of community building, segregation, bad teachers. The first thing that could be addressed, is simple education to teachers and staff about the DD community, self determination, disability rights, and disability pride, so that teachers stop treating students like non-humans. Employment: Major lack of jobs for people in the community. There seems to be ample amounts of job training programs, but the jobs they are placed in after are either unpaid, or underpaid. They need equal opportunity employment! and not with Goodwill or something like that! Equal pay! Self-Determination: DD/ID folks should be able to be in leadership positions, know their community and peers, and have an understanding of their community needs to make decisions for themselves but also on boards, committees, task forces, etc! |
| 819 | Harbor Regional Center help, education, home visits and resources |
| 820 | Education |
| 821 | I help this young lady (now 51) who needs a social worker to help her. she has been robbed twice and taken advantage frequently. |
| 822 | Although I am not a person with an intellectual/developmental disability, I am an advocate with in the disability. There is a great need for all |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | of the above services, however, the services I have checked are the most important because these provide a foundation to be laid for every person with an intellectual/developmental disability to be able to live a good, healthy, happy and satisfying life. |
| 823 | Need for day program that is not babysitting; need for support in the entire process of finding and keeping employment; need for housing that provides both support and respect. |
| 824 | Well over half of our work at an independent living center involves housing. |
| 825 | More early intervention along with more support thru schools meeting each individuals levels of education. More health options dental and vision support. |
| 826 | lack of qualified respite providers. Transportation issues |
| 827 | Supported employment opportunities are needed for meaningful employment that is satisfying for the worker. Independent living and supported living opportunities are not available in south Orange County CA. No housing available in Irvine and in southern Orange County. |
| 828 | Many consumers want to work but they cannot get there due to the lack of public transportation. As well, consumers wait over a year to get into affordable housing. |
| 829 | Working on community committees to further employment. |
| 830 | My daughter needs and uses extensive help with housing, living independently, help "translating" the world around her so she can participate in it, figuring out bus lines, etc. she also relies heavily on her people with the Regional Center and Lifeworks. |
| 831 | We are a small community and our business owners are very much involved but there are not enough jobs to go around. We have Rec nights through ARC but not many opportunities for weekends or weekend activities. Transportation if good during the week but there is no transportation weekends for our people to get around outside program. |
| 832 | Not enough QUALITY respite workers. Not enough QUALITY adult programs for individuals with behavior needs. Not enough QUALITY group homes. Programs need to be better funded to insure QUALITY. |
| 833 | I have encountered numerous people that have encountered difficulties with medical devices such as walkers and wheelchairs and the difficulty to have them looked at or fixed leaving that person not being able to leave their home or using and unsafe or in situations where it takes many months to even be assisted. |
| 834 | I have to drive everyone in my family everywhere because we are not within a mile of a fixed route and 2 members could not wait at a stop without a bathroom and supervision. |
| 835 | Not enough choices for ILS/SLS. Weed out services/programs that are no longer relevant or reflective of best practices. More employment support options. Promote collaboration amongst stakeholders. Housing affects everyone; we need to be at the table whenever affordable housing is the topic. Providers can't. to be stretched to the breaking point w/ unfunded mandates. (See On the Brink report of the DDS system). |
| 836 | Housing, SE |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 837 | Early intervention programs that provide quality programs/resources so the children have a solid foundation to build a healthy life. Respite for the parents, so as to maintain a balanced, happy family unit. Quality Assurance... It's challenging to determine what services are available for a child with special needs. We spent a great amount of time searching for such services. |
| 838 | education, transportation, respite |
| 839 | Recreation, Housing, Formal and informal community supports |
| 840 | in home respite |
| 841 | In Transition program for my 19 y/o daughter. Great service. |
| 842 | Health - should be able to EASILY get all care that they need...Medical, dental, vision. |
| 843 | The clients with aggressive behaviors are having a difficult time accessing resources that meet their needs. Transportation is not equipped for our clients; Day program services are very limited or do not work with the service provider in the best interest of the client. Rate of pay for services is not sufficient to supply services needed by current population |
| 844 | It is extremely difficult for my consumers to get jobs that pay minimum wage. And it is becoming almost impossible to find Section 8 housing in San Diego, and for people without Section 8, rents are out of reach. Transportation corridors are limited and even worse on weekends. |
| 845 | The Council does an amazing job of making me feel that I matter. They help tremendously when it comes to individual advocacy -- by offering suggestions and guidance when individuals and their families seek support and understanding about options available to them. |
| 846 | Housing in the community. You can't close DC's without community housing. You can't have Supported or Independent Living Services without housing. There will be no full inclusion without housing. AND, housing take money. Recreation is needed for everyone. Especially for adults who are beyond the school age. Adults with autism need something for them in each community. |
| 847 | I've received respite care, early intervention services, educational assistance, and community support for my family member. |
| 848 | Difficulty finding employment- lack of Dept of Rehab assistance is a major barrier Accessing formal and informal community supports is difficult- everyone point to the other agencies t provide assistance to people Self Determination- will it every become a reality for people to chose it! |
| 849 | Programs to allow my child to become more independent. Transportation which is a plus for working parents knowing that they have safe transportation to and from programs or work. |
| 850 | As a parent of a special needs child, we find that the services provided are very helpful to us. They provide emotional and physical support to our family. The caretaker have provided relief to our family and mental support. |
| 851 | The students that I currently work with need more life skills including jobs/training, support from the community services, and life skills |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | English and math. |
| 852 | I am the parent of a 12 year old boy with Down Syndrome. Early intervention & education has been very valuable. Respite is valuable for parental breaks and knowing our son is with a caregiver that knows how to interact with our son and keep him safe. |
| 853 | Not enough respite providers as they are drastically underpaid. The 2009 budget trailer bills also took away funding for some very important and needed services for people with disabilities. |
| 854 | My daughter is 16 years old and is currently in school and the family receives respite services. Hopefully there will be a good opportunity for her to live in a safe home and have a good care provider. |
| 855 | Need for more work programs and tailored day programs and behaviorists that will follow through with their assignment !!! |
| 856 | There isn't enough trainings in my area and my respite hours are very little |
| 857 | More respite hours and transportation services are really lacking. Our daughter cannot drive and we spend every evening taking her to activities. We can never go on a vacation longer than a couple of days. |
| 858 | My 20 yo son is in Supportive Living. Is job is an unpaid internship. |
| 859 | Respite is the most pressing need , would be lost without it ! |
| 860 | My son received early intervention in school and attended a non-public. Received a certificate of completion. Found a supported job. Lives with supported assistance in his own apartment. Regional Center has been and continues to be the key element in order for his life to work: And, it takes a lot of Advocacy as a parent and for him as a participant. The stress has left a mark in both of our lives! |
| 861 | My child is a young adult who is struggling as he tries to get a job. Although he is in an educational environment which encourages students to look for jobs the concept and the steps he needs to take seem to either be confusing to hi or overwhelming.. A young adult with intellectual disabilities struggles with trying to "fit in" and they struggle with when to ask for help and when they think they are suppose to be independent. |
| 862 | Respite and early intervention |
| 863 | Once a consumer turns 22 there are very few job or leisure opportunities available. They are cut loose from services they were receiving since childhood. |
| 864 | Services are far from home. A van service used to pick up my son for his after school care, but when funding for that program dried up there was no transportation to the only other program that would accept him. |
| 865 | My child receives ABA and Respite care. He also receives OT and Speech from a local school but is unable to obtain these services over the summers because school is out. |
| 866 | Over the years our daughter has received services ranging from day programs, transportation, respite and opportunities for community inclusion. |
| 867 | Respite Care, emergency funding \$ for medical supplies, educational advocate---(no longer), advice to navigate system, social groups, etc. |
| 868 | respite care |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 869 | ILS |
| 870 | We utilize respite services (which are a true blessing), as well as transportation services for our disabled daughter. We have never had safety/Abuse Prevention but it is our biggest fear and we would like to see programs in this area. |
| 871 | Insufficient affordable housing for people with DD. No support from the state. No access to Section 8. People are forced to live in congregate settings solely because of available housing. |
| 872 | Respite has been such a great help to me enabling me to have caregiver time to recover from the great needs of service for my child with a disability. Education is so very important. Employment and the planning involved for that is of value for ensuring that all checks are in the box as we travel to the employment time frame. |
| 873 | Respite |
| 874 | My child is in ARC San Diego and receives IHHS. Life for her would be very difficult without these services |
| 875 | Respite! Regional center picks and chooses who and how many hours To give. child care, to expensive for any 1 income family to afford. |
| 876 | Service needs that people get are not as well as they could be. Better transportation, housing, more money for more activities at day programs would be great for people. |
| 877 | lack of affordable housing options, clients with more significant needs needing housing that can meet those needs, fair wages, more paid work options, not enough monitoring of services due to lack of staff and funding to accomplish this at the necessary level |
| 878 | very minimal at best. It seems as if information is being hidden and not shared with people who request help. |
| 879 | Statistics show that there is still a great need to increase competitive employment positions for persons with ID's. Parents have voiced their concerns that w/o competitive employment or an increase in SSDI their children will not be able to afford housing. MTS and NCTD lost funding for their training programs for people with disabilities and there are few alternatives for affordable transportation. |
| 880 | I receive an MTS Compass card, served in the Self-Determination Unit, and receive ILS services. |
| 881 | socially isolated, living in poverty, lacking access to basic health and dental care |
| 882 | I have heard that once those in the DD population are in their group homes (evenings and Weekends) there is little if any recreational opportunities. I also think that something needs to be in place so that if a person is ill and can't go to work or to their sheltered workshop, there is a way for them to stay home with a level of supervision that is necessary for their needs. |
| 883 | Education & Early Intervention: Services are important not wait until the youth is out of school to provide benefits counseling, financial literacy, asset development, etc. Parents should be required to complete this step to assist the government to educate, promote and evaluate the best interest for their youth with disabilities. Disability awareness is not promoted properly to the communities, employers, educational facilities, faith institutions, corporations and community leaders. In today's globalized marketing, we still don't see people with disabilities been displayed in billboards, television shows, media, posters and etc. Remember if you want people with disabilities to fit in today's society, you need to have them be part of the daily lives of individuals. People will recognized them as contributors to our labor force and society when |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| | they see them as part of their lives. |
| 884 | The need for Supported Employment Services is evident in the lives of our clients. With the minimum wage increase, employers seem to be wanting more bang for their buck and our clients' earning potential is a direct result of available work in the community. Some of the clients will never be capable of integrating into the streamline of working in the community, especially without support. |
| 885 | People are not getting the support they need to get jobs. |
| 886 | Difficulty accessing community programs(generic programs, after school, childcare, youth development) due to disability |
| 887 | Schools are not preparing students with disabilities to become members of the work force. Children are not getting IEPs to help them progress forward rather getting IEPs that reduce schools responsibility and funding |
| 888 | poor health services, no dental or vision services, no transportation in rural areas after 7:00 PM, not enough subsidized housing and difficult to employee |
| 889 | Education - I have found that without the proper education/knowledge individuals are often unable to make the best decision. Employment - Living at or below the poverty level restricts an individuals ability to enjoy life, liberty and the pursuit of happiness, the rights provided in the Declaration of Independence and our Nations Constitution. Employment can open doors of opportunity. Self-Determination - I am a firm believer of the independent living philosophy of nothing about us without us. Every one needs to be equipped with the knowledge, skills and ability to determine their own destiny. |
| 890 | My adult son is employed and doing well, but needs a better understanding regarding self safety and protection regarding extortion and sexuality. Another huge need is in the area of health. His meds cause weight gain, but there are not "built in" exercise routines within his day (day program) |
| 891 | most medical transportation is gone in our area doesn't take Medi-cal any longer. No one tells you what services are out there you have to research it yourself and even then are told they don't do this anymore. |
| 892 | Employment is limited by the communities lare of understanding about peoples abilities. Housing is difficult to find and maintain due to limited availability. Transportation via public bus system is very limited on Saturday and there is none on Sunday. |
| 893 | lack of affordable housing and wheel chair accessibility. Have to drive for two hurs to get dental care as son has to be asleep to have dental care and had 22 cavities and teeth pulled by the time he was able to get an appointment. Takes a year to get in for care. Services being cut to the bone and workers paid low wages so he has a constant turnover in his care that jeopardizes his health conditions and he ends up in the hospital for lack of training by staff. |
| 894 | More housing for developmental disabilities |
| 895 | Serving people in employment I often found that these workers need an additional amount of support to keep transportation, maintain adequate job performance, and the handling of daily life challenges. With a little more help, they often maintained a great deal of autonomy and engaged |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

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| 896 | fully in the local community. |
| | With so many Developmental Disabilities, effective early intervention reduces the needs for services later in life and also improves outcomes. Advice that my parents received, testing I had, and therapy such as swimming really helped me emerge strong and capable. |

Survey Monkey Results

Question 3: In the areas you checked, describe the services and supports you need but have not received.

California State Council on Developmental Disabilities Survey Monkey Results: 5-year State Plan Needs Assessment

| | | Response Count |
|---|---|----------------|
| <i>answered question</i> | | 697 |
| <i>skipped question</i> | | 415 |
| 4: What kind of training or information would you like to receive? | | |
| # | Response Text | |
| 1 | Finding ways to create healthy and safe living environments Over site of current and future vendors for housing, respite, behavior intervention, etc. Greater respect of the needs of parents/caregivers | |
| 2 | Better and more public transportation to include Fallbrook. | |
| 3 | They can offer to pay for my vinego passes as well as taxi scrip. | |
| 4 | Training on how to navigate the system of support at the various stages. Such one for parents of young children, one for parents and the individual as they are transitioning into adulthood | |
| 5 | Teaching them with assertiveness together with self-advocacy and making them aware on the forms of bullying and abuse in order to avoid it and step up from it if experienced. | |
| 6 | Help get business to hire people with ID | |
| 7 | eliminate regional center | |
| 8 | I feel that transportation could be improved. our people on limited incomes can not afford to buy MTS tickets if they do not have a job or go to a day program. I have seen over the years that when someone does have a job they receive a lot more tickets than they need. As our clients become older and don't want to go to a program anymore there should be MTS tickets available to the elderly client to be able to get out and have access to resources as it is not always easy to find affordable housing near convenient accessible resources, The landlords that accept Section 8 have greatly decreased in the last few decades. | |
| 9 | Transportation and early intervention. | |
| 10 | An increase in respite hours provided to families with special needs children would offer much needed help. | |
| 11 | More training and education to self-advocates and the provider community on the Employment First policy, bills that would impact employment services, and information and training on self-determination. | |
| 12 | Support equal and quality employment opportunities for consumers. | |
| 13 | Assure Olmstead is implemented. Make sure Regional Centers are doing what they should for housing and reaching out to communities and | |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | not just working in silos. |
| 14 | Stay in touch with the visibly impaired community what our needs are with what I mentioned above |
| 15 | Promote more services to the community |
| 16 | I don't know how the State Council can help other than to help provide more support to our advocating agencies and help to ensure that places like our group/private homes that are paid/funded through the state are living up to the quality that our kids need and deserve. No body deserves to be locked up and only spoken to when there is a directive or an issue to attend to. |
| 17 | Begin preparing/educating young adults w/DD and their families about what they'll need in their adult lives earlier than junior year in high school; assign each family with a "Transition counselor" to help them prepare for transition; educate employers as to the benefits of hiring from the DD community |
| 18 | Empowerment for the families and the individuals with disabilities: training, grants to open daycare centers run by BCBA, provide advocates to go to the schools |
| 19 | Help us know what resources are available and how to obtain them. |
| 20 | More and intense services training to teenagers |
| 21 | Increase funding to provide adequate services |
| 22 | assure that Lanterman and IDEA are being implemented; provide oversight and advocacy |
| 23 | Keep sending us information that is up to date. Most people don't know their kids' rights or how to obtain them. Do anything you can - no one else is doing anything. Realize autism is a spectrum - a highly varied spectrum. my 18 year old son who has a 117 IQ and received a diploma is in a work program hanging up clothes because he has never had the social skills available to him through school or Regional Center, or any type of behavioral help, and now that he has been kicked out of college due to outbursts. The work programs are all based on low intellectually functioning people - not high functioning with other issues. Where is the "I" in IEP and IPP??? |
| 24 | Please provide answer #3!!!!!!!!!!!! |
| 25 | Self advocacy training should begin in high school. Our disabled young people need to learn how to advocate there needs and the sooner we can teach that the better. We need college programs that work with these students. Job training and safe housing options. |
| 26 | Support their inclusion and involvement as full members of the community. Work with us to educate those who do not understand developmental disabilities. |
| 27 | Are they planning at all for the young adults who are aging out??? what will are people do and where will they work?? |
| 28 | provide necessary funding for intellectual/development disabilities to prevent languishing in underfunded facilities with substandard care. |
| 29 | pressure the CA Dept of Education to create a fair Due Process system. Currently the CDE picks the hearing office and has a conflict of interest and families rarely win. New law needed that says that if a consumer doesn't have an attorney the school district can't have one either. Same is true for Regional Centers. |
| 30 | Provide or secure a resource for advocacy, especially with IEPs. I have called the DRC, Area Board 3, and all other agencies on the past and either did not get a return phone call or was told they don't do IEPs unless the issue is systemic. |
| 31 | More Funding |
| 32 | Provide more psych help to older Clients Because you don't find doctor or hospital who take Medicare and Medical |
| 33 | By just trying to understand that this is a person with a disability - not a foreign body to be shunned. Therefore this person has the same needs |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | and desires as they do - shelter, food and care. |
| 34 | consider the person abilities along with limitations |
| 35 | Provide training, jobs, counseling. |
| 36 | Education about providers and services |
| 37 | Funding for appropriate, deficit focused services. Support groups for kids, county and mental health engagement at the school/IEP level, and CUT THE RED TAPE. Check boxes, endless protocol and useless procedures only delay services from reaching those in need. Failure should not be the call to action- interventions before kids are hitting rock bottom is critical to long term success & treatment. |
| 38 | Unsure |
| 39 | Be willing to advocate on an individual basis for families/consumers in situations when there does not seem to be another advocate and/or Regional Center is not responding to their needs. |
| 40 | Schools need to be proactively engaged in developing meaningful transition plans with goals that are relevant to the individual's needs. NOT just a couple of general goals so they can show they met the requirement for a plan. The districts here in No. CA need to engage with post secondary providers, Dept of Rehab and community colleges to begin the transition process sooner rather than later. It is a broken system in No. CA, they are not communicating with each other. CDE has \$ for this purpose but is not actively instructing the districts, voc rehab, providers, community colleges, etc. to engage. There seems to be no motivation to do so. |
| 41 | Have the people w/ID/DD AND THEIR FAMILIES, be the decision makers collaboratively to tell lawmakers what they want. It seems as if lawmakers are making rules w/input of a few of their constituents that have family members w/ID/DD, put that isn't reality. Reality is that most families are not going to have the financial means that the constituents have. So there needs to be REAL grassroots from regular middle/lower class people. |
| 42 | The purpose of the State Council on Developmental Disabilities (SCDD) is to make sure that people with intellectual/developmental disabilities and their families get the services and supports they need. I think that it is unclear to families and consumers as to what the state council can do for them and their families. |
| 43 | Just by not cutting the states funds and remain having specialist to help others with disabilities to pass off their goals in life. |
| 44 | By advocating for the quality of services provided by community non-profits who have not lost sight of the reason for their existence. |
| 45 | Have a system where the aids and special ed teachers are observed with out thier knowledge to see the real picture. My daughter is being told by aids to help supervise other special ed kids, then she helps and tells aids when thier is a problem and they say it's not your job. Well if the aids were doing thier jobs less talking to each other , on cell phones it wouldnt be a issue So glad next year is a new teacher and new aids. |
| 46 | Increased transparency. Parents don't know what services kids are eligible unless other parents tell them! Regional center or state council on developmental disabilities should make sure everyone is educated about services and supports. |
| 47 | Employer engagement, employer intensives, job development for people with disabilities |
| 48 | Provide direct advocacy again along with education/training and outreach. |
| 49 | Be a stronger and vocal voice in the State Capitol. |
| 50 | lobbying political officials so there is more awareness |
| 51 | work with supported life and help them with people who want to come the conference |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 52 | Offer policies and procedures, assist family and or advocates be better informed to follow policy and procedures to ensure "appropriate" intervention/treatment to avoid or diminish further disability and promote inclusion of impaired individuals to be members of community. |
| 53 | NA |
| 54 | Know that each has his or own needs and may need time to achieve his goals. Growth and development is a process.. |
| 55 | We need to continue educating our community so there is no stigma or fear of ones capability. |
| 56 | Continue Quality Assurance follow up; be a resource for families and help advocate for eligible students in the education system |
| 57 | The State Council needs a balance and check system to oversee the programs in the county. I have been a special ed teachers assistant for the county and I can first hand attest that our county is out of compliance on many levels. |
| 58 | Provide work opportunities / incentives for our clients to be come employed, so they can show businesses their value to their organization. Continue to provide self advocacy training to our clients - through grants vendors can apply for. Encourage alternative transportation options, especially in rural areas |
| 59 | to assist and provide any/all type of services to either the individual with the disability or to the families who will be providing their care to create a community where the providers of these individuals to work together so that they are close by to the housing where adults with disabilities to live independently and to give their parents/provider their own space and assist each other in caring for these kids who will grow up one day |
| 60 | Continue to lobby for legislation that increases budgetary support for developmental services across the lifespan so that service providers receive a cost of living increase and case coordinator for Regional Center clients have lower numbers of client caseloads so that they can develop relationships with clients and understand their needs. |
| 61 | Talk to the families and start holding people accountable for maliciously reporting families to cps with no repercussion. |
| 62 | A rate increase for vendors would be a good thing. We need to hire quality people who will stay. In order to do that we need to be able to offer them a competitive wage that will allow them to make a living. |
| 63 | Provide self-advocacy training. |
| 64 | Train assistants better in psychological relations, audit assistants better for honesty for productive hours turned in. |
| 65 | Be more open to alternative programs. The state is unduly rigid in it's ABA approach to autistic children. I know of a program which is far more effective for a fraction of the cost. |
| 66 | I lot of people and agencies say they are working to help adults with disabilities but who checking in on them? Sometimes I wonder are they just creating jobs for themselves (non-disabled). |
| 67 | Continue with outreach to the communities and trainings. |
| 68 | Facilitate better inter-agency collaboration among local agencies committed to working together for the greater good. Create better awareness of Area Boards and their areas of expertise and responsibility. |
| 69 | Provide quality services, a continuum of services crib to career |
| 70 | Provide direct assistance to individuals struggling to navigate the system and obtain services |
| | Support expansion of the FECs statewide so that parents will have local resource for advocacy, system navigation, parent to parent support, parent rights, etc. |
| | They can advocate for their rights. They can place checks and balances into the system. In addition, they can provide the services necessary to |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | meet the needs of those they support by staffing the office in Chico. They can honor their employees by abiding the labor laws. |
| 71 | Shawn is listed as autistic without speech or ability to function on his own. We need you help in keeping reasonable funding for client like Shawn. |
| 72 | Stop making the process for receiving services so difficult to obtain and access. Too much paperwork, relying on government employees who are heard to contact, or get contact back from |
| 73 | Engage in conversations with employers demonstrating unique skills of people. |
| 74 | Provide community outreach to systems such as Kaiser; medic Cal; doctors; all health care systems and community employers to begin the process of eliminating discrimination and segregation. |
| 75 | Affordable housing. Emergency housing. Assistance keeping, finding and obtaining an affordable home. |
| 76 | Look at a PFCA report from a hearing at the State Capitol, oh maybe a dozen years ago... then Just Do It |
| 77 | Increase the IHSS rate to include the 7%reduction give back and either more money per hour or overtime rates. |
| 78 | More staffing and funding for the schools, ie one on one paraeducator, one on one behavior services. Teachers need help. More secure facilities. |
| 79 | I think the State Council can better help people with intellectual/developmental disabilities by helping educate the community about the strengths and abilities of individuals with disabilities. We need to help our communities focus on what individuals are able to do and bring to the table instead of focusing on what the cannot do or have difficulty doing. I think the more we educate our communities, the more supportive our communities will be and the more natural supports we will have to support individuals with disabilities in being active and productive members of society. |
| 80 | GIVE THEM FUNDING NOT THE BULLET TRAIN |
| 81 | Provide more proactive services for adults and teens. |
| 82 | Promote awareness to employees and companies who tend to avoid hiring individuals with ID. Provide more programs that fund job coaches and on-the-job training. Continue to support and fund programs like College to Career at the community college level. |
| 83 | more funding |
| 84 | Provide them with more instructional aides in the classroom. |
| 85 | Advocate for services and funding. |
| 86 | Fund day programs for longer hours so family members can have jobs like other people. Day programs that I've encountered are only 6 hours long. This makes parents of disabled children unable to work a typical 40 hour per week job. When you have a "typical" child you can drop them at Day Care as early as 7am. The day-care will take them to their school and pick them up after school and take them back to Day Care until you get off work at 5pm and keep them until 6pm when you can get there and pick them up and go home. This is what parents of disabled children – who turn into disabled adults – need. Also drop-in respite is crucial. It would be nice to get up on a Saturday, see a sale at the mall and actually be able to go and try on clothes, maybe even stop for lunch, or get your nails done maybe with a friend (that you would still have because you hadn't dropped off the face of the earth to stay home 24/7 with your disabled child – you can't invite the friends over either because the door jams and wall corners as well as all the furniture in your home is bitten up or broken in some way and the carpet is mega-stained and while that's embarrassing enough the worst part is when your disabled family member does sexually inappropriate things in front of your guests -pretty soon people don't really want to come over) anyway - instead of having to order everything on-line (at least that's an |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

option now) and then have to send it back when it doesn't fit or look good. Also to be able to wake up on a nice day and go on a picnic with your other children AND your husband. I know, it seems like we should be able to take our disabled children along on a picnic but when he is a child that "elopes" your picnic experience is not a relaxing time like it should be. It's one of constant vigilance – worried not only that he'll disappear - get hit by a car – drown in the lake or get kidnapped but also that he's not taking other's food or drinks or pooping somewhere on the grass. And then when he's 18 and 250 lbs and takes strangers drinks or throws a tantrum until his pants fall down in front of a bunch of little girls, or possibly begins masturbating where he's sitting well we just really don't want to take him along and he really doesn't want to go. Also it doesn't allow parents to give attention to their other children because the focus is always on making sure the disabled child is not doing something untoward. It's not always easy to find a respite person (who is also a stranger in your home with your non-verbal child) especially on a Friday night when you want to go to your other children's sports activities. Unfortunately when you have a disabled child they don't grow out of having to be watched 24 hours per day. This puts a lot of stress on families. There are a lot of activities that families need to be able to do and often times the disabled member is unable or unwilling to go along. This puts these families at a great disadvantage: Not allowing them to be as supportive of their other children as they need to be and also not allowing parents to be as cohesive as they should be; Which is why I believe many parents of disabled children end up divorced. My husband and I haven't been on a vacation together in several years. We love our disabled son and don't want to have to put him in a home away from his family where no one will take care of him or love him or understand him like his mom and dad. But with the respite supports that are currently in place if we ever want to be able to have any kind of life – like most people get when their children are grown, I believe that we will have to put him somewhere where he will be taken care of by strangers and it breaks our hearts. However, if we could drop him off for a few hours or a few days or even a few weeks here and there we would be able to have a life, take a vacation together and keep our son in his own home with people who love him. This would also create an astronomical savings to the State by not having as many disabled individuals living in group homes year-round funded by the State. Instead the vast majority of the year they'd be in their own homes.

Many families of children with disabilities become second class citizens – having to stay home and watch the world go by. I took my non-disabled children to Disneyland without their father - who stayed at home with our disabled son. They had a good time but as a parent I would have loved to share their joy and the care-taking responsibilities of my "typical" children with their father. That's why we got married and had children - to be a family.

As a society we still give/hide our disabled away from the rest of the world. Only now it's group homes instead of State hospitals. We say we don't but we do. I can't tell you how many people, friends, co-workers, professionals have asked me, "Are you going to put him in a home?" My typical answer is, "That's probably where he'll end up." And they nod and say "That's good." Is that good? I don't think so. I think it's sad. While I know that group homes are necessary for some people they are also not necessary for many people. They wouldn't have to end up in "A home" that's not "Their home" if there were more supports in place like after School or after Day Program Care or just longer Day programs and Drop off Respite Care. That's what we need. Please help us. (sorry I rambled) :)

87 SC can better help people with disabilities by ensuring their safety, freedom, and advocate for them in terms of future financial stability that will help them support themselves in the long-run.

88 Gather more information on what is happening in schools in inclusion, transportation needs and funding.

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| 89 | Perhaps help find services for after program day care or extend the program hours |
| 90 | By being a resource or bridge between possible individuals with disabilities and potential vendors or exploration of possible funding for areas that are lacking |
| 91 | Stop cutting back In the budget. |
| 92 | Effective communication with family on related information/services |
| 93 | to have special counselors in the schools for kids with learning challenges to help them in planning their classes and just be there to support them. |
| 94 | By functioning as advocates when needed rather than imposing/decreasing by activism. I believe the special needs population should be identified as CLIENTS, as before, rather than as CONSUMERS. |
| 95 | Organize parents to be an effective advocacy interest. |
| 96 | Encourage and require more employers to hire people with disabilities by giving them incentives. There are far too few of the employers willing to hire people with disabilities. Create more programs to provide opportunity for people with disabilities to interact with typical peers. They are sadly too isolated and excluded. |
| 97 | Provide trade courses towards certification |
| 98 | Give us more guidance in how to find these opportunities for our adult children. We live in L.A County even though our daughter attends the program in Orange County. This seems to be a problem. Were told frequently we can't receive services because of the different counties. |
| 99 | Encourage companies to provide their own job coaching. |
| 100 | By providing services they need, like free health care, and help finding part time employment. |
| 101 | More classes for high functioning autistic as well as immersion to local community. |
| 102 | Help those without Regional Center support/funding with job coaching on the job. |
| 103 | More interaction to be sure the person is thriving and not being taken advantage of, it seems as though once the person leaves high school the backup systems fall apart. Finding a best buddy program for adults is non existent. Integration into the community is very hard. |
| 104 | Have more support |
| 105 | Help provide awareness of the challenges faced. Build business community partnerships to help educate employers. Help attain affordable housing options that are safe. |
| 106 | Medical and community support |
| 107 | Keep the curriculum challenging and the rigor up. Push districts to comply with set standards or loose funding or be fined. Don't just give them a slap on the hand and force them to get more training. Make consequences more severe so that recommendations, mandates cannot be ignored. |
| 108 | Get more housing set up for Orange County, CA |
| 109 | Have more sports/things to do that are affordable for young adults with disabilities. Also, more things to do with people without disabilities. |
| 110 | With this kind of services in schools that don't involve IEP because. IEP's most of the time don't help the student. |
| 111 | make typical private daycares accept a minimum of disabled students per ratio. Private daycares do not accept students with disabilities. A child with autism has behaviors and the typical private daycares kick them out because they have no hitting, pushing, disruption policies. Change the law so that each typical daycare privately funded and licensed has to meet a quota of disabled students in attendance. For students |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | that have significant disabilities, they could require a one on one to attend so that the students needs could be met. |
| 112 | Improve the quality care of state-licensed care facilities, Adult Residential Facilities. DSS licenses these, but has insufficient staff to monitor well, and can only respond to complaints. There is no oversight/audits over the use of the funds. Most of these places are dumps where owners embezzle the monies and pay unqualified staff minimum wage. I don't want to put my family member in one of these places, but have few options. |
| 113 | Better centralized resource listing of VETTED/quality community resources and services - both for intervention and recreation. Provide financial assistance for proven additional/alternate therapies (such as therapeutic riding for autism/sensory issues) that may not be accessible to families due to cost. |
| 114 | Provide support groups and services for parents who are advocating for their children with learning disabilities. Provide direction for parents who are seeking answers. There are no resources for parents who have been denied services for their children. I had to educate myself on my home computer. It is an unfair advantage that the school systems have over the parents and the state needs to recognize that! |
| 115 | I don't know |
| 116 | give every kid and parent the chance to receive help or support |
| 117 | Put control back in the hands of the individual Regional Centers and let them make decisions on what is best for their individual families. |
| 118 | Have better programs with easier access throughout the community |
| 119 | Advocate for funding of services. |
| 120 | ENFORCEMENT IS NEEDED |
| 121 | Work with adult agencies to ensure better use of empirical practices. |
| 122 | Providing training, information and support; advocate for their needs at the state level. |
| 123 | Work with employers to provide more jobs for people with ID |
| 124 | Open up to more Q & A. create panels with broad knowledge. Travel more to Antelope Valley for functions. Have you visited Desert Haven? |
| 125 | To start, you need more people that are knowledgeable in this area, and more available staff. Once these students are out of school, an even bigger set of problems start when there is no way for them to find employment or to live independently. |
| 126 | Figure out how to make the self determination program available beyond the few that have it now. |
| 127 | Based on the self determination, "people not qualified SD for locked up facility" must be revised because even those patients are victimized as a consequence for not getting self-determination right |
| 128 | to provide variety of classes and programs for community inclusion |
| 129 | more communication |
| 130 | Lead systems change in the area of oversight for Supported Living vendors. Correct the exploitive use of Consumer Choice. My experience is that it id used as an excuse for taking responsibility and/or protection of consumers. |
| 131 | Make parents and clients more aware of the services available to them, and provide advocacy support, as needed, to receive required services. Increase training for staff supporting clients in the college and employment settings. |
| 132 | Educate folks on what services are available and make more services easily available. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 133 | Put programs in place outside of the school system for therapy. My son is non verbal, because of this he receives no speech therapy. |
| 134 | Get funding to provide additional services and activity options. |
| 135 | Working with the state government to allocate the proper funding and resources for these programs, and for the schools to be able to properly educate children with special needs so that when they grow up they are able to be independent as possible and lead productive lives with gainful employment. |
| 136 | Please look at small community housing projects, like large assisted living facilities that have activities, classes, meals and small apartments in house. These are currently not available for people with disabilities, only group homes, which may not be appropriate and are also underfunded and closing down - especially in expensive areas like San Francisco, where they're being sold. |
| 137 | Help us get a Day program that meets my daughter's needs. Help make PCP's more available to young adults. Provide more recreation and social activities for adults. |
| 138 | Insure that medicare is funded fully, that the regional center is funded enough to have adequate social workers with realistic case loads so that they may oversee all the services for their clients in an efficient way eliminating waste and insuring their clients are getting all that is required to keep them safe and as independent as possible. |
| 139 | Provide support to regional center offices by working with the state legislators to reinstate the programs and services that were cut and currently underfunded. Non-profit agencies do not have a capacity to help those in the community who need services. |
| 140 | Support privately initiated residential projects that provide safety, jobs and community interaction |
| 141 | more advocacy to ensure that individuals with developmental disabilities retain choice and are not maneuvered into what seems to be politically correct such as managed care and competitive employment if that is not the choice of the individual. |
| 142 | Advocate for rate increases across the board for the DDS system. |
| 143 | Early Education/Better Intervention Services |
| 144 | more education , more support. |
| 145 | Provide training/workshops/conferences parents, educators, providers in our community. |
| 146 | More financial help. |
| 147 | Stop budget's cuts to centers |
| 148 | Education, directory of resources for persons with I/DD, etc |
| 149 | We require more funding. We serve individuals that are severely involve. Most of them are on wheelchairs, can not use their hands & are non verbal. We pay minimum wage with health benefits. But staff can go else where & not work as hard. They wouldn't have to bathe, change diapers, feed, transfere clients from wheel chair to bed, etc. We would have better staff if we could pay more. |
| 150 | Transportation has always been my major concern with my daughter. I was lucky with the help of her counselor to obtain transportation via Roundtrip. The system of Access and Dial a Ride may work for senior citizen and those that defend themselves but not for individuals who have poor speech and are unable to protect themselves when taken to the wrong program. |
| 151 | The State Council, if concerned about consumer rights and freedom of choice, should conduct a survey of those people working in employment training programs(often know as sheltered workshops), to see how they feel about their programs and how they feel about working in community integrated settings. The State Council should also have the regional centers do surveys of businesses in the various communities to forecast job opportunities for those with moderate to severe disabilities. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 152 | You are all doing a great job, which is greatly appreciated, but if the facilities to take care of those in severe need(s) are close I worry about them. Opportunities for abuse in community care may become very serious. At least in central sites like that in Glen Ellen can be monitored by parent volunteer groups. |
| 153 | If better services were available. |
| 154 | Train legal counsel for i/add individuals, ie: PVP attorneys, to better represent their clients desiresw. |
| 155 | Better awareness of services that are currently available for newly diagnosed families and a shorter waiting period when confirming eligibility for services. |
| 156 | dont know enough about the state councils resources to answer this question |
| 157 | Please consider increasing the number/frequency of trainings for families around accessing school, Regional Center, IHSS, Dept of Rehab, SSI, and other services. Also, trainings geared toward educating professionals are greatly needed--if more professionals were aware of what is available and how they can guide families through the often very challenging processes, it could help the families. Lastly, if the State Council sought input/feedback from professionals on a more frequent basis, e.g., could choose a topic/service area and ask for examples of where the systems are not working, I think they would get a better sense of where the major problems are, and that could drive some of their education efforts. |
| 158 | Eliminate budget cuts from 2009. Consider repealing/revising current State Law requiring families to access private insurance for services. Review and revise audit criteria for natural environment. Shift the paradigm focus of DDS auditors from semantics to solutions. Rethink priorities when considering the State budget. Invest in the First Five concept. As an Early Start Service Coordinator, I have witnessed hundreds of children successfully exit the Early Start program at age 3 with little or no continued educational support. Financial priorities should focus on spending a little now to avoid spending a lot more later on. Sacramento needs to take a step back and realize high-speed rail and Delta Smelt should not be in the top ten or even twenty of priorities. Social Services, education, and the Department of Mental Health need to come first. |
| 159 | Need more options for housing and independent living strategies. We need qualified people for respite and teaching independent living skills. Long term employment and mental health support. Desperately need more programs for lower functioning consumers. Everything is for the higher functioning and funds are being used in this category only. It's like the discriminated are being discriminated. Lower functioning people can be productive too! |
| 160 | 1) Make sure that NO ONE is left behind; 2) That any changes being implemented cause no harm; 3) Ensure that citizens with disabilities receive a preference; 4) NO unfunded mandates! 5) Consumer CHOICE is Imperative! Whatever our state's plan for implementing WIOA and the New CMS regs, these five points must have an over-arching mandate throughout the plan. |
| 161 | Using their influence and power at the state level to make sure the funding is allocated for services. This includes the depopulation of the DC's and the funds saved following the clients into the communities they choose to live. |
| 162 | Educate families that things change when you leave school. New language new process told service coordinator working for you but they answer to people and work in a process that is non responsive |
| 163 | Additional education for parents, teachers, the community and Case managers regarding the availability of services and how to get them including understanding how to appeal, what to do when told, "no" |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 164 | Fund programs that support education, employment, and community integration with individuals with disabilities. For example bookmark funding for post secondary educational funding, Workability, Regional centers, and other community out reach programs. |
| 165 | concentrate on the autistic adults that are over 22 years old |
| 166 | Believe that this group of people can learn and be a functional part of society. With appropriate intervention this group of people can be beneficial to our community. It sometimes just takes th a little longer to learn what u and I take for granted. Let's educate our communities. Our schools, our teachers. So much discrimination in School districts. It a against the law, but it happend every day. Education is key. All people r equal and deserve access to education and socialization in the least restrictive environment. |
| 167 | To help intervent in cases that help single parents of adult disabled children and not take so long to help get services. |
| 168 | Make the process simpler. Make it clearer about what services are available, how to get them, and where to go to apply. It is an advocate's full time job to wade through the process. |
| 169 | Need more programs for adults at age 22. Programs that exist have waiting list. More work programs that do not exclude adults. |
| 170 | There needs to be accountability for the success of students with disabilities, and measurable gains of success! |
| 171 | Schools have different goals; they did not do enough for my daughter or her friends. Given proper training, these individuals can be productive workers in types of work that interest them. They deserve to be paid at least at minimum wage too! |
| 172 | 1) Develop a statewide crisis home for people who need emergency placement due to severe behaviors that can't be handled by the person's family or in a group home or by an SLS. Psychiatric revolving door 5150 interventions not appropriate and can be very damaging. 2) allow more families to get involved with self determination model. 3) Provide money for creating new programs and start up money- tell the legislature this will be cost effective 4) |
| 173 | Individual case management and advocacy |
| 174 | Make sure there are trained and experienced counselors in the system - guess that means you need to increase funding so regional centers can keep good social workers and service providers can keep dedicated, smart community instructors and job developers/coaches. Fight for better transportation - hard to keep a job without it. Make sure Employment First is NOT Employment Only - We need to keep meaningful day activities. Oversight - Quality assurance. |
| 175 | support services funding |
| 176 | create a realistic plan for developing, including identifying a dedicated funding source, for creating affordable housing options in the community. The Council needs to be involved in advocating for this funding at the level of State Housing and Community Development and the Tax Credit Allocation Program level to enable the limited funds dedicated for this purpose by DDS, to be leveraged to create this housing. |
| 177 | Generate funds and grants to support organizations that provide assistance to this population. |
| 178 | Help organize recruitment programs to staff adult programs. Train, educate, assist in development of new programs. |
| 179 | Continue operating Regional Centers, group homes, and employment opportunities. |
| 180 | support the 10% increase in DDS funding for next year, plus make reforms to have the payments to the local agencies like SARC be adjusted to reflect the cost of living in their service area. Also, support a bond issue for building new government-owned housing for this population, as there is a huge shortage now and the current system primarily uses rental housing that has gotten too expensive for the clients and agencies supported by DDS to afford it. |
| 181 | More supportive vocational and employment venues. Those who can work should attempt to work. Entitlement should not breed or enable |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | avoidance for motivation, effort, contribution and participation. |
| 182 | Advocate, advocate, advocate. We must have more people in our communities that will HELP people with DD, and their families. |
| 183 | Focus on helping us with housing for people with developmental disabilities. |
| 184 | You need to talk directly to parents through the schools. Develop a better partnership. Most parents don't even know that things are available and where to go and find them. Information also should be given just on a single night at some meeting, it should be made available all of the time through some site, etc. |
| 185 | Help people that are middle class. |
| 186 | Offer programs and vendorized programs and have levels within this population. Also, I see public schools having to cope with ALL students and we are not able to handle the aggressive students. We need residential placements that are close to their homes. |
| 187 | Advocating to improve quality of life |
| 188 | Researching opportunities and educating people concerning the opportunities discovered. Therefore presenting more choices, better fits and various opportunities. |
| 189 | provide funding for employment opportunities |
| 190 | I don't know what the State Council's job is, or what it is. What would help us would be programs to help people with developmental disabilities who have a lot of anxiety, but don't have a cognitive disability. Then we need help finding these programs. The RCOC couldn't find any programs. I'm trying to contact all the programs I can find from the RCOC listing. |
| 191 | Have more case carriers to help with more services at the county level. |
| 192 | Conduct more seminars relate to the services and supports for people with intellectual/developmental disabilities and their families |
| 193 | Support Kern Regional Center as it fixes myriad problems. |
| 194 | Advocate for legislation for the above services |
| 195 | Better quality services through school districts, local advocacy organizations, more recreational and educational services for people with disabilities, self help, jobs and education for those with disabilities |
| 196 | Advocate for funding for affordable housing. |
| 197 | Continuing education after high school, social and recreational resources |
| 198 | Helping the parents because Social services are hided for most of the people if we don not find out for ourselves we never know :(|
| 199 | More direct job finding and coaching assistance |
| 200 | Work with DDS, DHHS, HCD, etc. to develop a pilot program similar to HUD VASH that can provide rental assistance. Help improve the HUD 811 PRA program. |
| 201 | Continue to provide training on how to navigate the system and impact the existing system so that positive changes can be made. People with developmental disabilities often cannot advocate for themselves so caregivers need training and advocacy support. |
| 202 | EDUCATION FOR THE general public to help everyone learn that DD/ID people are real people who have the same feelings, thoughts, desires, urges, etc as everyone else. Plus, see that even those areas of CA that are not heavily populated have adequate resources for even the basic needs like employment, recreation, and child care. We need additional VR counselors, Regional Center coordinators, and educational options and services for our fast growing population of ID/DD individuals and we needed it yesterday, not 5 years from now. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 203 | more funds |
| 204 | Have people (such as adoptive parents of FASD kids) on the State Council who understand the devastating effects of FASD. I volunteer. Paulette Benson 310- 204-1926. |
| 205 | Provide more seminars available regarding self-determination and free to low cost programs. |
| 206 | Offer more in the way of extracurricular activities for the disabled. These help with their progress as do the various therapy methods. It is hard to find places for dance and sports for kids like my son. Stuff for "regular" children are everywhere, we have to really look to find things for special needs children. |
| 207 | Continue advocacy around the need for affordable housing for very low-income people with developmental disabilities. |
| 208 | When reasonable accommodations are asked for from section 8 I believe a state program, as it is parents are already overwhelmed & overloaded and an extra bedroom is a safe haven for a parent to escape to instead of being in each others way. |
| 209 | Widen the supports offered to those with higher functioning developmental disabilities. |
| 210 | Housing, mentor programs, less red tape programs like regional center and DOR and more opportunities for support that don't require the clients to fall under certain diagnosis umbrellas. I understand that you need to prevent people taking advantage, but I have seen so many youth who need those services not be accepted for one reason or another and they fall through the cracks. Also more assistance for residency and citizenship with these groups, especially since that prevents them from being eligible for aid like SSI. |
| 211 | Expand Employment, Health, and Housing options. |
| 212 | 1) Help with personal advocacy. Increased presence of SCDD - improve SCDD regional-local websites to provide frequent updates to local links, resources, events. 2) Mandate more city/community services for social/leisure/recreational/therapeutic needs for teens/young adults with a view to promoting independence and smooth transition into the community. |
| 213 | While our adults with developmental disabilities have significant needs, I believe meeting those needs starts with you (the State Council) supporting the necessary services and supports to children with developmental disabilities and their parents. If you give a child a stable home and a community childcare with the appropriate supports to meet their needs, then that child will likely learn the necessary social skills to live in the community and get a job. |
| 214 | Assist in setting the affordable housing priorities at the state and municipal levels |
| 215 | Providing more respite care for families. |
| 216 | Higher more competent (better trained and educated) 1:1 aides/facilitators, respite providers to keep these individuals safe. Sometimes the respite providers seem to need support from the state themselves in one way or another (mental health issues). How can you put these individuals in charge of such a vulnerable populations? |
| 217 | The resources that are out there are some time hard to get in contact with a person from that agency, so better and easier access. |
| 218 | Provide funding and appropriate training for schools and educators to be ready for our children |
| 219 | There needs to be more active and direct support of advocacy for people with DD. This population needs support in sorting out financial issues, care provider issues, ensuring that services delivered are of the quality that was promised, locating medical and dental care providers. |
| 220 | Help them connect with one another, to band together to create housing options and develop other service models for Self-Determination, using today's technology tools. The State Council should be directly provided with contact information for all consumers in the state. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 221 | Reviewing and addressing every case individually to meet individual needs. |
| 222 | Demand instructional materials provided to inform ID & DD students have accommodations listed in the 3rd response. |
| 223 | Check Regional centers on how they regulate care homes. Lack of follow up from service coordinators and support on consumer needs. |
| 224 | Family members are really concerned about safety for their family member with IDD in day programs, transportation, group homes, etc. Our family members are prime victims. How can we make sure they are protected? |
| 225 | Advocating for the needs of people with developmental disabilities in having the best life experience possible. |
| 226 | 1. Continue to lobby for sub minimum wages for those individuals who cannot perform well enough to earn minimum wages. 2. Hire more people at SCDD that can review and decide on health and safety waivers so response times can be shortened. |
| 227 | Advocate in Sacramento for appropriate funding and the return of programs lost in budget cuts during the recession. Stop allowing the Lanterman Act to be eroded and supports and services cut but never reinstated. |
| 228 | Oversee the practices by school districts. They utilize substantial share of what funding is available, but the funds are spent on administrative expenses. They force parents to place their children at special schools. |
| 229 | Provide legal support to more families. |
| 230 | lausd is making it so they deny services at the IEP meetings, and then give it to the parents who go to mediation with a lawyer. That shouldn't be allowed when we are talking about intensely dangerous elopement issues. the child could very likely be killed. |
| 231 | Money...for all services from housing to recreation to the ability to use transportation to where people need to go for daily activities such as jobs, shopping & volunteering. |
| 232 | Providing the services that are mandated |
| 233 | Offering more individualized supports not just a one size fits all program. I would like to see more adaptive/recreational sports, hobbies, groups within my local city areas. |
| 234 | Come up with a way in the IPP's with Regional Center to allow for money to be set aside for each client and then the money spent on what the client needs and wants for enrichment, programs, etc. rather than trying to make the client fit into a box. For example, music therapy and related programs, which are not funded for groups or individuals, but have shown to create vast improvements in mental functioning as well as being recreational and fun. |
| 235 | Hired people to best access what each individuals needs |
| 236 | Funding for: Better insurance coverage for early intervention therapies, medical tests, family counselling and support groups |
| 237 | Community awareness and inclusion. Employers need to offer internships and training |
| 238 | I found when the State Council went to IEPs it helped my son and daughter get the services they needed. I unfortunately didn't know about this council until to late in his education. I have recently been told they are no longer able to go to IEP's which is a real loss. |
| 239 | There needs to be transparency with the regional centers. Clients need to know EVERYTHING that is available to them and need assistance in accessing all services. |
| 240 | Protect our children's access to FAPPE without forcing them to be vaccinated. Home schooling will not help a child who already has issues with socialization and speech. Provide information on how to plan for our children's future, what the course of it may look like. |
| 241 | By working with the Regional Centers, DMC, and other related organizations/agencies to create more opportunities in above mentioned areas. |
| 242 | Fund the programs that support them. Please! |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 243 | more programs for them , stop budget cutting people with disabilities start budget cutting somewhere else |
| 244 | Stop treating them as nothing but a problem think of them as human beings and are as important as the voting public |
| 245 | Listen to parents of kids that have these challenges because they are the true people that know what its like to live and care for a child with disabilities. I feel like they just care about budget and not really care about helping these kids. |
| 246 | Allow parents to chose how funds from regional center and schools will be spend. Use funds to provide services not to prevent services |
| 247 | Be more willing to help parents with children who have Asperger's. |
| 248 | Not sure |
| 249 | Workshop on employment and housing. How to get these processes started. |
| 250 | For my son it is very important to find social groups, where he can learn how to deal with others. Autistic case is unable to communicate, so we need to teach him how to do. How to keep his safety and other's safety. |
| 251 | There should be a better process of being able to pursue when they are mistreated this way. This causes a low self-esteem and violent nature to many because of judgmental treatment. They can't call harassment as quickly as others can or wrongful termination. |
| 252 | Quit doing what you are currently doing . Start a whole new program. Become relevant. |
| 253 | The State requires credentials for teachers but once an person ages out of the education system the day program staff have little to no higher education. They are paid close to minimum wage to deal with our most fragile population. The funding for day programs needs to increased to allow programs to pay a living wage so they will have and maintain quality staff. |
| 254 | Help to get lifetime supports in place for the thousands of families affected by autism, most of whom do not receive benefits from the Regional Center or SSI |
| 255 | Providing a list of resources that can help vocational counselors understand the needs of people with intellectual/developmental disabilities (reasonable accommodations, assistive technology, vocational planning, career assessments). |
| 256 | ENSURING that their rights are being upheld, they are NOT being discriminated against, and that the supports and services are available to ALL who need them. This is NOT happening now. |
| 257 | Better support and resources to help kids get a decent education. |
| 258 | Advocate for funding |
| 259 | Continue working to develop employment opportunities in our communities. Work with service providers to develop social groups for our DD community. Advocate to broaden the definitions set forth in the IHSS supports that allow for young people to remain safely in their homes. |
| 260 | more staff |
| 261 | Early intervention and education for the care takers & educators. |
| 262 | Encourage and help fund community colleges to provide educational/life skills programs for these individuals. Excellent examples are the found at Cypress College in Orange County and the TiP Program at Taft Community College in Taft, CA. |
| 263 | First low through with long term, fair pay for employing people with id. |
| 264 | Continue to advocate for more funding and better supports and services. Recognize that the autism epidemic will create HUGE challenges for our developmental services system moving forward. We are simply not prepared for it. Self-determination, I fear, is not the answer. Parents and family members, and consumers, will need a lot of information to be able to make good choices. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 265 | Listen to their mothers!!! |
| 266 | Raise budget for dental funding |
| 267 | Better mental health services!!! |
| 268 | by making service a priority over budget cutting. |
| 269 | De not ignore their needs. These are people who need complete care and attention. They have to be treated with dignity and become top priority for the state. |
| 270 | Educate health care workers and employers and the general public about respect for the disabled. |
| 271 | They can low executive director wage to support regional center client |
| 272 | Advocacy |
| 273 | Better and more frequent assistance from our Regional Ctr counselors, it is difficult to get their attention and services, they are too overworked. They should be our best contact for help, but they don't respond to emails or phone calls unless it's an emergency, and then that's still not dependable. |
| 274 | To be more aware and to inform us of new laws/services/and anything else that can help out kids but having a newsletter with updates |
| 275 | Please come visit the special needs public school see it to yourself, this way you will feel for them being there & you are robbing them of quality education for them to hopefully learn & be better but not. I can just see frustration in them. |
| 276 | i dont know |
| 277 | Having someone to ask when support or resources are needed, like Scarlett VonThenen at Area Board XI, made the difference in my son's quality of life. Please reinstate the ability for them to do personal advocacy again! It is a lifeline for consumers when even Regional Center disappoints them. |
| 278 | Visit programs, ask questions about their personal wants and needs. |
| 279 | More direct advocacy for individuals. Currently only classes are being offered. Also, lobbying for employment and housing and support services with state government. |
| 280 | get more help for dissabilities |
| 281 | Supply more funding |
| 282 | I'm not sure what the State Council does---I am pleased with regional center responses but realize they lack the resources to provide housing/employment/training of staff who work with DD clients |
| 283 | Our experience was that if your diagnosis is not in a certain box, you do not get services. My son is challenged - intellectually, socially, academically - yet he has often been ineligible for services based on his diagnoses. |
| 284 | Reduce case manager loads. |
| 285 | More day and night programs that keep the adults with disabilities to keep them better intergraded with the community and more behavioral programs for adults with autism.y daughter has been taking behavior meds since she aged out of her last program. And those meds cause so many more issues. |
| 286 | Raise school district testing (assessment) scores or have tiers in which the child may still receive services to better meet their level. It is all or nothing for schools. The therapists/specialists who evaluate children in the school district have to much power and claim testing findings are higher than what they truly are. No true quality assurance with these therapists. Thereby, decrease work burden for therapists. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 287 | Be more sensitive to the disable children and their family's needs. Please do not cut the budget of theirs. |
| 288 | Programs and opportunities to enhance lives on a daily basis. |
| 289 | To make sure the policies that are in place are taking place across all areas |
| 290 | Advocate for rate structure changes. !! Better over sight of community providers! Expect more and pay for it! |
| 291 | Fully fund the Lanterman Act to pre 2009 budget. |
| 292 | More coordination between services. Lighter case loads and therefore more individualized support through the Regional Centers. More job preparation programs that lead to competitive employment. |
| 293 | continue the good work of educating caregivers of law, resources available monitor and ensure quality of service providers |
| 294 | RESTORE FUNDING AND STOP BUDGET CUTS..... |
| 295 | They need to listen to the parents and family members of these individuals. Often the political atmosphere dictates what needs to be done and it's so off the mark and it results in frustration and anger. |
| 296 | Reach the people with disability to get the service they need and make sure no discrimination for people with disability. |
| 297 | Start including services for communication when someone is deaf. Every worker dealing with deaf individuals should know basic sign language for communication. |
| 298 | add your voice to forstall the collapse of the system and advocate for new structures like self determination and new funding methodologies that have some relation to the cost of providing support - and to the value and quality of the services |
| 299 | Encourage more ADHC-type programs specifically for folks with dev. dis. Encourage other day programs for folks with medical needs, e.g., volunteer work, recreational programs, etc. |
| 300 | support the 10% increase in our budget |
| 301 | listen to family's concerns and correct those issues-in a timely manner. preferably in a year. appropriate housing is such a problem-but if it takes years to correct the families never end up seeing a solution, and never get a break from the constant care giving |
| 302 | Overall the state does a great job, I think california is ahead of most states. Maybe get more business s to accept or even let people in the spectrum work or even volunteer for them. |
| 303 | Advocate for more support for after program hours/socializing and also providing the transportation for the family. Find ways to support families in navigating the health care system. |
| 304 | Educate families on the various services that are available and may be of a benefit. |
| 305 | My daughter had to wait a considerable time for ABA services. Their needs to be more resources and options to be able to provide our children the services they need. |
| 306 | Create more opportunities for them to be involved as an active participant in the community. |
| 307 | Get involved with employment and education for the dd population regarding avoiding perpetrators. |
| 308 | Be more consistent and more stable when introducing children to teachers and helpers. They/ We have a right to be treated with as much and consideration as "normal" people. |
| 309 | Do a better job of getting the information out there of what is available. It is almost like a hidden secret. I had to hire an advocate to get what we needed for out son. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 310 | <p>Allow parents to advocate and speak with and for their children even after the child turns 18!!!!</p> <p>Also, community colleges need to be more aware that more students with disabilities will be attending college than ever before. The campus Student Disability Centers need to make some changes that allow parents to be more involved with the student's education especially if the student has been conserved!! More about this subject must be addressed!</p> |
| 311 | <p>Considering the amount of state budget dollars that are SAVED by our consumers being actively engaged in work programs and related vocational training programs, versus being institutionalized or "housed" during the day, the State should work to develop more support for work programs and related consumer support.</p> |
| 312 | <p>Be educated about the tsunami of children that are growing up NOW, and that are going to need services/support to become part of society. We cannot let these children "age out" of the school system and think that their disabilities go away.</p> |
| 313 | <p>Listen to what parents and persons with disabilities say about themselves and their needs. Fund the needs. My son's quality of life and intellectual stimulation is much lower than it was when he was at home and in school. Yet, he wants to "move on in life", live away from home, have new experiences. There is a universal Underestimation of the abilities and mental capacity of people with disabilities in the system. Especially those who don't speak. There is a universal fear of technology, lack of education about it, etc. He uses a communication device, but they don't encourage it, know how to support it, or participate in any of the enrichment activities we do/did as a family. He goes to "program" and watches television. that's it. He shops for sundries with them but sometimes they make him wait in the car (with staff) while others shop independently. Not a social life! He does a few chores at the house, but his life has no meaning or purpose. He only goes to social activities on the weekends he comes home. He had a very rich social life all through school, and has many and varied interests, (horseback riding, swimming, hiking, meeting friends, church, dance lessons, amusement parks, restaurants, theatre (both live and movie), choir, camping.) The house says they can't afford these outings, even though most of them are subsidized and low cost. The residence are taken on outings to shop for junk at the dollar store that no one needs, rather than spending their money on outings or things that would enrich their lives and relationships. There is an assumption that they have a preschool mentality, and that their choice is for "trinkets" rather than enriching experiences.</p> |
| 314 | <p>Find housing. Find jobs. Don't just let people with Autism sit in their houses with their parents.</p> |
| 315 | <p>Provide more support and advocacy in the above areas.</p> |
| 316 | <p>Work on policy and organize interest groups to push for what is needed. Coordinate trainings for those who need it.</p> |
| 317 | <p>Provide classes that develop employment skills. Provide nice times for companies who hire people with int/developmental disabilities.create. local county or federal jobs for these population.</p> |
| 318 | <p>Moe funding for life coaches.</p> |
| 319 | <p>Teaching other people with developmental disabilities they can be self advocate</p> |
| 320 | <p>Regional center only helps extreme cases, cases which they can see</p> |
| 321 | <p>Help the schools both public and charter - support w/training classes for the teachers and especially the aides.</p> <p>Visit special Ed class rooms and campus 's to see how students with disabilities are being served.</p> <p>Work w/SELPA'S And Dept. Of Education /special Ed. Services are so different from district to district. City to city in CA.</p> |
| 322 | <p>Insure better wages and training for direct care staff. Housing for staff AND for people with developmental disabilities is extremely expensive in our area. How do you maintain high quality, compassionate support staff when they don't make enough in wages to afford rent.... How do</p> |

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| | people with DD afford rents. |
| 323 | Get rid of the Regional Centers and replace them with an accountable state agency that has to publish its policies. People should have access to a list of services they can qualify for. It should not depend on if you live in Harbor or Westside whether you get services or not. |
| 324 | Stop putting so many restrictions on how or what a family can do to provide the best care and environment for our loved ones. Make automatic monthly payments to family members who are trustworthy, and good providers...so timecards are not necessary. Fix the timecard mess!!!! |
| 325 | By increasing hours of respite due to over exhausted parents. ABA insurance going down to little or nothing. |
| 326 | By having the state funding for an agency representing and advocating to families . No IEP should be conducted with out this assistance . |
| 327 | provide more seminars |
| 328 | Better advocate for them more programs. |
| 329 | More oversight of the care providers and housing for people with intellectual/developmental delays. Need to allow computer monitoring systems in the residential/independent living homes' common living areas so that families of residents can make sure their loved ones are being treated with love and compassion and are not being abused, as this family has learned of abuse that has gone on for years because there wasn't enough oversight of these homes and their owners. Also, hire on more trained/educated people for the local Regional Center offices. They need more staff! Most have over 100 clients PER representative. This is an impossible number for any human being to have to service at one time, let alone keep track of everyday! |
| 330 | Find a way to educate law officers identify and interact with this population. My son will not understand or sit still for anyone trying to hold or grab him. He just wants to stop the pain and he pulls away or runs. Officers are only trained and want to forcibly control situation. I am afraid of teachers and law enforcement harming if not killing my son. Improve instruction in schools and allow more assistance for better supervision. |
| 331 | See #3 above. |
| 332 | I'm not sure, it's so much help needed in many different areas. |
| 333 | Support our local agencies that do support our families such as Inland regional center, as the resources are limited. Illimate obstacles that the school districts put up for parents that make it difficult to get services that would benefit your child and their needs. Provider more in thorough screening processing for individuals who have access to our children, and mandate trainings that educate on safety, behaviors, child development, psychology, Life skills, and safety. Listen to your parents, service providers, advocates and persons with disabilities. |
| 334 | Accessibility to free resources regarding rights. |
| 335 | Provide more money for programs. |
| 336 | Transportation is a problem for many people with intellectual/dev. disabilities. More social events would be wonderful. |
| 337 | Be a stronger voice. |
| 338 | our children need to be fully included in regular education classrooms but general Ed teachers and aides have no specialized training in how to teach and nurture children with Down syndrome. We need schools to be trained and ready for our children |
| 339 | Have a positive attitude and don't make parents and caregivers jump through hoops. Provide assistance in the procurement of advocates for special ed wars. Why is it a war? |
| 340 | Full funding IDEA. Investment in housing options and education about housing. Meaningful vocational training for all children with autism at the HS level beginning at age 15 to improve their employment opportunities. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 341 | Commit to fully funding IDEA. Invest in housing options and education about housing. Offer more vocational training for all children with autism at the HS level beginning at age 15 to improve their employment opportunities. |
| 342 | Continue to ensure the creation and expansion of Transition Programs and quality Day programs tailored to the needs of Autistic individuals. More options are needed. |
| 343 | Provide community trainings / presentations in the Coachella Valley together with CALTASH, to address the lack of meaningful inclusion of students with significant disabilities (my son has a mild ID) in our general education classrooms and community recreation and childcare centers. |
| 344 | Don't roll over and play dead with AIDD. |
| 345 | Keep family and advocates empowered with knowledge |
| 346 | Provide individual with real opportunities for growth in the work arena. Provide workers with education of these populations. |
| 347 | Stop putting these services on the chopping block. It's hard enough that we have children with special needs that require constant assistance, but we are always fighting for support and retaining that support. We fight hard everyday, we shouldn't have to battle what's already in law. |
| 348 | Making the process easier. Not deny every request. Forthcoming with information. |
| 349 | Educating public |
| 350 | By providing individuals with an opportunity to work and be productive members of society. |
| 351 | Improve access to my concerns. Too many personas with disabilities are homeless. |
| 352 | Contingency planning. What happens if there aren't enough vendors? |
| 353 | Give I on I counsel and support at IEP meetings. It is the parent against 15 people from the school district in the room. Some of us have no one to support us at IEPs that know he law. |
| 354 | Provide quality jobs, not merely service industry jobs like grocery store baggers or stockers at Pet stores. |
| 355 | provide the same supports they do to autistic families. |
| 356 | I find that as my son got older, the important things he hoped for were, having a "real job", & wishing for more planned social activities with other people with disabilities. Also transportation that does not require standing on a corner waiting for a ride. |
| 357 | Build more welcoming generic services and advocate for the resources needed to provide the services you advocate (e.g. better pay for the direct service workers to secure higher quality/trained staff; affordable housing that is needed for supported living to be a viable choice) |
| 358 | Let them or their advocate pick their own services & needs. |
| 359 | Be advocates for the full range of needs of individuals with intellectual and developmental disabilities. |
| 360 | 1.) ADVOCATE for more funding for all Services Area, with more emphasis on the 3 I checked. 2) Provide a comparable pay to organization that provide this service. People who work with my family member with disabilities have not received a raise to reflect the current standard of living since the 2008 financial crisis. |
| 361 | Collaboration with local and state entities and also coordination with advocacy groups to bring these issues to the forefront. |
| 362 | continue advocating. need better job options. Improve the quality of day programs. |
| 363 | I hope to see programs that provide people with disabilities are properly funded, rather than cutting services. These programs include, but not |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | limited to: adult day program, respite, supported living, independent living, supported employment, transportation services, etc. I've heard that these programs have had the same rate to provide clients with services. It seems to me that they should be getting an increase due to inflation. How do these programs continue to assist people with developmental disabilities become more independent, when they aren't compensated properly for the services that they provide. Minimum wage is rising, so should the rate that these businesses are getting for whatever services they're providing. |
| 364 | Promote and support collaboration with high school transition programs. |
| 365 | get the word out, that they can become useful members in the communities they live in |
| 366 | We need the State Council to be more hands-on with the people that we served to understand the day-to-day obstacles that care providers face with. To often, the decision makers are not the people who know or ever worked with intellectual/developmental disabilities. Having experience with directly working with the intellectual/developmental disabilities should be required before becoming decision makers. For example Community Care Licensing knows very little about our field and they people that we serve. But, are decision makers?? |
| 367 | Spend some of billions on opening residential homes. Ive been caring for my son for 25 years. The regional center says there are no homes because the State is broke. |
| 368 | By developing alliances with large companies to hire people with disabilities. Also to invest in infrastructure that will help all Angelenos get around L.A. |
| 369 | Stop taking away what already giving to them. |
| 370 | Help in putting the word out to clients by letter, email, facebook, in the client's own language about what options are available for community integration. I know the booklet on the Lanterman Act is a valuable resource but the Orange County Area Board ran out of copies in 2011 or 2012 and was not able to get English versions back in stock. People need the information in a variety of formats because there is no one size fits all for clients to process information. There need to be pilot programs set up to let clients see how working in the community benefits them and how to go about finding and getting a job in the community. Support of different types of community housing is also of major importance. Information on the different types of community housing available in each of the 13 regional State Council Districts should be made easily available and clients need an ability to be able to cross from one district or regional center to another for support and services they need but may not have in their home district. |
| 371 | Increase employment opportunities. Enable non-verbal children and adults the opportunity to learn Facilitated Communication. |
| 372 | Whit quality assurance- putting money on real programs, not on paper. |
| 373 | Working on more access to supported employment and mental health services for those dually diagnosed. |
| 374 | #1. Provide more funding for the programs and services needed through State funding not legislature pay raises, put the money where it is needed. #2. Increase the number of transportation vehicles and drives available to transport clients. #3 Open the lines of communication between Medical, the County and DDS and have them review the number of services provided and the need for more and new services to help everyone. #4 Have DDS evaluate the discretionary tactics that R/C's use when it come to CCF's. Why are some R/C's able to cut the number of client's in a CCF when others are able to work fine with the larger numbers in the CCF. If homes are not providing services then have licensing the R/C work together to correct the problem don't place barriers on those care providers who are providing a services that is needed. |
| 375 | Focus on the clients were are that "in between" (gray area) of functioning...higher than the low-functioning Day Programs and not quite as high as the Employability Programs. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 376 | Community Involvement |
| 377 | Continue to provide the oversight that you do, and, ensure that clients (and their families) know that they are represented. |
| 378 | More funding! |
| 379 | Providing a back up for interventions not covered by private insurance or school systems, provide for secondary health insurance in addition to private insurance if needed to cover necessary services even if child does not financially qualify for Medicaid |
| 380 | Provide more training on self-advocacy |
| 381 | More lectures about services and opportunities in the community for adult with intellectual/ developmental disabilities |
| 382 | Please continue your informative workshops. They are very informative. |
| 383 | Provide more assistance for job training, employment and more support for agencies providing resources. |
| 384 | More support and involvement |
| 385 | Provide variety of access. |
| 386 | We need strong advocacy (advocates/attorneys) system at no cost to the families to help fight for the rights and services. Families and individuals with disabilities don't have the money to fight for their rights and for services so we need advocates/attorneys who will go to IEP's, help with the IEP process, and go to Mediation/Due Process, etc. so the children and adults with disabilities can get the help/support they need to be independent, successful members of society. |
| 387 | To continue to advocate for additional financial supports. |
| 388 | Listen to what the individuals ask for!! |
| 389 | Actively find \$\$ for small local SNF and other similar homes Be a watchdog to make sure that regional center staff know the resources available and pay enough so we have enough good useful non-time-wasting case managers. |
| 390 | Work with providers and state agencies to establish more facilities as many individuals aging out of schools have no program available. |
| 391 | By giving them direct access to the supports & services and not make them go thru a 'committee' to determine what they are. |
| 392 | Work in collaboration with school districts and other agencies. We need all the help we can get!!! |
| 393 | Be fair. There are assertive, well-off families with high levels of money and services for their family member; at the same time there are very similar clients with far less in the way of money and services. This is Governmental/tax-payer provided monies. The system is not fair to those with less aggressive advocacy. There must be a better system. |
| 394 | By training people with intellectual/developmental disabilities and their family members about their rights and responsibilities, services, and resources; by working with community agencies to provide better access to services and resources for people with intellectual/developmental disabilities |
| 395 | Many educators have no concept of how to deal with children who "present" as neurotypical but aren't. A one-hour session for every school employee should be required, to be taught maybe by a parent advocate and clinician, about what each teacher and administrator can do to make all disabled children feel safe, accepted and competent. |
| 396 | In sure that services related to the identified needs of the client, verified by the skilled client, parent, care provider, service broker....are provided, or are continued. Clients conserved or not need to participate in making decisions but also in taking whatever financial responsibility they are able to provide. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 397 | Have more therapy available through health insurance and state (speech, independent skills training, social skills...) |
| 398 | Provide more options for housing in non-segregated living situations. Provide support- practical help- for those who struggle to be independent, ie, someone who is available at the regional center daily just to answer questions and give advice on how to negotiate the systems, fill out a form, etc. |
| 399 | Providing more services when they are under three would make the strongest impact on their future. |
| 400 | Work to ensure that the state funds a wider variety of work day programs for persons with extensive daily care and behavioral needs. |
| 401 | Increase funding to the RCs |
| 402 | It would be WONDERFUL to have a conference for clients to participate and social activities. |
| 403 | Help increase the budget by 10% to offset costs that have not been given to providers in over 20 years. This will allow vendors to hire quality staff who care about their jobs instead of inexperienced employees using SLS as a stepping stone to get through college and move on to something different in their lives. |
| 404 | by giving more time of hand-on training before placing them, or even thinking of direct hire. More programs we can take students to be trained at, so they can be prepared for future placements. |
| 405 | Create incentives to apartment owners and housing developers to create more affordable housing. The incentives shouldn't take an 'army' and 2 years worth of paperwork and process though. It should be mainstreamed. Create incentives and awareness to employers to create jobs. Create a team or a committee to provide awareness and education to all related groups. |
| 406 | Please don't reduce budgets for much needed services. Please bolster and provide incentives for new day programs and also the proper training and regulations for positive, healthy, & respectful home care providers. The program I work in operates on a 6:1 individual: staff ratio and yet we needed more staff to best meet the needs of our participants. Ironically, there is a belief that people dependent on social services who are on the highly-capable and highly-intellectual end of the spectrum of abilities, require less staff supervision. My professional opinion is that certain programs tailored to meet the needs of such capable and potentiated people, need just as much staff-participant ratio as programs catering to the severely disabled. People who are more capable need those capabilities to be achieved, which requires more direct job training, more counsel, more off-site experiences, more attention to customise programming to meet their unique needs. |
| 407 | Ensure that school districts are meeting their mandates especially in the area of transitional services. My son attends school in the Hart District and there have been many accounts that they are not providing appropriate services to students in the 17-21 year range to support transition to adulthood. In some cases I believe they may be exiting students from special education at age 18 without adequate transitional supports. |
| 408 | Put more restrictions on school staff and districts to be more accountable about the decisions they make regarding students and their immediate needs and safety. |
| 409 | Continue what they are doing. Lobby to get more funds to increase the monies going to every aspect of the system. There needs to be more political pressure to increase funding. |
| 410 | Create jobs or programs that will help the individuals feel better about themselves and teach them more independence |
| 411 | provide grants for extending bus services |
| 412 | Help them to better understand, in their terms not the government terms, what they are going to either get or not get. |
| 413 | Fulfill the Lanterman Act mandate. |
| 414 | Provide more quality day programs for special needs adults that emphasize community experiences and train for possible work placement. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | Also, fix the RediWheels public transportation program. It was absolutely terrible with no consistent drivers and extremely late with no consideration for special needs customers. |
| 415 | How about how funds are allocated ...how about helping the kids who are most employable with aid they need, so they are not a burden on State/Federal but can work and pay into the system. Instead most of funding goes to the most disabled, who will never be employable. |
| 416 | up funding and quit utting it on the chopping block. Limit some of the extensive red tape. Make sure that medi-cal ccs supply people are giving quality products without stealing the state blind. |
| 417 | Better supervision (abuse prevention) over care in the adult group homes. |
| 418 | Educate people to understand more about i/dd, especially public agencies like school districts, cities and other big cooperation should provide special program to accommodate people with i/dd. |
| 419 | Pay more attention to consumers before they get into bad situations! Once you have a consumer living independently who is addicted to drugs, it is very unlikely that the situation can be fixed. I know that California places the greatest value on independence, but I think you have to make safety an equal value. |
| 420 | 1. Advocate for our rights. 2. Intervening when Regional Center takes control & doesn't support family advice. 3. Advocate for therapy, classes, & programs to help me become more independent. |
| 421 | Helping those in need find services. A faster easier way to the resources and funding. |
| 422 | Create resources that are culturally and linguistically appropriate to non English speaking families |
| 423 | They should be able to serve a client with a one-to-one approach and a case manager model follow up. |
| 424 | The State Council beside funding must push the organizations over see it in more details. |
| 425 | Outreach to. under serviced communities |
| 426 | more outreach to families to hear what's REALLY going on with Regional Center/services/supports. |
| 427 | Please hold educators accountable!! Please provide no or low cost advocacy to families. |
| 428 | Continue to push to increase overall funding. |
| 429 | increase supports for advocacy. |
| 430 | More support for a free and appropriate education, talking with the governor and other people who make financial decisions to increase the budget for programs that have been frozen for years, conduct surveys of parents satisfaction with the ed system, help write grants for low income housing projects that includes middle income units. Send staff to requested IEP meetings, work with the Dept of Rehab to find out why they are not serving our population for training in real job sites, why does medical pull teeth or repair them when no one will hire a toothless employee, increase courses at junior colleges for our population and stop the number of times a student can take a course. |
| 431 | Improve their methods of early intervention versus relying on the concept that everyone develops at their own pace. |
| 432 | It's all about self-determination...in order for many of the other pieces to be effective, individuals have to have the skills and opportunity to make their needs and preferences known. Families and professionals need to communicate more effectively -- professionals need to facilitate conversations that are more than just 'checking the box' that the plans are person-centered or person-driven. |
| 433 | Help them to live a full life. With jobs, friends and hobbies of interest to them. They need support be successful in these areas. |
| 434 | The state council needs to start thinking that our disabled population are worth the time, effort, and care. If this does not happen, there will be |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | no change for the better. |
| 435 | Provide more financial assistance to families and organizations providing services to family members with intellectual/developmental disabilities. |
| 436 | More funding, but, admittedly, I'm not sure where that would come from. |
| 437 | Provide funding for Self-Determination at EVERY AGE. The general education classroom setting is not a one-size fits all approach, nor is segregation of disabled children grouped together with a severe lack of qualified professions and a horrifying ratio of too little adults to too many disabled children. |
| 438 | Standardize the RC system, some RCs are great at coordinating services and some seems to have know idea what they need to do. Or tell you they have the services in place when this is not true. |
| 439 | by have more opportunities |
| 440 | Providing more and better coordinated services for children with disabilities who are school age; respite care for parents of children with disabilities |
| 441 | We would like to take them to their limit but still have some one watching over, like big brother-sister) |
| 442 | If there were advocates for the parents, a liason worker that can arrange services and supports and all the paperwork involved my son can get the additional help he needs. |
| 443 | Provide services that deal with safety and prevention of abuse which leads back to educating people with these challenges about sexual behaviors and safety. |
| 444 | Help support providers as they transition to new models of services which are based on inclusive opportunities and best practice services. Sponsor trainings on behavior supports, customized employment, transition from site based to community based services etc... there are great presenters out there. Grants to providers to transition or augment their employment first services. |
| 445 | More advocacy for more State and or Federal funding, legislation to provide funding to support services. |
| 446 | Expand services to accommodate multiple disability individuals. Put more supports in place to allow individuals to remain in own home. |
| 447 | Make certain there is help provided when they have completed highschool |
| 448 | be stauncher advocates |
| 449 | More actively partner with the community to address the areas of lack that I have outlined above. |
| 450 | Develop incentives for businesses to hire people with disabilities. As minimum wage increases, jobs that require special accommodations will be further reduced. Requiring workers who can't do the full job to be paid minimum wage is a nice idea, but probably not realistic. Develop resources for low-cost housing. Section 8 is nice, but the waiting list is about 10 years long. |
| 451 | Active involvement in from policy into real outcome. Create more housing project for adults with DD |
| 452 | I'd like to propose that the State Council consider partnering with California Health Advocates to educate service providers, caregivers, and consumers on topics such as Medicare, prescription drug coverage options, how other health insurance coordinates with Medicare, long term care planning, etc. Go to www.cahealthadvocates.org or contact Elaine Wong Eakin, Executive Director at eweakin@cahealthadvocates.org or 5108851995 |
| 453 | The state council needs to push Governor Brown for additional funding of services for our people with intellectual disabilities by increasing |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | funds to DDS. |
| 454 | Make sure family members have all of the information they need to make informed choices for their loved ones with developmental disabilities. |
| 455 | Better financial assistance and health care |
| 456 | Instead of lumping all DD students together, figure out how to group those with specific education needs, training needs, etc. |
| 457 | Better training for Regional Center and DOR workers to understand the high functioning population of individuals with Autism Spectrum Disorder who, with the appropriate opportunities, can become responsible, independent, tax-paying citizens who rely minimally on public benefits. |
| 458 | There is a great deal of disparity across the state in terms of what is available for people with a variety of intellectual/developmental disabilities. It would help families to have some continuity. |
| 459 | See item #3 |
| 460 | affordable home, community jobs, and, no cost day care to parents. |
| 461 | Develop better programs. My Son could really benefit from an exercise program. Like a lot of disabled people, he is very over weight and could benefit greatly from an exercise program designed to help high functioning people with developmental disabilities. |
| 462 | have rallies at the state capital and hold these politicians accountable like the despicable Dr. Richard Pan |
| 463 | Providing state wide website with listed resources for all age ranges. Mandated to be on all school district special education websites. |
| 464 | Proper nutrition. A healthy diet will help them feel better mentally and physically. |
| 465 | There is nothing as good as a loving family. They need some financial help, but it is far less costly than what we have at this time. Our educational system needs a great deal more help in accepting our clients in a regular classroom. the socialization goes far beyond into our society. There is much more, but not enough space for a true recognition of what needs to be done in this survey. |
| 466 | Have more affordable housing in more areas as our son has a long waiting period for Section 8 in order to receive a voucher |
| 467 | By having more options such as day programs and community access. |
| 468 | Need creative people to sit in the chairs of making decisions and develop programs. |
| 469 | Protect funds that are directed to the Regional Centers. Assure funds are spent appropriately. Lastly, prepare for the incoming flux of additional consumer given current and anticipated rates in autism diagnosis. |
| 470 | Advocacy, workshops, and advice are tremendously important. |
| 471 | More education for care givers. |
| 472 | Advocate for the full range of services Not everyone will be able to work enough hours to have a reasonable quality of life. For those who can not work or can not work very many hours a month, there should be options other sit at home. Day programs enhance the skill that help support independence and work behaviors. |
| 473 | Provide to the budget that will allow education, employment and other support services to the DD population |
| 474 | Support and train for Self-Determination. There is a lot to learn about the program, and people need to know they have choices. |
| 475 | Increased work and volunteer opportunities. |
| 476 | Have more parental involvement. |
| 477 | listen and implement |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 478 | Proactively educate parents/caregivers on supports and services which are available instead of withholding information unit a crisis. |
| 479 | Quality assurance with employment, housing and health care coverages for adults with I/DDs. |
| 480 | Better support at the legal level...bring in people willing to work pro bono or a reduced rate to help the disabled. I am paying \$400 an hour for my attorney in order to fight the school system. I may have to sell my house so I can get appropriate services for my child. Something is wrong here. |
| 481 | Improve support in the area listed above. |
| 482 | Take positions on current legislation so that the Council can lead the advocacy efforts. |
| 483 | Empower parents, and hold the schools responsible for their abuses, neglects , unlawful practices, disregards for our children,cand stop them from disabling Parents and children's right to an education. |
| 484 | Gave them programs will allow Themselves by home |
| 485 | Give at least a COLA increase after over a decade of none along with rate cuts and lost income from Mandatory days off without pay aka "The Uniform Holiday Schedule". The cost of everything has gone up. Providers are the primary link between the person with I/DD and their quality of life. If you don't provide adequately for their care you don't deserve the paychecks you collect for planning for their care. |
| 486 | Give the funding necessary to run quality programs. We are having to fundraise 20% of our budget. Help! Give us a raise...we have not had even a cost of living increase...This is a forgotten group of people... |
| 487 | Encourage communities to support recreational activities on a daily/weekly basis. The employment rate is so low for people with disabilities. More employment opportunities need to be created in mainstream arenas. |
| 488 | Needs to be more services offered |
| 489 | Continue to provide funding, with increases that keep up with the economy, in order to make services available to all who require it. Ensure that Regional Centers are educating families/individuals regarding the services that are available to them. |
| 490 | Get services in rural counties. MediCal is supposed to be providing ABA services but is slow to find providers to serve rural counties. Get more respite opportunities for parents. Get funding that will allow more respite and transportation reimbursement to parents of minors for long distance medical travel. |
| 491 | Check on the vendors - especially the group homes. Do not tell them when you are planning a check so that you see that some are not following your instructions to the detriment of the consumers. The quality of workers in group homes could be a lot better in some instances - paying a decent wage would help. |
| 492 | Get more help |
| 493 | Provide more employment opportunities Better quality housing and supports for consumers |
| 494 | advocate for more supports and services |
| 495 | Better support and more funding for supported living tailored to each individual's needs. |
| 496 | Push for better early and aggressive intervention including speech, ABA, OT and PT services to have better outcomes. |
| 497 | keep on the state government and federal government regarding funds to regional centers and to service providers to serve our clients with the |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | best possible staff. |
| 498 | There is an affordable housing crisis. Supporting programs that partner with all bay area cities and housing contractor to develop appropriate, interional communities that that have supports built into the design and model much like Sunflower Hill Project in Pleasanton/Livermore area - we need this in Alameda, San Francisco and San Mateo counties. Cites and the states have abandoned properties that can be made good use of.... |
| 499 | Provide better post required training and better job training. |
| 500 | Besides being a parent of a person with ID, I also work as a parent liaison for school districts that serve over 14,000 families who have children with disabilities. Many families and PWD who have good internal resources and support are able to do the time-consuming and difficult work of getting the services that are provided under the Lanterman Act and IDEA. However, for our most vulnerable citizens -- PWD who have no family or for families who do not have the time and resources to devote, they are often the ones who most need the services and are the most likely not to receive what they need to survive. In my experience Area Boards were the only ones who had the ability to step in and do the individual advocacy that was needed. They got results when no one else could. Without this individual advocacy the laws are irrelevant. This is also the best way to teach people the necessary skills to advocate for themselves -- telling them their rights and what to say in meetings is not effective -- they need to see it in action and see that it works. Employment -- again we need individualized support -- well paid and trained people who know how to create employment opportunities based on individual strengths and characteristics. Finally, and most importantly, reimbursement rates for vendored programs severely restrict the quality and retention of good staff. There are good and competent people out there who are willing to support our adults well for minimum wage, but not many. The good ones are typically in transition to more highly skilled and paid jobs. They daily struggles of people working for minimum wage and the overturn of competent staff makes for unstable support and frequent emotional, health and safety turmoil for our family members with PWD. more advocacy towards the rights of individuals with disabilities |
| 501 | Advocate for them, better services, less fighting to receive those services. Support us in Sacramento. How do we have a Governor who doesn't support us yet we have a State Council????? |
| 503 | Advocate for rules that truly people receiving services to earmark funds to meet their priority needs. |
| 504 | Help get kids to college instead of asking them in high school what job they want to have. Most high school kids don't know and that's why they go to colleg |
| 505 | Get out there and see where our clients live and what they are provided and not. Be involved, be hands on. Truly see... |
| 506 | Accountability of Regional Workers in getting resources to individuals |
| 507 | Provide more funding to lower income areas to ensure access to professionals providing services |
| 508 | dont keep giving us phone number after phone numbers that lead to dead ends |
| 509 | OutReach and offering services to our Youth |
| 510 | Make our legislature aware that the needs exist and with the right support an individual can become a contributing member of society, thereby lessening the cost to the State. |
| 511 | Support sheltered workshops. Improve the level of funding and services provided within a sheltered workshop. |
| 512 | Allow parents/family members freedom to choose what services to support -- allow them to "buy" what works with the dollars dedicated to |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | their child. |
| 513 | Provide greater financial support to non-profits that service the needs of people with disabilities. Funding increases will allow us to expand our service provision. |
| 514 | Make sure that each agency works with agencies to provide consistent assistance across the board. |
| 515 | Assist with affordable housing development, advocacy for more housing vouchers. Encourage development of supported employment vendors Advocacy for better transportation |
| 516 | Get more funding |
| 517 | hack this is what you need to do how workshopmommy needs to tell the communion what is out there to get help I mean just for people just to talk about their problems |
| 518 | Advocacy, education and support for the services that do align with the new HCBS regulations |
| 519 | I think in the advocacy realm things have dropped off a bit. I think there should be more interfacing with adult ed students in transition programs, so that there are advocacy groups the feel right for the younger set. |
| 520 | Better marketing to highlight abilities and accomplishments of adults with intellectual disabilities. Also, education for the families about employment and access to services and disability payments and insurance. |
| 521 | Overhaul the Regional Center Services; a non-profit should not have so much control over tax payer monies |
| 522 | Use CPP money to aggressive develop services to meet all 1000 clients of DC who will be displaced within the next 5 years through California. |
| 523 | Community awareness and advocacy |
| 524 | Recognize the value of a continuum of services |
| 525 | more social events and recreation for quality of life, financial and legal support |
| 526 | See above and hire people who care- NOT JUST WORKING FOR A PAYCHECK! |
| 527 | Outreach to seniors with intellectual/developmental disabilities assuring their rights to self determination and independence are secure |
| 528 | More information, more support, more coordination of services. As a parent, I feel very isolated & only receive info from other Mom's who also feel like they are in unchartered territory. |
| 529 | put more resources into the end user and less at the top. |
| 530 | Assist families with more legal and advocates to help them understand policy and services with in school districts/private school services. Help family understand their rights and provided more support and guidance with intellectual/developmental disabilities. |
| 531 | 1) take a leadership position 2) work to build partnerships on behalf of people with disabilities and their families 3) provide information/education to the legislature 4) work with different parts of government to get our issues on their agenda |
| 532 | Move away from vendored services which have an implicit bias towards self-contained services and do not provide equal services to consumers who do not use vendored day services. |
| 533 | Of Course we need more money in the system. Better rate setting system that is equal for both old and new vendors. |
| 534 | hire more Regional Center Workers. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 535 | Open the criteria for qualifying. Some individuals do not meet the criteria levels yet experience the challenges associated with disabilities. |
| 536 | Early intervention & diagnosis with realistic prognosis.. |
| 537 | Educate pediatricians how to diagnose infants & help them better so that precious childhood days can be used to help them develop through early intervention. |
| 538 | 1. Funding, 2. More opportunities in the community |
| 539 | more services, education for families/community in our rural areas. get self-determination going |
| 540 | Funding and continued appropriate oversight. |
| 541 | Keep work activity programs and other entry level training opportunities available for people that want them. |
| 542 | Put people first and ask dds to consider if they are discriminating against people when they implement practices like denying services to families with working mothers by demanding a parent participate in 100 percent of services provided to their child. Only rich people who dont have to work could possibly meet this demand. |
| 543 | Assist in pushing the schools to provide appropriate services and implement the IEPs. Provide inclusive recreation activities and adequate support for school related activities. Pressure the schools to investigate when a child is sexually abused to assure all children at the school site are safe. |
| 544 | Continue to educate, advocate and support families and individuals affected by ID/DD. |
| 545 | More training for Police Dept. on Special Needs adults ...and how to deal with adults with disabilities |
| 546 | By advocating strongly for real needs and to get away from rhetoric and "paper pushing" |
| 547 | Provide high quality services |
| 548 | 1. Develop Affordable Housing Options: New housing, New Financing Options and bring back Section 8 to our counties 2. More accessible Transportation - more hours of operation and transportation to outlying areas like: Rovana, Chalfant. Big Pine-to Bishop, June Lake |
| 549 | providing more hours for in home and school support would greatly help. |
| 550 | Encourage DDS to get more funding to Regional centers to develop supports and services for clients moving into the community from developmental centers or from where ever. |
| 551 | extra programs/better communication, psychologists that care and do their job because they love it not because of a paycheck |
| 552 | Educate the public, schools, physicians, mental health professionals. Create a system where everyone is treated with the same level of respect and dignity. Not everyone is capable of self advocacy, and I believe people are mistreated based on their knowledge or lack of knowledge. |
| 553 | Provide a coordinated approach to supporting individuals once they exit the school system. Adults who do not have non-disabled advocates are stranded and allowed to slip quickly through the cracks, services and resources are not consistent and do not provide an adequate safety net for disabled adults, and services and resources are counter-productive in many instances by limiting activities such as transportation and support for recreational activities which encourages social isolation and disengagement from the community. |
| 554 | Use TOM techniques. Have ongoing interviews with the consumers and compile date that can be used immediately. There is explicit and tacit knowledge that can be harnessed and used to improve the quality of life for these individuals. If you want to give me a call regarding some of my thoughts, maybe I could help. 707-294-3811 |
| 555 | Need to be able to respond in a timely matter to consumers needs |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 556 | Same as #3 above. |
| 557 | The self determination program will be helpful to provide services that have been denied by school and regional center regulations. |
| 558 | Continue to work on employment first and self determination |
| 559 | I like being supplied resources such as videos that are included in your e newsletter. These are very useful to me. Provide counseling services for the students when an evaluation shows that counseling is needed and would be beneficial. |
| 560 | Advocate against budget cuts for existing services |
| 561 | More funds and less red tape. We have to fight to get any help. Service Coordinators act like they are guarding gold and if you are not very knowledgeable and experienced (experience with paper work and knowledge of how funding works or disability law) then you most likely will get absolutely no help. We shouldn't have to be lawyers in order to be granted services, the people that need the most help are not getting it. The one's that fight and threaten to sue receive the most help and that is not how a disability program should be run. |
| 562 | Create levels of educational and practical standards to help them achieve and complete better with typical peers towards a more normal self sufficient life And independence. |
| 563 | Make the community more aware of their capabilities and assets. As people are more accepting of students with special needs they will be more inclined to include them in everything. |
| 564 | ensure inclusive practices are in place to allow access to services to those in need. |
| 565 | Help families get more respite. Happy parents who get a break better care for the child with an ID. |
| 566 | All service areas mentioned above are critical. To be denied these supports puts people at a disadvantage for their future lives. These services need to be available for all people who need them. Regional is suppose to support people. To deny supports is the opposite of what the are entrusted to do for people. |
| 567 | Better teaching in schools of what intellectual/developmental disabilities are so that pupils can understand them from an early age and be more inclined to accept and befriend a child with intellectual/developmental disabilities. |
| 568 | Help direct individuals for one and one services in the three areas I selected |
| 569 | Relax efforts and priority on resources for persons at the state developmental centers at the expense of the 99% of individuals in the community. The Regional Centers will continue to move the remaining individuals out and eventually close another SDC. |
| 570 | Support community action from the bottom up, not from the top (State) down. |
| 571 | Money - more programs need to be funded to provide the services. Vendors can step up for those services however, funding, development of these programs need to be backed up with MONEY! |
| 572 | In form of benefits and rights |
| 573 | By increasing legislation that mandates affordable housing options. |
| 574 | I'm not exactly sure what is within your purview, so I'm not sure how to respond. I've worked at Kern Regional Center for 15 years, but I don't know much about SCDD. I do want to thank Joe Bowling and Vicki Smith for attending our board meetings and educating the board and public about the board's regulations. |
| 575 | You are all doing a great job. In terms of housing, perhaps someone would like to attend/join Partners in Housing in Ventura County - a nonprofit housing development corporation focused on improving housing for individuals with special needs. We have one project in development right now in Ventura. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 576 | Advocate to keep supported employment in place. Advocate to increase SLS/ILS rates to providers to keep up with rising costs to provide services. Remove the barriers that prevent providers from owning housing units and renting to clients. |
| 577 | Provide better one-on-one legal assistance. |
| 578 | Not sure |
| 579 | They need more opportunities which equates to funding/reimbursing vendors who are willing to provide these services for their work. |
| 580 | More individualized surveys for the individual and family. Then provide the services. |
| 581 | LOBBY MORE |
| 582 | STOP hurting the majority of DD with this totally idealistic policy on sub minimum wage group. First rule of SCDD should be "first do no harm". This means no only harm to consumers (should change to "clients") but harme to families. I have helped with employment of over 130 clients as a for profit business manager. STOP and get some business advisors. Since 2005 the percent of clients earning wages has dropped by at least 20% not to mention number of hours worked or number of days worked. |
| 583 | Has there been a serious attempt to raise the issue in schools (in PTAs) and through other possible contacts with affected parents? |
| 584 | Support full funding for Regional Centers and community recreation programs. Support funding for dental care. Support more funding for community living, enable family member with dd to be close by to maintain contact. Outreach to legislators. |
| 585 | Review current offerings and funding levels for Supported Living (for Adults with severe autism). |
| 586 | Continued advocacy and support to advocacy groups. |
| 587 | Once a person is "deemed" aka "institutionally deemed" and becomes a life-long client of the regional center, it would be wonderful if the family didn't have to re-apply and/or prove eligibility every year for programs like Medi-Cal, HIPP, personal assistant hours from GGRC etc. It's actually really scary to receive those letters from Medi-Cal that say you may lose your benefits so fill out all this paperwork and show proof of income. Every year I write "GGRC Deemed" over the forms and worry THIS is the year it won't matter. Again, I think once a regional center client is deemed, there should be LESS red tape obtaining and maintaining services. Oh, and more camps and after-school options for kids with severe disabilities. My daughter is largely non-cognitive. A regular camp, even for disabled kids, isn't appropriate for her. But a camp focused on pool time or some other sensory activity like music class or massage or something to enjo passivley would be great! |
| 588 | Push for more availability of Section 8 housing. |
| 589 | Continue to provide advocacy for my family |
| 590 | I think helping by advocating for more money but also better quality of services. |
| 591 | Assist with the above mentioned needs. |
| 592 | Better Quality assurance of current supports and get rid of supports that do not work |
| 593 | Give information the community through email or mailing flyers |
| 594 | Educate them with resources and ease of obtaining resources. Show them how to make contact, don't just tell them! |
| 595 | Giving more training and support them to find information, and education about where to go who to ask for services and resources. |
| 596 | Keep going to Governor's office and advocating for our cause let the people that are getting the services talk to the Sacramento let them know how there life is day to day more services in tune with Regional Center, Bring Lake County up to the 21 st century and advocate more for a faculty in Lake County to help everyone with developmental or intellectual needs no one should be left behind and this sits right on the lap of |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | the corrupt board of supervisors they would rather spend there 400,000 on a skate board park then invest into there community and mental health. |
| 597 | Advocacy. Both for specific programs (i.e., housing and employment) and for more money in the system (for both service providers and Regional Center operations/staff). |
| 598 | Set up programs with the individuals in mind that meet their personal needs and goals. Stop telling providers to not develop personal friendships with their clients. That just makes them feel like they are not accepted in the REAL world or by NORMAL people. It tells them that they are only to associate with their "peers", many of whom are less capable of maintaining a friendship that they are. |
| 599 | Support with resources advocate and guide to find where and how to get help |
| 600 | job support |
| 601 | There needs to be more government/community awareness of the needs of this demographic and the will to serve these needs. |
| 602 | Self determination should be initiated whenever it is possible. It gives an individual a sense of self worth and confidence. It takes individuals with developmental disabilities out of the dark ages. |
| 603 | Talk to the clients and ask what the needs are from them. |
| 604 | By continued community collaboration to build supports for those with developmental disabilities to be fully "included" in the community. |
| 605 | I think we need more community awareness that you exist & what you do. |
| 606 | Support public education, the regional centers and education and training for experts in the kinds of services that will help people with developmental disabilities. |
| 607 | Oversee the Tri-Counties to make sure they are following up on referrals and are being responsive to those individuals who need their help. |
| 608 | The most important work the State Council does is the one on one advocacy when a person is falling through the cracks. When supports are not being provided, having an area board staff in your corner can be extremely vital. |
| 609 | For jobs, more public relations on abilities. For housing advocate for supplemental housing allowance in high rent communities. |
| 610 | Accountability of adult agencies-make sure they are provided the services they are paid to provide. |
| 611 | Secure more funding for programs and services. |
| 612 | Providing more money to the elementary/middle school for Special Education, so that we can have the staff and materials needed to provide a positive educational experience for the students. |
| 613 | Advocacy for improved rates and reimbursement structure for supported employment for more people to be gainfully employed. |
| 614 | Advocacy for affordable housing. self-determination training for advocates, families, providers and RC staff. More housing options |
| 615 | Make certain more good/safe services are available for individuals and their family members. Limited services in smaller rural towns, again local community colleges need to step up more. |
| 616 | More educational opportunities/local workshops for individuals and their advocate/caretakers. |
| 617 | Help to keep programs available and easily accessible to people with disabilities, especially when they are out of school and have no built-in supports anymore. And also, on the opposite end, helping to fund and design early intervention can help families and schools learn about how to help their child with disabilities and promote lifelong learning for the whole family. |
| 618 | Get rid of the regional centers |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 619 | make a separate wage category, lower than minimum wage |
| 620 | Make sure the older ones have housing, and make sure family members know how to get them help |
| 621 | I don't know. |
| 622 | Attend IEP meetings with youth. Schools often mislead parents and parents are unsure of their rights. |
| 623 | They could stay by educating and screening children to catch these types of often overlooked disorders. As it is in our country there is only one occupational therapist for children my son's age and is 45 minutes away |
| 624 | As a parent, it would have been really nice to have an advocate from the time of initial diagnosis to help guide us in the right direction for services, medical care, education, etc. |
| 625 | Continued support to programs falls short. In home support or support in our communities is lacking. There needs to be more education options and support to home based programs etc... |
| 626 | This all starts at the roots. State funding drives services and supports as well as case management that can assist and advocate. We need to put more funding into regional centers and their vendors so services can expand and continue to develop including being able to provide information and training to individuals. |
| 627 | I think that the State Council should assist people in realizing their rights in reality; such as, housing and support in residential services, employment services that pay living wages for all people, insuring that the regional centers are providing the services to clients (QA), access to all services that are needed in the community. |
| 628 | The local offices must get to know the community and its needs, and build a real partnership with the regional centers, to determine the best methods for making improvements in that community. The managers must be leaders who are effective, positive communicators. |
| 629 | Need to move funding from Day Programs and Sheltered Workshops to Integrated Competitive Employment. Need to start to reduce and then eliminate funding for Day Programs and Sheltered Workshops. |
| 630 | Education of nurses, doctors, etc on the needs of our clients. Transportation to better help our clients. Dental care has to be dealt with as that's the least taken care of aspect of our clients. Clients who are aging is also something that is popping up quite a bit, putting in supports to help aging disabled clients rather than resorting to nursing homes would be hugely beneficial. |
| 631 | Lobby for a separation between highly qualified evaluators and funders. If schools IDs a student - they must pay for services If the regional center IDs a child in need of services - they must pay for services. This results in under recognized developmental needs - and delayed access to care. |
| 632 | Treat them with as much value, respect, and potential as you do the Neuro-typical children. |
| 633 | Convince the governor and all government representative to give support to the most defenseless people in our state. |
| 634 | helping all people with employment support after they reach 18 years old. And having free employment and life coaches who are qualified. |
| 635 | Work closely with persons with disabilities and their families |
| 636 | Work with people providing or developing services for Not just DHCS. often mgmt. out of touch with needs and DHCS and Denti. Cal totally out of touch. . |
| 637 | Provide accessible ways to access flexible budgets and get the family fully involved. |
| 638 | It's simple, think of the client first and everything else should be secondary. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 639 | Start at young age to provide support for families. |
| 640 | Monitor the regional center better to ensure they have programs people need and are regularly funding them. Currently regional center acts more of a roadblock to services and supports than facilitators. |
| 641 | More services to help the families . |
| 642 | consider siblings that are not challenged when setting up respite. I have 3 kids 2 have challenges. But since the 3 child can not be left with the worker, it doesn't give parents a true break. |
| 643 | Families should not have to beg, find out from others what services and opportunities would support each client. Choices and possible amounts of various services should be visible such as respite care, DOR, behavior services, IHSS, other agencies for day program supports. There are differences in possible options given to clients within regional center. Adult Individuals living with families should not have only 4-5 hours of respite care, while others clients receive more services because that family knows of more service options. Agencies that serve should continue to have a plan with printed materials to train for nutrition, meal preparation & cooking skills, and behavioral plan as needed for individuals that are followed through by agencies providers that are serving TCRC clients. |
| 644 | Provide efficient training to community resource providers serving families/people with intellectual/developmental disabilities. Parent "Bootcamp" Orientation to community resources; a booklet (?) Having family members, parents of children with developmental disabilities, on every decision making council to best provide input on necessary support systems; how to best improve? what else is missing? In what ways will "this" help this population? |
| 645 | I would appreciate it if the State Council could spend more time focusing on the current housing model and its limitations. Section 8 waitlists can be incredibly long, to the point where people may move out of county or out of state in order to be able to live. Perhaps some outreach programs designed to educate landlords about people with disabilities and to help remove some of the stigmas attached to landlords and people with disabilities. |
| 646 | I'm not sure. |
| 647 | We need more supports including financial incentives to get resources like the above to come up and provide our clients with these services. This is especially true since we often have to get established, out of the area providers to come up to our rural area to set up a program in our area. |
| 648 | I believe that if the community resources were available, parents would utilize them to improve their families and to better serve their children. State Council can better help people by working to get these community resources available. |
| 649 | From my perspective, it would be beneficial if regional center staff fully understood what the vision of the State Council is and how to describe the State Council to clients and their families. Service Coordination is the first point of contact for clients and families, typically, and without that understanding they may not be able to assist clients and their families in contacting the State Council until there is an emergency or an issue with the local regional center. In addition to that, advocacy, outreach and lobbying to increase awareness and opportunities for clients is a huge asset to our communities. |
| 650 | Provide training for providers in the area of strong ISP / appropriate goals/objectives, boundaries and professionalism. |
| 651 | Support additional funding for the development of much needed programs and to increase the quality of existing programs. |
| 652 | Outreach and being visible in the community. Education of legislators and local government and community members that have influence. |
| 653 | More supports for Dual Diagnosis clients as they take up a majority of time. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 654 | Promote the develop of these resources, particularly affordable housing options. |
| 655 | Continue to advocate for mor elow cost housing (or alternatively more access to "section 8 rental certificates", self determination and safety training (incl. advocating ith/law enforcement in any way possible to take crimes against/by people w/ disabilities more seriously. |
| 656 | Offer varied support for people with rare conditions. |
| 657 | Continued advocacy and information regarding available community services. |
| 658 | ensure the regional centers are providing the services and support they are tasked with through the lantern act. provide the funding necessary to train service coordinators to be better advocates for clients and their families. make the process easier for those wishing to start or engage in meaningful day programs. |
| 659 | I feel that SCDD could be more active as an advocate by directly contacting regional centers on behalf of consumers when regions statewide express similar concerns about regional center services and practices. |
| 660 | They can give more money to these programs so that they don't have to stop and I can keep getting all the help I need and get even more help. |
| 661 | I am not sure! Do folks even know about the State Council? What it is for and what it can do? I work in the industry and I don't know, not sure how families could even know. |
| 662 | I am very please with all the services that area board9 provides |
| 663 | Outside tutoring, placement with organizations to work on social behaviors |
| 664 | Get rid of redundant services, revamp services to include all STEM w/in any program w/in the region to be competitive. People coming in the system, specifically those w/autism, have all been raised on technology, and almost 100% of any programs are not utilizing technology in this fashion. |
| 665 | Increase the availability to the above. |
| 666 | Advocate for realistic funding of services for adults with intensive needs. |
| 667 | Continue to provide advocacy. |
| 668 | Help advocate for appropriate funding so quality services and these increased services are possible.. |
| 669 | Continue to help make sure I get the services I need. |
| 670 | They can continue to offer individual-advocacy to individualizes with developmental disabilities. I feel that is one of the most important ways they have supported me in my life. |
| 671 | There needs to be more choices for the future of the disabled after they age out. New programs or idea for these individuals. There needs to be more safety checks to make sure that the disabled are being taken care of and not abused. More education on autism and other disabilities. |
| 672 | acknowledge that these disabilities cant always be seen |
| 673 | The State Council could provide more funding for programs that deal with people with intellectual/developmental disabilities. If there was more funding we would have more supplies and materials to do our job better. Cheaper bus passes so everyone can get where they need to go in the city without the worry of not being able to afford it. People could take the bus to get to school, go to program, and doctors appointments much easier. The State Council could make housing cheaper, which would keep a lot of homeless people with disabilities off the streets. |
| 674 | Supported living for people with significant physical disabilities. Expand supported living for people with intellectual disabilities. |
| 675 | Employment: CA state law/Action needs to be taken that requires companies of a certain size (50+ employees) to hire person with a developmental disability. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 676 | I think the state council could help by having more resources open for the people with the disability and not be limited on how long they could use a service. also I think they could help too by bettering schools services for people with disabilities. |
| 677 | Help families with the transition to adulthood and the conservator ship. It is crazy that we need to hire 2 lawyers to represent us and our daughter who doesn't even understand what is going on. |
| 678 | Let the families chose what is best for them. |
| 679 | One of the pressing problems for the students and their families is to be able to get needed services for their children. The families either needs to learn how to connect to services, or more options are needed. |
| 680 | provide after normal business hours service coordination, access to translation services, supplement transportation training, development of more day program activities, more active quality assurance and visits to service providers for residential services. |
| 681 | aertwert |
| 682 | Reaching out to meet to new people and show them how this would be better a place for more opportunities working in 4 years from now even with intellectual developmental disabilities. State Council wanted to show them how they were respecting and understanding the people has disabilities. |
| 683 | More knowledge on family wills and so forth |
| 684 | Participate more with on the job observation. |
| 685 | Be proactive about finding out from locals what they need in their specific city. transportation? housing? work? recreation etc. |
| 686 | Please continue to fund sheltered workshops such as Hope Services, provide incentives for companies to contract with sheltered workshops so our family members can have a place to be productive members of society while being able to socialize with their peers. |
| 687 | Continue paying for related services through age 12. Or cover copays and deal with billing insurance. It's a terrible hassle and financial burden that there are no therapy providers that take medi-cal. So we have to go private or do without. |
| 688 | Service coordinators need to be more attentive to many of their clients. Many have had to wait 6mo to a year before seeing action to their request of what is available to them. We need a list of different organizations that have contracts for work for the Disabled. |
| 689 | I don't know. |
| 690 | I believe that the State Council can better help people with disabilities is by actually listening to what we have to say. I feel like many of us are pushed aside because we are labeled as "different" which we are not we are all people and we have feelings that should be taken into consideration as well. |
| 691 | Secure specialized grants for program development.....(e.g., for a specialized dental clinic); continue to offer individual advocacy on a case-by-case basis. |
| 692 | More available/inexpensive housing. Roommates and in house care. Health care benefits and schools with more classes and interesting activities to do. |
| 693 | Provide more opportunities for people with disabilities to come together as a community |
| 694 | Create more ways for parents to provide housing for their adult children with disabilities without compromising their SSI. Create ways for people to create housing that is specifically for their child. |
| 695 | To continue having Advocacy for our families. |
| 696 | Have more resources within the classroom and at home. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 697 | Do more trainings |
| 698 | Help support their families. |
| 699 | People need a place to live. The system needs to be more efficient. The process to get housing and services takes too long. |
| 700 | Service providers need to be funded at a rate where they can provide quality staff, oversight and quality assurances. |
| 701 | More resources available for them, to get them out of the house for few, reliable services |
| 702 | Reach into the remote areas... watch what goes on here... Even our schools are inadequate. We need technology options for these students. My son got an IPAD after he got out of school and that was only because I went to a fair hearing with RC and MediCal.. THIS is the device that helps people with DD organize and be independent and we have no one here that knows about it and no one at the college that cares about it. |
| 703 | Provide better advocacy experts at iep's, and disputes too better inform support parents. My son's school bucked off what myself and advocates for him had stated his needs school avoided the one on one intervention he needed. |
| 704 | Good programs cost money, and not every family has the resources to pay for the programs their family member needs. We need to find the best programs, and find ways to make them available and affordable to all who need them. |
| 705 | Make sure communities have recreational opportunities |
| 706 | Listen to parents...especially the stories/complaints that seem too far-fetched to be true. |
| 707 | We need more adherence to oversight. We need more accountability for CCL and Regional Center personnel. They are lax in many cases as they are all unionized and have no repercussions when they fail at oversight. |
| 708 | Give more funding to DOR to help and provide our children support and training until they're capable on their own with their chosen employment. |
| 709 | housing other than care homes, more supported living on their own. training to get jobs help support the day programs already in place. |
| 710 | Make families aware of what services are available. It is so difficult to transition from school into adulthood. |
| 711 | A lot of programs are struggling due to the low pay for employees. There is a lot of turnover in many agencies. We need to get better funding for the programs we have and pay better so we can keep employees. |
| 712 | Talk with someone on an individual bases. |
| 713 | Provide support, education and opportunities in these areas. Conduct activities ensuring that all parts of the service system are working in concert toward collective goals and objectives. Promote new thinking on the values underlying services and supports. Bridge the disconnect between Sacramento and real life. |
| 714 | More education, a lot of people still don't know about the State Council. |
| 715 | By providing local grants that immediately meet the needs of the community. By empowering the Regional Advisory Council with the ability to serve the community through advocacy opportunities. |
| 716 | They can supply more funds and resources to help mentally disable people |
| 717 | Advocate for more stable funding with cost of living increases for services. Keep the lives of our folks in the forefront of legislators. |
| 718 | funding for dental and vision |
| 719 | Listen to us. |
| 720 | Increase in funding for services. The income for residents do not meet the challenges residential programs face when increases in minimum wage, pay roll taxes, liability insurance, food, gas etc costs rises while the pay for care decreases. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 721 | Help with transition from high school to adulthood. Heard there are not much out there for adults w/severe delay once they are out of the school system. |
| 722 | Advocate for the whole system. It appears we are only fixing things piece meal. We need to look at the system and see how this system can be run more efficiently and effectively. The infrastructure definitely needs to be revamped. |
| 723 | Be a clearinghouse for information and ideas and get the word out to people with developmental disabilities and their families. Address 'paternalism' within the system and encourage independence and dignity for those who have their own lives and desires and wills and plans. |
| 724 | Continue to hold forums, visit programs and speak with participants and their families. Talk with service providers and community members. |
| 725 | Continue to offer and share the information in all areas to best fit the needs of the individuals as a unique individual. |
| 726 | Continue to advocate for services based on the current needs of our population, including wage increases for those who work with our family members. |
| 727 | Proactively develop housing, supportive services, employment and vocational training, recreation, and community integration options for the massive numbers of adults rising up through the system. |
| 728 | Please listen to the parents and non profit advocates who are dealing with this on a daily basis. Think of this as an opportunity - like Lanterman - to do something that really makes a difference. |
| 729 | More funding is needed from the state and federal government to make sure that services and supports continue to be available, especially since we the families will not always be here to help care for them. We are draining our personal resources to support our adult children with disabilities. |
| 730 | See #3 |
| 731 | CREATIVE HOUSING OPTIONS AND FLEXIBILITY FOR THOSE WHOSE NEEDS DO NOT FIT NEATLY INTO ONE CATEGORY AS WELL AS ADEQUATE FUNDING AND TRAINING FOR SUPPORT STAFF. ALSO THE LACK OF BEHAVIORAL SUPPORT FOR ADULTS RESULTS IN MANY DD INDIVIDUALS BEING UNABLE TO MAINTAIN A STABLE ENVIRONMENT REGARDLESS OF WHERE THEY LIVE OR WHAT DAY PROGRAM THEY ACCESS. THE CUT-OFF BASED UPON CHRONOLOGICAL AGE IS COMPLETELY CONTRA TO THE NEEDS OF THE DD POPULATION. WE ACKNOWLEDGE THAT EDUCATION PROGRAMS SHOULD NOT BE CUT OFF JUST BECAUSE SOMEONE IS A LEGAL ADULT, BUT WE CUT OFF BEHAVIORAL SUPPORT AND TRAINING ON THAT BASIS BECAUSE ???? |
| 732 | We need a safe state wide option for difficult guys like my son with autism and mental illness. I am thinking state facility with much oversight and the ability for residents to get outside and move on a daily basis. |
| 733 | Supported living or temporary shelter (hospital) for dual-diagnosis or extreme behavioral challenging individuals that pose a danger to self and others. |
| 734 | Keep pushing the agencies to help based on what the families are saying the consumer wants/needs. |
| 735 | It is quite scary because our children are vulnerable and could be taken advantage of very easily. We need individuals who could provide opportunities for our children to get transportation w/o fear of whoever assists us will bring any harm. I would like to see perhaps a group of family caretakers, or individuals who have been touched by this disability to assist one another in arranging some type of services for each other w/o causing undue financial hardship. |
| 736 | Partner with local colleges and universities to provide health services at reduced fee or free. The AB9 People 1st Advocacy Conference in |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | 2013 was fantastic. |
| 737 | Get more free programs with people with disabilities. Social programs. How to live independently program. Housing program. |
| 738 | See above. |
| 739 | Create awareness for all programs and help individuals be where they choose. |
| 740 | ensure that Regional Center follow the law, and actually allow families to develop IPP's. They often do not tell families about available services, and when families find out, they delay, and deny. |
| 741 | Lobby for improved funding and knowledge about the need at all levels - state, county and city |
| 742 | yes |
| 743 | By asserting a zero-tolerance for evictions resulting in homelessness for people with developmental disabilities. |
| 744 | Recruit doctors to take continuing education courses freely available (from I think the Kennedy Center on DD website). And help develop additional trainings |
| 745 | Work on public / private partnerships to fund gaps and develop solutions. |
| 746 | Provide adequate training for those caring for others with autism. Give financial and professional incentives for support providers to continue in the field. |
| 747 | The State Council should partner with community colleges and summer camp programs to offer some tax benefit or stipend for supporting a focus around inclusive learning and opportunity. The State Council should partner with public school districts in the same manner that ESL to those that need it and mandate the 41 Developmental Assets to the broader curriculum through Health or PE class. |
| 748 | Additional funds to support individuals/children with special needs, more work opportunities |
| 749 | Be part of the answer not a hurdle to overcome |
| 750 | More things that are TRULY TAILORED for the individual at the Adult Day Programs. With budgets always being cut, I'm surprised they are even staying open, PUT MORE MONEY INTO BRINGING UP PROGRAMS. |
| 751 | IHHS wages better than fast food jobs. |
| 752 | Build safe, affordable places where they can live. Support businesses willing to employ them. Help in early years is a plus, or course, but there is an older generation who COULD be employed and productive and paying taxes INTO the system rather than taking it out. |
| 753 | Fund RC and service providers adequately. Build homes for our DD adults. |
| 754 | help us develop better responses to crisis of adolescents with extreme behaviors so that they are helped and their families have support in the home to keep everyone safe; allow SLS staff to utilize CPI training methods that include hands on guidance to safety if needed and if approved by IPP team for certain situations. Help us get approval more easily for SLS to begin so that money isn't lost on rent or mortgage for empty homes while approval is being awaited for many months. Help us develop better daytime programs that will engage our adult children, possibly with some level of family volunteer support. |
| 755 | We need to restructure the entire system to vastly expand the supports available for adults with autism, focusing on adult day programs (supported employment, when viable), and supported housing options customized for the complex, intensive needs of adult autism. |
| 756 | Please provide child care of special needs kids. |
| 757 | Increase the rates so that compete staffing can be hired and retained providing consistency and quality services. |
| 758 | Secure more money for transition to adulthood and early intervention services. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 759 | continue to advocate for state of the art programs from cradle to grave. This vulnerable population needs to be heard from, and the council needs to make sure these voices are heard. |
| 760 | Identify disabilities and work with various groups (IL Centers for example)to streamline assistance that address their needs. |
| 761 | Adults services, support |
| 762 | Possibly provide resources that we can pass on to our students. |
| 763 | Request that the Regional Centers include employment as an outreach activity. Regional Centers should be graded on their ability to find suitable employment for these individuals. |
| 764 | Increase hour quota for respite care |
| 765 | Provide more services |
| 766 | Demand that providers Identify strengths and weaknesses of these individuals. Educate their advocate or parent, so they will be prepared to counter the one size fits all pattern we see in many of our schools and programs geared to assist the student/client |
| 767 | I do not know enough about this Council to answer this question. I am willing to learn more |
| 768 | Provide Housing and employment.Also provide summer camps for Special need kids. |
| 769 | Put in more training for parents and caregivers on how to increase their independence. |
| 770 | Providing alternatives to a traditional high school diploma. Offer classes that will benefit them. Auto shop. Wood shop. More ROP classes. |
| 771 | Focus on fewer areas, maybe 3. SCDD sponsored legislation on employment first and self determination were excellent for leading the state in a positive direction. Continue with leadership in legislative arenas. Consider working on legislation to make regional centers more consistent throughout the state & to make DDS function as an overseer of RCs. |
| 772 | Have a representative at every school to communicate between school staff , the student and the family re: school services, goals, next steps, homework, therapies etc. Families need to be involved constantly. Provide opportunities for music, sports, art, dance, reduce isolation, promote inclusion in high school sports and clubs. Train and use student tutors at all grade levels. Use lots of them in all classrooms... even "regular ed" kids could benefit from a "study buddy". The kids who are tutoring will learn from it. |
| 773 | Advocate for them to get the appropriate services needed. |
| 774 | Make available more recreational activities and places they can get together with their peers. |
| 775 | The State Council can start providing direct advocacy to families and individuals with developmental disabilities |
| 776 | Please train, counsel and teach (ALL) teachers responsible for teaching a class with students with disabilities or special needs, from elementary all the way to high school so a child can be encouraged about learning and enjoy learning and therefore succeed in his/her academics, and be able to obtain a good quality paying job. Do not only (pass) the student because the State requires this because of the student's (age) many students are not ready to go on to the next grade level i.e., from elementary to high school. Many times these kids are not emotionally or intellectually ready to move on to the next grade, and they end up not enjoying school and learning. |
| 777 | Fund OT services to assist with vocational assessing including a direct observation component. Increase funding for OT's to have a larger stake in job matching and self-determination specific to the individual's medical disabilities Increase funding through habilitative services |
| 778 | I am not sure. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 779 | Ensure that children with disabilities are adequately served between the ages of 0 to 3. |
| 780 | Make sure that advocacy continues. Parents and adults need help to be stronger advocates for their family members. They can only do this if they get assistance from a state council group. |
| 781 | How to get help more support. to cook more who needs more transportation on weekends. |
| 782 | By working collaboratively with other agencies in OC (RCOC, DMC, & OCHA) as well as community leaders to achieve mutual objectives for developmentally disabled adults in Orange County in the areas of employment and housing. |
| 783 | They are doing a great job |
| 784 | N/A |
| 785 | More resources, less red tape for case workers at Regional centers (administrators are a huge barrier to consumers receiving services because they are driven by the dollar figures & not what is in the best interest of consumers), |
| 786 | More support and get funding - don't keep cutting from this area of great need. |
| 787 | Help advocate for more funding for Regional Centers and other such agencies that are helping the population. |
| 788 | There needs to be information and awareness in the employer community, so that local employers feel more compelled to take a chance and hire someone with a disability. There seems to be a disconnect between our clients and potential employers in the community. |
| 789 | provision of funding for programs to educate parents of services available for these community. |
| 790 | Simple!!! Return the Area Boards back to their previous model. |
| 791 | Housing and services that keep them living independently in their community |
| 792 | Make affordable housing accessible to the intellectual/developmental disabilities. |
| 793 | Background checks on all people that work with people with disabilities. Outreach to low income Black inner city communities. Protection from harm. Training for everyone that comes in contact with special needs people. |
| 794 | Provide more employment opportunities for people with disabilities. Maybe provide incentives to companies that hire people with disabilities. |
| 795 | Oversight over regional center services and SLS companies. |
| 796 | I don't have any idea what the State Council does to help the intellectual/developmental disability individuals |
| 797 | we are hearing disable |
| 798 | awareness from police etc |
| 799 | Provide incentives for companies to hire more people with disabilities. Provide education to our communities about disability. Find more job training programs. Provide more opportunities for independent living. More funding for supports. |
| 800 | Implementing more leadership roles for people with dd/id, training them for leadership roles and self advocacy, working with school districts for cultural competency training. |
| 801 | The State Council can help people with intellectual/developmental disabilities by keeping them in mind when making decisions. |
| 802 | More education for parents to bring awareness of services. |
| 803 | Listen, listen, listen. |
| 804 | The needs of someone with a intellectual/developmental disability, as anyone with any type of disability begin at birth and continue throughout their lives. These individuals and their family need financial help as well as support with information and/or services for their individual needs. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 805 | Advocating for services, supports and training that lead to individuals being able to live independently in their community. |
| 806 | Provide funds to pay for videos to be made to illustrate the capabilities that people with intellectual/developmental disabilities do have. |
| 807 | How about encouraging regional centers, etc. to hire more of us? "Nothing about us without us!" |
| 808 | Open more doors for them to have the most independence as possible. Living on their own. |
| 809 | Better quality control when hiring workers who provide support/assistance for people with idd as well as better training for those who are hired to support/assist. |
| 810 | Empower Regional Offices to have more funding and decision making power to address unique individual needs of that specific area. Trust the people living in their own communities to know what their needs are. Empower the people living in their own communities to address and meet those needs by supporting local State Council area offices and boards. |
| 811 | Continue to be advocates at IEP and IPP meetings and to lobby for expansion of generic resources such as public transit. |
| 812 | Continue to work collaboratively with schools. |
| 813 | The State Council can keep the needs of people with intellectual/developmental disabilities front and center. The disabled often cannot advocate for themselves, but with their needs accounted for, they can become a vibrant part of the world around them. Getting over the hurdle between the world as it seems to them and the world as it actually ticks along around them can be very frightening. Often, families can't be of much help because the more help they give, the more helpless the disabled feel. Help from the greater community has a much more empowering effect and does the double duty of communicating a much needed sense of acceptance to the disabled. |
| 814 | Maybe advise us how to obtain a workshop where our folks could earn a wage. Such as a sheltered workshop. |
| 815 | More uniform funding, for example San Diego County seems to offer less and pay workers less. |
| 816 | taking a look at how long it takes for a person to get a OT visit scheduled, to the time it takes to be seen, the time it takes the person to be assisted could be very lengthy... |
| 817 | Poway School District should actually cooperate in establishing and facilitating goals in a person's IEP that can be carried through other programs after school age that assists with formal and informal community supports, Quality Assurance and jobs. Can you help with that or are Poway Special Ed students always to be held prisoner to a school district that disrespects and hinders it's students? |
| 818 | You do an amazing job; our local office (N. Valley Hills, formerly AB 6) is a valued support. They have provided unparalleled advocacy support...I am grateful as are the folks we serve and their families. |
| 819 | Increase the budget and creative housing options |
| 820 | The State can provide funding for programs for people with intellectual/developmental disabilities. |
| 821 | increase training requirements for staff working with the disabled |
| 822 | Continue providing resources in these areas. |
| 823 | Provide households with additional respite hours and make the process easier for families |
| 824 | Better medical help. |
| 825 | More financial support. As a family member/care provider our family has been very negatively affected financially since by DD brother came to live with us after the death of our mother. Why should my retirement be in jeopardy because I have taken on the responsibility of my brother. Of course my parents should have made plans for him....but they didn't. |
| 826 | Advocate for service providers to receive better services from the regional center; proper funding; |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 827 | continue individual advocacy so that no family or disabled person feels alone and unsupported. |
| 828 | Advocate. Throughout the system we need more money. For housing, for employment, for MediCal & Medicare, etc. If we don't serve those within the DD system, the entire society fails. |
| 829 | Provide advocacy help in their communities and beyond Become a leader in this field so systemic change can occur when the SCDD gets behind an issue Keep local input by keeping regional office open |
| 830 | More programs, funding for transportation and job opportunities for the above individuals. |
| 831 | We would like to see more hours provided to the child in need. |
| 832 | ensure that the local state council offices remain intact so that consumers can have more direct and immediate support from an advocacy agency. |
| 833 | Give kick backs or tax breaks to companies who hire students/adults with developmental/intellectual disabilities. |
| 834 | Health insurance would not pay for therapies needed such as speech or occupational therapy. Schools will only address "education related" needs. So there ends up being a gap where therapies are needed but no resource to pay for the services. |
| 835 | Advocate for fair wages and to restore funding to programs that families need to remain healthy and thriving. |
| 836 | Make the medical waiver system more user friendly and making a system that provides accountability. Every year when we must reapply there are always issues that arise and our services are in jeopardy - there is no one accountable to when mistakes are made. |
| 837 | Advocate for clients who can not speak for themselves. Our son has autism and is not able to speak for himself. He had a problem with a vendor and could not explain what was bothering him so we tried to contact your agency and other agencies and we received no help because it was required that he advocate for himself! |
| 838 | Listen to the advocates |
| 839 | More employment opportunities. Now if the individual can't perform to a certain level they can't be employed. |
| 840 | State budget does not adequately support job coaches & supportive living companions. This is forcing people into Adult group programs which do not support individual interests, desires and capabilities for a rewarding life. |
| 841 | Please don't cut respite hours! |
| 842 | The advocacy component within Regional Center does not function properly. It is so poor in terms of advocacy that family is pitted against the institution. In my experience every effort is being made to exclude family advocacy and yet family (in our experience) is usually that first and last resort. When shove comes to push, my son, always turns to us (his parents and siblings) for support 24/7. We don't take holidays, vacations or breaks from helping our differently abled son. |
| 843 | Helping them create 6 months goals and three steps they need to take to reach these goals then follow up after the 6 months to see if they have reach their goals. |
| 844 | Early intervention programs such as First 5 are important. The sooner they have service the better chance of having ordinary lives. |
| 845 | Be stronger advocates for the aging population |
| 846 | Keep on doing what you are doing. You have helped so many of us with severely disabled children get through crises. I would not have survived without you connecting us to the right resources and helping us through information overload and defending our rights. |
| 847 | Fund programs that help people with disabilities be included and educated on how to be as independent as possible |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| 848 | My son would greatly benefit from social programs. Many children with Autism need help in learning how to interact with others and this is something that is lacking in Ridgecrest. |
| 849 | Provide funding for more resources and services. Many of the service providers are underfunded/understaffed for the numbers of people they are trying to serve. It is difficult to find and retain capable caring staff when competing with public companies offering better pay and benefits. |
| 850 | From a parents outlook: a clear picture of services, advocacy, opportunities for success. More funding. |
| 851 | More opportunities for recreation. More opportunities for job training. |
| 852 | Take a stand regarding Regional Center's unchecked power |
| 853 | Provide funding for programs that support individuals and families with these types of disabilities. |
| 854 | advocacy |
| 855 | More of an intimate direct counsel and interaction. |
| 856 | Reduce the amount of red-tape for legal citizens to obtain services |
| 857 | Support these needy people |
| 858 | Looking into regional and having a set standard for services given. Regardless of income. |
| 859 | They can give them more benefits, money to Day programs so they can enjoy being in their community. |
| 860 | Help with the people who were put in place to help/serve the people, The state has given money to use, please use all the money on the people instead of paying the gate keepers. |
| 861 | If the SC can assist key stakeholders with lobbying for increased RC staff and services (and the funding that would necessitate) much could be achieved. |
| 862 | Develop training materials for clients on the importance of taking responsibility and follow through |
| 863 | advocate for more service dollars |
| 864 | Ensure that providers actually focuses on the individual. Many of the sheltered workshops that I have seen tend to offer group activities at specific times, with no choice making ability by the consumer and no alternative options. Also, there should be drop-in visits to various programs, workshops, job-sites, so that what is observed is reality, not "show and tell". |
| 865 | More participants attending the monthly meetings. |
| 866 | Please continue to advocate for the services for so many individuals who are just trying to enjoy a life with the opportunities that we all are able to enjoy for ourselves in our communities. |
| 867 | look at the way the state spends it's money. if less than 2% is spent supporting individualized employment, there is room for vast improvement. keep vendor rates competitive |
| 868 | Promote a positive image of people with disabilities as active members of their communities |
| 869 | work with school systems to foster work and educational skills. |
| 870 | advocate transportation in rural areas, propose an increase in subsidized housing and educate employers on the advantage of hiring people with disabilities. Advocate for improved health coverage |
| 871 | By not using a cookie cutter approach in service delivery, one size does not fit all. Seek new and innovative approaches to service delivery that would empower consumers, their family members and care providers. |
| 872 | Provide more opportunities for community inclusion in the area of health and recreation. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

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| | Provide built in trainings for individuals with autism regarding sexuality and money/physical safety. Most of the trainings out there are for intellectual disabilities, and the learning style of people with autism is often times at a different level then what is offered. I would also like to see more community awareness trainings at health and fitness oriented businesses. |
| 873 | Being more aggressive about issues and working more closely with client rights attorney's at regional centers and their supervisors regularly, with monthly phone conferences. |
| 874 | create a manual on what agencies are out there and what services they can provide (not want to) and how to get those services, for parents to use. everything seems to be secret and you are only told what they want you to know. |
| 875 | The state council could help with getting support staff agencies rates increased as they have not been increased for over 10 years. |
| 876 | Provide funds for dental clinics in rural areas to have the ability to provide anesthesia. get the government to provide more funding in rural areas for housing. support Self determination and the programs that support independence. Work toward a fair wage for caregivers. |
| 877 | Help them be more independent out in the community |
| 878 | By facilitating training, employment options, and full inclusion thinking as a paradigm change. |
| 879 | Be a stronger advocate for the rights and services of people with intellectual/developmental disabilities. Make sure that community is always at the table and part of the discussion. I see Disability Rights California and the ARC at meetings but not State Council on Developmental Disabilities. |

Survey Monkey Results

Question 4: What kind of training or information would you like to receive?

California State Council on Developmental Disabilities Survey Monkey Results: 5-year State Plan Needs Assessment

| | | Response Count |
|---|---|----------------|
| <i>answered question</i> | | 697 |
| <i>skipped question</i> | | 415 |
| 5: What kind of training or information would you like to receive? | | |
| # | Response Text | |
| 1 | Training for caregivers, especially in areas of physical, medical, behavioral needs of clients | |
| 2 | I'd like to see housing for women with aspergers syndrome. Also voter information. | |
| 3 | Training and services for teenagers and adults with autism on social interactions and generalization/inclusion while being independent in the community. | |
| 4 | available services | |
| 5 | Development of classes for individuals with intellectual / disabilities that are geared to the work programs. When I was going to a community college in Oregon they had a program that could determine what jobs would be best for an individual through a question and answer tool and then was evaluated. The outcome would help an individual help focus on those most desirable jobs that were determined for them. Then I would like to see our individuals to receive training and be taught what those jobs responsibilities require and be able to get preparatory tools to prepare for the jobs they have chosen that would better prepare them for the real thing. | |
| 6 | none | |
| 7 | See information above. | |
| 8 | N/A | |
| 9 | Future planning including housing, what happens to my child when I am gone. | |
| 10 | More help with finding a home for my family . Training in the computer field for people with low vision | |
| 11 | Flyers, emails, links and possible training sessions on what is available | |
| 12 | I personally do not need any training/information but I that there are so many parents/caregivers who just do not know how to care for their loved ones who need extra assistance and the caregivers and/or homes do not have qualified staff. I believe that there needs to be more mandated training by the state and not leave it up to the homes especially in the area of behaviorally challenged people with varying intellectual/developmental disabilities. The quality of care is profoundly lacking on all fronts!! | |
| 13 | Referral of statewide agencies that can help with employment and housing | |
| 14 | How to better advocate for my son | |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 15 | A review of what types of services are available to my child that will be helpful with his specific disability. |
| 16 | Transition |
| 17 | Information on what is going to change |
| 18 | ongoing trainings about available services and supports throughout the lifespan, how to access those services and supports, understanding laws that relate to services for I/DD, and what to do if rights to access those services and supports are being violated |
| 19 | I have to track down most information myself by hunting the internet. I created an ABA home program back in 1998 when waiting lists were long and CARD and LEAF were the only ones available in Orange County. I am better trained than most teachers and aides out there, and the lack of consistency is appalling. |
| 20 | All of items on answer #3, but 1. He needs self care skill & independent living skill raining. |
| 21 | Any college programs and scholarships available for special needs students. Also any job training opportunities and summer camps available. |
| 22 | Building trades, computer skills (and not just assembly), art and music. |
| 23 | I would love to find out what services are actually avail for my child rather then having to rely on other parents and private networking. Our social workers are never up front about what is available. |
| 24 | I would like to see very carefully supervised housing and staff that bring out the most potential in each intellectual/developmental disability person regardless of age. |
| 25 | I feel that I have access to the info I need through our organization, Families for Early Autism treatment |
| 26 | Legal advocacy |
| 27 | Job training |
| 28 | computer training/ mobility training/job training |
| 29 | I would like to know that when I die that my son will have a safe place to live and people to make sure he is healthy and happy. |
| 30 | driving and interwiving |
| 31 | Everyday life skills. Money management. Eating healthy, food prep. Job coach. |
| 32 | Same as 4 |
| 33 | resource for parents and caregivers providing information on all available services, where and how to access services, and what to do when you're STUCK. |
| 34 | More training incorporating the persons disability with work/jobs, and the availability and funding of adaptive technology.. |
| 35 | I've attended all kinds of trainings but there seem to be relatively few quality programs that fit the individual needs of higher functioning teens and adults with DD. I am constantly scouring to find what's out there and how to access it. |
| 36 | Employment, Housing, Transportation. Certified at Community Colleges for family members seeking to utilize their 20+ years of experience to now go back into the work force and help make the system better from the inside out. They shouldn't have to be certified or credentialed. Their experience speaks for itself. Real input, from real middle/low economic structure families. |
| 37 | I think it is unclear to families how the regional centers provide services. 1) A training on the services that are provided would be helpful. 2) also it is my understanding that it is very difficult to get vendorized with the regional center and there is such a need for services. there are waiting list or no services in many areas. there are many young upcoming adults that are aging out of the school system and not enough |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | service providers. the regional center system in California needs to get creative and become innovative. |
| | 3) Self determination- not so much what it is but examples of peoples lives and the supports and services they get. |
| 38 | Education and being able to pass off my goals of what I am majoring in as a Radiologist technician. |
| 39 | More help with sensory processing and how to help over stimulation. |
| 40 | Iep training is always useful, but how about training in what kinds of supports are available outside of the school district? |
| 41 | job development |
| 42 | Advocacy training. Bring back Partners in Policymaking! |
| 43 | written guidelines and contact persons |
| 44 | on how to be a good board member |
| 45 | More legal advocacy, procedural, after hours resource center, books and materials, advocates or council, work with OAH to bring back the outreach program to fund education re policy and procedures. |
| 46 | None at this time |
| 47 | Training us an ongoing process..what ever is available i am flexible |
| 48 | I want our county program to improve!!! |
| 49 | Opportunities for grants |
| 50 | Extensive Parent training for ABA and how to communicate with your child/adult not just a few sessions and then the trainers don't follow up or provide intervention when the approach they taught is not working or is done incorrectly |
| 51 | Self- advocacy; legislative advocacy |
| 52 | Conservatorship |
| 53 | Legal, personal, Employment Training. |
| 54 | Would rather give the training and information |
| 55 | I would like information that I can give to parents for support--like how to help their child with social groups, with getting and keeping a job, with continued adult learning/recreational experiences--without having to fill out lengthy applications again and again. |
| 56 | I attended a training on Trusts and Will's and I would like to receive more information and training on that topic so that I can better assist families. |
| 57 | Training that is appropriate for people with difficulties in communication and who need information that is concrete, not abstract. |
| 58 | Common Core State Standards Self Determination |
| 59 | How to become vendorized and ongoing support to develop a vendorized program |
| 60 | I would like to know how the State Council is going to fix their broken system. |
| 61 | Updates on funding issues and programs for these clients. None |
| 62 | My family would like to know more about why the multitude of systems and millions of dollars put into the system has not achieved the simple goal of eliminating institutions and increasing community resources as of yet. |
| 63 | same as you've done, ongoing |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 64 | Assisting technology training | |
| 65 | State and county programs ie, in home resources. | |
| 66 | I think training and information on Self-Determination would be great. | |
| 67 | ANYTHING that will help the people who are unable to advocate for themselves. | |
| 68 | More trainings to help with finding persons with disabilities a job. | |
| 69 | I think that all disabled individuals should learn how to use Dragon Naturally Speaking. Also, all disabled individuals should receive services from Regional Center, Westview Vocational Services, Department of Rehab, and Dayle Macintosh Resource Centers. | |
| 70 | How to get a grant to start a group home/respite home so I can utilize it myself. | |
| 71 | Information on Employment opportunities and how to find a job. | |
| 72 | More information on what the State council does. | |
| 73 | Informational and how to go about seeking funding for these gaps in finding of services for adults, employment and relationship or social skills concerns | |
| 74 | School/Service placement | |
| 75 | I would like to be kept apprised of the 5-Year Plan Development. | |
| 76 | None | |
| 77 | We are always so afraid of our kids becoming victims of ignorant officers. we mandate police officers to regularly visit local schools and agencies servicing disabled students/people to familiarize themselves with the difficulties they face and help them what to do in case of emergencies. There should be a training of the officers role playing with real people with disabilities, like autism, so they understand the reality. It'd help people with disabilities to feel safer and protected. | |
| 78 | How do we handle going across county lines and receive services that would enable our daughter to use transportation services, training and support. | |
| 79 | How employment can affect disability benefits. | |
| 80 | Job training not through Department of Rehabilitation but through the school. | |
| 81 | Job Development | |
| 82 | More job training for employer, maybe tax benefits for employers to encourage them to give people with disabilities a chance at employment. | |
| 83 | Where to get jobs | |
| 84 | Employers need the training and it should include people with disabilities doing the training. | |
| 85 | Training for care providers | |
| 86 | I want to know what the next upcoming level of education has to offer for my child before i get there. At this time everything is treated as a secret. The last thing the district wants me to know are all of my childs options for education and support systems, that way i will be more willing to accept because what they suggest is all i know. | |
| 87 | How to prepare my son for middle school and high school socially. | |
| 88 | Any camps/groups for the summer. My daughter is 19 | |
| 89 | Parenting Low cost support for autistic people | |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | Low cost advocates |
| 90 | Researched based facts about autism treatment. Trajectory studies on long term outcomes of early intervention treatment in autism. Research based interventions to improve Joint attention, language, socialization. |
| 91 | Provide resources for parents to utilize. Provide advocates for parents who are fighting against the school districts on behalf of their children. |
| 92 | Hands on |
| 93 | how to make the school understand that processing problems are real and are not solved with speech therapy only |
| 94 | How to handle a disability patient with dignity |
| 95 | LAWS PRINTED IN A WAY I CAN UNDERSTAND THEM |
| 96 | More extensive services to teach people with mild/moderate disabilities to drive and pass driver's education. |
| 97 | Best practices for quality programs for transition aged youth (ages 18-22) and young adults (ages 22-30) |
| 98 | Going from 18 to 21 what are the choices? 22 and up how to plan for that? |
| 99 | Access to advocates that can truly help without costing parents all their savings. Easily understood information about laws that apply to our circumstances, and information regarding exactly what help there is. Need some plan to work successfully with public schools to: A) make sure that students with developmental disabilities get the education they deserve |
| 100 | I'm looking for programs from my regional center to get additional benefits(money) to support my necessities while living low income with my parents |
| 101 | independent living skills, health and recreation |
| 102 | terapias |
| 103 | What day program / adult services are available? What community settings are trained and ready (appropriate modifications/adaptations) for our population? |
| 104 | transition services, community services, mental health services, social skills services, job training |
| 105 | Any |
| 106 | What will happen to our aging population? Who will train aides to work with them? Where will they live? |
| 107 | Provide contact information to families and/or professionals so they can speak with someone directly about concerns as they occur. |
| 108 | Self determination training, person centered planning, new accreditation for teachers --both general education and special educators so that they learn how to teach and differentiate instruction for the full spectrum of students. |
| 109 | How to work with our city to get people with developmental disabilities their rightful place in line for affordable housing. |
| 110 | I would like to know what happens to a 100% disabled child when his parents can no longer care for him with a system that is not fully funded. |
| 111 | Housing for my daughter. Employment and training to provide for herself. |
| 112 | I want to know what you are doing about question 4. |
| 113 | State Council seems to do a good job in this area |
| 114 | information on emmloyment and day centers |
| 115 | How to advocate effectively for school-age children. Parental rights in the school system. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 116 | Sometimes there are classes, but they are expensive. |
| 117 | A list of all benefits available |
| 118 | How to manage prepubescent years, latest research on ways to improve cognition, best educational practices, safety instruction for my child, etc |
| 119 | You name it we could use it: Communication, health safety, driving skills, behavior skills, cooking, etc. |
| 120 | If I had a younger child and would have benefited from programs that would assist me in learning how to make my child a productive person that can function in society to the best of their ability. I as a parent had to learn it all on my own but not everyone is lucky enough to have a medical background. |
| 121 | I would like to review the findings of the surveys after they are completed that I mentioned in question number 4. Responses from consumers and businesses can have a major impact on decision making and the success of proposed services. |
| 122 | Assurances that those in need of help (health and physical safety) will available 24/7. |
| 123 | Are there other transportation services available in addition to MTA and access? |
| 124 | Training regarding access to mental health services is needed. |
| 125 | Housing options for independent living and the supports that are available to make it happen. Alta needs to provide a list of agency's that participate. We have the right to review them, observe them, check if there is any infractions. |
| 126 | Methodical Lanterman Act Training for ALL Consumer Coordinators, Management, Regional Center Management and Service Coordinators. |
| 127 | Information that would help direct advocacy efforts where they are best utilized. Give the information to all advocates how to help us make the politicos understand the financial situation they have pushed service providers and families, care providers, etc. |
| 128 | Could have used some before but our attorney does it now. God help those who don't have the resources we have. |
| 129 | Simplified information on generic resources and appeal rights and the organizations responsibilities |
| 130 | All professional development training for M/S special education. |
| 131 | a main data base for those w/disabilities that can find safe employment, transportation and housing |
| 132 | InIntervenor - this person van help deafblind individuals but I believe it could help all individuals who r developmentAlly delayed. Check it out => |
| 133 | how to wade more successfully through the current process to determine how to best obtain services and supports. |
| 134 | I would like to receive the amount of money that is going towards each RCEB client starting with Alameda County. This would include any money from the Dept of Rehabilitation. |
| 135 | I want to know who out there is willing to work with students that have the ability to work and have disabilities! |
| 136 | We'd like to receive training that can lead her to productive work of her interest. We'd also like to receive information that may provide her safe housing for progressively independent living. |
| 137 | The providers of services for our adults desperately need training (SLS, ILS and IHSS workers and adult day program staff) - almost no funding given for this and they are expected to learn on the job. This is a dangerous situation especially in SLS and ILS setting. There are computer programs that can provide the training. First responders need more training to address how to appropriate handle crises with adults with autism. I would like information on how to find conservators to address my son's needs when I am no longer able to be his conservator. |
| 138 | How to fight and prepare for hearings and appeals |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 139 | Your housing plan. Assurance that Employment First is NOT Employment Only. |
| 140 | job training |
| 141 | More information on housing and funding to create housing for people with developmental disabilities. |
| 142 | I have adequate information now. |
| 143 | A first Aid kit to deal with client's associated personality disorders. Employees need training and understand the psychology of transference and the rescue syndrome. |
| 144 | Emergency assistance, self-advocacy, ability to function once parents are deceased. |
| 145 | There needs to be a comprehensive housing plan that is bigger than those coming out of the the Developmental Centers and CPP funds. I have been doing housing for over 18 years in the State, everyone says that housing is important but there isn't a focus on it or funds. |
| 146 | At this point, I like like with adult transition. What are our options for jobs, housing, integrating into the community etc. How do we move forward with and adult with IDD? What should we be doing and planning for? |
| 147 | How to change the rule that only poor people are able to get help for there child. |
| 148 | The schools and the outside providers need to work together. Often, the outside just comes making demands, and this is not helpful. |
| 149 | Housing, transportation and employment (no particular order). |
| 150 | employment advisement for students with ID |
| 151 | How to help my son to the road of independence. I'm hoping their is a program out there that can help. They said he has to be more positive, and say he CAN do what they ask of him. He takes things literally, and doesn't lie. He doesn't know for sure that he CAN do something, until he has already done it. He says he can try. Communication is one of his areas of disability. |
| 152 | Face to face trainings. |
| 153 | Information for people with disabilities know what they need to be independent and an active part of their communities |
| 154 | Updates on KRC's progress in fixing it's system. |
| 155 | Resource lists with Dr.s, Dentists, and child care for teens with multiple disabilities. |
| 156 | Help through IEP, behavior training, knowledge of how to access services in my community. |
| 157 | Social Security system navigation |
| 158 | Now,maybe about medical |
| 159 | Help with job search more intensely |
| 160 | Information on self-determination. Anything about the DC Task Force convening's. |
| 161 | In addition to what is now provided... information and training on who to contact and how to advocate for more funding to support day programs/employment and housing options and greater self-determination. A clearer understanding on how the current support system is organized and where the impact points are. |
| 162 | I think all agencies that provide services to this population should be interconnected in some way that would increase the likelihood of those services being utilized appropriately. |
| 163 | out in the real world activities |
| 164 | See answer to question 3 above. Do you help those with intellectual and/ OR developmental disabilities or just those with both? |
| 165 | Self determination, coping with teenagers with disabilities, programs available for all ages. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 166 | I would like to know more about how to help my child with the types of things they learn in therapy so that I can see potential problems and help to abate them. For example, my child is delayed globally with no diagnosis of a syndrome or "medical condition" it is just how he is. I need to know the difference between a symptom of a condition and just his delay. How to know to recognize symptoms of underlying issues and not just chalking things up to that is just him. |
| 167 | More training on the needs of high risk infants; more in-depth information on medical conditions/diagnoses leading to developmental delays/disabilities i.e. various syndromes; prenatal drug exposure |
| 168 | my daughter is given through regional center a certain amount of conferences per year, special needs network give one free conference per year, what used to be known as area board 10 give a series of helpful seminars, I received from them a booklet on accommodations head regional center worker right to section 8 why it was necessary to have the second bedroom, even that did not help. WHAT CAN YOU SEND ME THAT MIGHT MAKE A DIFFERENCE FOR ACCOMMODATION, THANK YOU FOR YOUR TIME |
| 169 | How to support adults with disabilities that can live on their own, but are unsuccessful in long-term employment or social engagement. |
| 170 | Training the trainer. I currently oversee our mentor program and have so many mentors interested in working with our youth with disabilities, however they need training that I can't provide them because I myself don't know much about working with these populations. So training on all disabilities, and how to work with them and how to be a beacon of support for the mentors. |
| 171 | Information and training surrounding how to expand Employment, Health, and Housing options. |
| 172 | Disability-specific training/information with useful links/parent support group information. |
| 173 | All parents should be trained in the basics of ABA and neurology.. that these individuals with disabilities are 'wired' differently and should be respected and loved, not treated in a punitive, belittling manner. |
| 174 | Behavioral training so that I can help my daughter coop with emotions when things do not go her way so that she will be able to get a job in her future and be a part of society. |
| 175 | Laws and information in inclusion schools |
| 176 | 1. I would like to see SCDD develop introductory training videos in Behavioral Therapy (BT) and Adaptive Skills Training (AST) in webinar form, so that parents can achieve this training at home, and can review it as a refresher as needed. Right now ACRC requires parents to travel to Sacramento on weekends for training prior to authorization of BT or AST, which discourages the initiation of BT and AST. It is a tragedy to see children who are missing critical windows in their development, and who will likely require lifelong high staffing levels, due to a failure to address behavioral problems early on. Frankly, it is irrational to require in-person classes for parents who have a duty of care for their children on the weekends. College and CPR classes are taken over the web; and if regional centers won't deliver BT and AST introductory classes this way, SCDD should. |
| 177 | Health Care benefits and Social Security benefits |
| 178 | How to create easy-to-follow alterations for materials that are not accessible to students with ID & DD. |
| 179 | How consumer's money are distributed. Care homes do all the work and it is just fair that the money received for consumers should be evenly and fairly distributed |
| 180 | Right now, info on anything related to Adult Transition. What's out there? |
| 181 | Community Involvement. I would like to see more information given to the community on how they can support their neighbors with |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | disabilities |
| 182 | 1. A class for family or friends who might be interested in becoming advocates to replace aging parents. Go over what all is involved. 2. A class on how to establish a group home. |
| 183 | Access to a menu of available support and services and assistance with obtaining funding |
| 184 | an overview of what to anticipate until my child is 22 in terms of services and options that will be available down the road. |
| 185 | Living in the community whether it takes Supported Living or Independent Living Services. |
| 186 | How to get the needed services |
| 187 | I would like to receive some training and more information with regards to Self determination programs. |
| 188 | Forget the training I have more training than most of the Regional Center staff!! And I am not kidding. For 27 years with Regional Center, I find myself training ALL of the service providers and RCC staff that we are assigned. They are not vested with these clients the way parents are. The parents should be the instructor trainers for the RCC staff and service providers, but God forbid we are paid for anything we do. I am convinced that had I not been the advocate I have been and continue to be, my son would be dead or homeless left to the service providers. These clients are high maintenance and we are a family fully involved, educated, etc. but it is not enough. We also have found out that with our son being high functioning, that monies that are paid to the service provider for him, and not used to directly pay staff to care for him are 'rolled over' and used for clients that require higher maintenance, rather than being used to enhance my sons life. This doesn't seem fair. Make the providers, including RCC, show that the monies being allotted for a client are being used for that client and not others. I know that things like CP require 24 hr care, but to use money from a high functioning client to care for a CP client doesn't seem right. Allow the correct amount for the CP client and use the money allotted to others (like my son) for them. Recreation, social, education, equipment, etc. |
| 189 | None |
| 190 | ADHD, social/pragmatic language/constructive classroom conversations , parent training about mental health of intellectual/developmental/differently abled teens |
| 191 | Education opportunities that transfer from high school to college to employment |
| 192 | I have noticed great training coming from my local state council. I wished I has known about them earlier because it would have been very helpful years ago. IEP help, dealing with SSI, the regional center...all good training. |
| 193 | I want to know what my child might be able to receive. |
| 194 | On our rights as parents to refuse vaccinations because we believe that our child had been injured by them, We need support and advocacy and from council that cannot be bought like the senators and congress of this state. |
| 195 | Where do young adults with disabilities go after they graduate from high school to further grow and function in society ? |
| 196 | None at this time. I will be getting involved with The Housing a Advisory Committee at RCOC to help coordinate more housing opportunities. |
| 197 | Fundraising |
| 198 | N/a |
| 199 | I have all the training and information thanks to Fairview |
| 200 | I would love more support in services that can really help you as a parent of a child with a disability. Because its so hard to do it at times and there is truly a lack of support out there for us parents. |
| 201 | I would have loved to have had the chance to have learned the techniques of Applied Behavioral Analysis. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 202 | Job application |
| 203 | I need to learn how to lead my son for better communication, and how to stop impulsive behaviors. More, I need to learn how to serve him better. |
| 204 | How to more effectively make changes in the system in a timely manner |
| 205 | n/a |
| 206 | Resources designed to better understand the employment needs of people with intellectual/developmental disabilities. |
| 207 | Tools to learn how to better advocate for special education services n health services. Dentist won't treat child |
| 208 | Realistic information to families. The "Dream" is not realistic without funding. Families must get involved in the political scene as all community services are dependent upon funding |
| 209 | Classes that guide families through the IHSS application and determination process. |
| 210 | Education on how I can advocate & be educated on how to help. |
| 211 | I would like to develop a program at Cerritos College in Norwalk, CA, like the one found at Taft. How can you help me do this? |
| 212 | More information on the kind of supports currently available and what is required to be provided. |
| 213 | How to be a better advocate, not only for my son, but for the system as a whole. |
| 214 | Would like to know why my child can't get a Medi-Cal Waiver (genetic syndrome) and why after filling out 6 IHSS applications with no success, we still don't have help. We have SDRC, with limited respite. My child is severe... |
| 215 | Info about all financial resources for dental beyond Denti-cal |
| 216 | It would be good to have support and training for families on how to cope with serious mental health issues. We got instant support and training when our son became diabetic, but no support of any kind, not a single phone call or anything when he tried to kill himself. |
| 217 | How to navigate through the bureaucracy to get to needed services. |
| 218 | How is the rate for vendors determined? |
| 219 | Represent disabled youth on the special education committees at state level because currently it is all educator representation as far as I can tell. |
| 220 | on how the budget need to fund go and we need a watch dog team to over see of consumer |
| 221 | Advocacy |
| 222 | Please tell us what monies are available; keep us informed of gov't programs and funding (e.g. HUD); help landlords see the advantage of renting to dev disabled; help employers find new ways to hire us, help us find good transportation so we can get to work; make use of the computer revolution and keep in touch with us better; help us gain some pride in our independence, we want to make a contribution to society. |
| 223 | Anything having to do with autism |
| 224 | Teacher, assistant teacher, police officer, community, parents to know more about special people with special needs how they are & for people to learn to accept, respect & protect them. |
| 225 | direction |
| 226 | Where do we go from here? What kind of safe, affordable HOUSING and protection will there be when parents die and funds run out? How do we guarantee our DD community safety, dignity, and protection? |
| 227 | Training on cultural and social differences, interaction with law enforcement and training designed to address homophobia, racism etc... |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 228 | IEP process, ABLE Act, SSI and IHSS |
| 229 | stop regional to be my paid |
| 230 | I would like to receive any information regarding programs, services for adults with DD. When my child was school aged I was much better informed but now as a parent of an adult with DD I am frequently feel out of the loop of info--no support for the problems that occur as our children experience independent living. |
| 231 | Help with finding appropriate work. |
| 232 | Autism and Behavior |
| 233 | How can families assertively advocate for their children. How can families receive 1:1 counseling and assistance with a non-partisan organization on how to secure services through the school district. |
| 234 | Customized employment. |
| 235 | what type of services are offered after 22yrs |
| 236 | Look at the standards of care for providers and the unacceptable rate structure! |
| 237 | Regular parent advocacy trainings, school district trainings for inclusion, Early Intervention 0-3 trainings, transition to adulthood trainings. rights advocacy where to get help |
| 238 | |
| 239 | I would like to know what I can do to help. How can I better advocate for my brother and others like him? |
| 240 | Right now, I would like some information on successful transitions for children into adulthood. What programs (governmental) should we know about? Where are there approved day care/long term care facilities...etc. |
| 241 | I need training to cover my employment gap to get opportunity to work |
| 242 | Is there a place for her to go we Here she can get tested to see what she might be good at or what might interest her. She doesn't know what she wants to do. |
| 243 | ABA and pre-teen/teen social interaction groups. Parent training and sibling training. |
| 244 | The states plan for employing individuals with disabilities. Subsidized jobs are on the chopping block. What are the plans to implement more opportunities for individuals with severe - profound disabilities? |
| 245 | Education regarding implementing the governor's employment first policy. |
| 246 | I would like more information on education and how to promote and inspire higher education for those with less extreme disabilities. |
| 247 | To easily know and access job training, housing, schooling for my son. He is currently 16 years old and in residential school in Utah. It has been a traumatic road to get here. I don't know what it will be like when he gets home, i.e., school, housing, job training, etc. |
| 248 | As a vendor, we do not receive training or information. |
| 249 | Our children need social skills training for middle school and high school. They need safety and abuse training. They need job training and employment that they can thrive in. They will need support/housing when I DIE. |
| 250 | I would like for you to require training and information for the people who staff adult day programs and residential homes. His staff is lazy, hate to say it, but, since the other residents are more independent than my son (even though it is a level three home), it never occurred to them to take him on an outing instead of dropping off the others at the mall and taking him home. My son threw a fit about this, and they reported |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | behavior problems, but this is what they call participating in social outings with the home. "Going for a ride in the car." Bullshit! He is 23 years old and had a high school diploma. He wants to go to college and have a paying job some day. He is more dependent since moving out than he ever was at home. yet he doesn't want to come home either. |
| 251 | Vocational. Wood working. Car mechanics. IT |
| 252 | Information on alternative supported employment options and the ability to help create more opportunities. |
| 253 | Not training for me, per se, but for providers and the community. |
| 254 | Are there employment training/classes in the community |
| 255 | Not sure. |
| 256 | to show people that live in group homes that they can live on their own |
| 257 | how to learn that there is really no help and when I get old I will probably be homeless because my mom will die of old age and all of you workers care only for your jobs and nothing will be done for help older ones |
| 258 | My son's support team (meaning his direct care staff, his Supported Living Agency and his Regional Center) does not have information or training on how to deal with issues involved with the Sexuality of people with DD. This is a problem right now. |
| 259 | Training in person centered planning; information on what services/ resources are available, diagnosis specific training in behavior (don't just lump us all in with the autistic families). |
| 260 | We know more about our son than most doctors or social workers; we have handled the situation for more than 50 years. |
| 261 | I would like to see more free training for the day program vendors. |
| 262 | Parent Support and help for the Severe Autistic Person |
| 263 | I like to receive free classes on how a works , child abuse and bullying and a list of resources that are available to your child . |
| 264 | IEP, self determination |
| 265 | Services available to individuals with disabilities. |
| 266 | quality adult services available. |
| 267 | sexual education (son went through puberty scared, yelling and crying. I had no help for this and he's 17 more to come.) parenting a young adult, Parenting through transition (18-22) |
| 268 | There could be many possible jobs: supermarket bagging, fast food service clean-up person, feeding animals., stocking shelves, returning supermarket carts, cleaning, yard work, etc. |
| 269 | Who to contact when we hit obstacles in trying to advocate for our kids. Education on our children's rights. |
| 270 | Information regarding community agencies that provide services to the community. |
| 271 | Occupational programs and transition from High School into the workforce. |
| 272 | How to protect my child when a stranger is trying to involve him/herself in our affairs. The biggest challenge we have had is with the school district and help with IEP as it has not been followed for most of my child's schooling. |
| 273 | i am already much more educated and trained in my daughter's needs so not quite sure what this question is about |
| 274 | Job training, placement and support services |
| 275 | Vocational training in my area is only offered at Miller HS in the San Fernando Valley. Miller can only accept a limited number of individuals and it is not open to enrollment before age 18. Vocational skills need to be taught starting at an earlier age. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 276 | I would like my son to have substantive vocational training in his HS which is not available. For example I would like to receive training like that offers at Miller HS in the San Fernando Valley. Miller can only accept a limited number of individuals and it is not open until age 18. Our young men need to begin life and vocational skills earlier. |
| 277 | As above |
| 278 | Self determination - how is this different from having an IPP and developing plans and services? |
| 279 | as a teacher with special needs mainstreamed into my classroom, I would love any training I can get |
| 280 | More information on work preparation programs and companies that are willing to work with individuals with intellectual disabilities. |
| 281 | No more training or information. We need services. |
| 282 | Behavioral approaches for consumers with limited communication. |
| 283 | Training on how to handle due process and mediation. |
| 284 | Jobs that provide a liveable wage and involve more than stocking shelves or wiping tables in a cafeteria. |
| 285 | ABA, Ds Conference (which Alta refuses to pay for unless your child has a dual diagnosis). |
| 286 | None at this time. But more local social integrated programs in our area would be wonderful. |
| 287 | Tell me what you are doing that makes a real difference |
| 288 | How to access services that my disabled child needs. How to find quality services . Laws that are easily understood . |
| 289 | Aba methods |
| 290 | newsletters and all kinds of training. |
| 291 | 1.) Advocacy |
| | 2) Training on who to refer to at the state level to know who to advocate to. |
| 292 | 3) Continue to provide information from Area boards so that everyone is informed of program and of any cuts to budgets |
| 293 | Further training and development for HUD and other agencies that provide low cost housing. updated information on what services really work to get our individuals better job placement, better activities and programs to enhance their quality of life. |
| 294 | more access to advocates to help us understand the rights and responsibilities, we as family members must adhere to in order to help our love ones. |
| 295 | I think that, not just me, but people in general, should receive training on the different disabilities and the services that is available for them. |
| 296 | None |
| 297 | we need more training in the behavioral areas |
| 298 | I would like more information on support groups for care providers, how to create a supportive system approach with CCL when dealing with situations. |
| 299 | Re placement |
| 300 | Vocational schools, self advocacy, life skills training, and community outreach programs that help disabled people to socialize and feel a part of the community. |
| 301 | None |
| 302 | Younger clients need information on supported employment programs and looking for jobs. Older clients need information on retirement |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | programs in the community. And, we all need information on housing. People need to know how working would impact their SSI/SSDI and medical insurance in a way that is to the point and easy to understand--this has been a soft spot in supported employment programs. |
| 303 | Information on what the Department of Developmental Services is doing to increase the number of agencies offering services in Customized Employment, Micro-enterprise, and supported employment. |
| 304 | I would like to receive self-determination information in Spanish. |
| 305 | Information about supports for those who would like to do something other than a day program. |
| 306 | I believe that the R/C's need to provide mandatory training for the vendors that provide services to the client's when they change forms and requirements so there is no reason for them not to understand. This will confine the coming out of R/C paperwork to quarterly blocks and not daily up-dates. Our R/C requires ILS Facilitators to submit reports to the SC's concerning the services and barriers of a client, however a Personal Assistant who also works with a client does not have to submit any paperwork to the SC. Why is there a difference? How can a planning team evaluate what is working and what adjustments need to be made to assist the client to obtain their goals. The R/C program design needs to be up-dated to meet the current needs of our clients. |
| 307 | I think it's the State that needs the training -- that there's this huge population of disabled adults, ages 21 and up who are underserved. |
| 308 | Thru regional center/service coordinator. If they get into from you as to available resources, then they can pass on to families. |
| 309 | Employment Support |
| 310 | Simplified information regarding Self-determination for clients, families and service providers to understand. Specifically, the differences between being Self-Determined and not. |
| 311 | Future options for a child including colleges with inclusive policies, employment support and opportunities. |
| 312 | Repeat the lectures for people can not attend due to schedule conflict, or for people like to attend again due to "too much information to absorb in one class" |
| 313 | Special Needs Trusts |
| 314 | Resources |
| 315 | I would like information on services available in my community. |
| 316 | We need training on the rights of students and their families. We also need information on how we can ensure that schools don't get away with doing illegal things. What we need most is schools not be able to mess with special needs students lives. |
| 317 | What exactly are the services RC's offer, we have to ask. I live in a very rural community and lacks supports for everything!! |
| 318 | Housing in West Sonoma County for my young adult medically fragile almost totally impaired daughter. |
| 319 | Nothing at this time |
| 320 | The kind that will help my son overcome his auditory processing issues. His behaviors are a direct result from this. |
| 321 | Information of services and funding available for the consumer as well as the parent caring for the disabled. |
| 322 | SSI affecting people with disabilities getting employment!!! |
| 323 | How Regional Center allocation of money works- giving more to those who have better advocacy. |
| 324 | Advocacy Adequate employment training Adequate Sex/Relationship Education |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | Adequate training for care givers of people with intellectual/developmental disabilities |
| 325 | A how-to guide on services offered by the state. The Regional Center has rejected us twice (our 10-year-old daughter is high-functioning autistic) so we are flying without a net. I know the healthcare system is supposed to be "absorbing" us, but we are still waiting for therapies from Kaiser 11 months after seeking them. |
| 326 | I would like more information on how to develop living situations for people with disabilities, that do not emulate the isolationist impression of a "Group Home" as they existed in the past...somewhere accessible to transportation, to close at hand supervision but allowing the client as much independence as they are capable of within safe parameters. I would also like more behavioral support provided sooner rather than later so parents do not smother they challenged "child" and create the large co dependence I observe in the best of families.....parent training as well as training for all case managers and vendors who work with clients with exceptional needs. |
| 327 | I'm fine- |
| 328 | ABA training and free parenting classes would be awesome. |
| 329 | Behavioral and social skills training. |
| 330 | My son will be 26 at the end of May, I need more training on ILS, Work programs that train adults for working in the general employment area & not just sheltered workshops. Training of service providers on dealing with high-functioning autistic/Asperger adults. |
| 331 | Housing is such a necessity and the rent increases are making it more challenging to find nice apartments for adults to live in on housing. |
| 332 | Additional courses on trainings to support persons with Autism better. Diabetic education classes. |
| 333 | training on how to include middle school age in getting employed and starting to make money, even if for few hours a week on a month to prepare them for jobs. |
| 334 | Housing, employment and self-determination |
| 335 | Information on transition, employment, and housing options and support for individuals transitioning to adulthood. |
| 336 | More information about special needs children and their civil rights and discrimination laws. |
| 337 | How best to reach the people who are going to be able to create change in the system, ie. community advocates, politicians, "movers and shakers". |
| 338 | Not sure |
| 339 | How better myself at communicating with people with disabilities |
| 340 | Negotiation skills, mediation skills. |
| 341 | Each adult special needs day program should have vocational assessment and training included. The day programs funded through GGRC should be required to coordinate and collaborate with DOR to be sure clients get training and access to employment opportunities. |
| 342 | There is Nothing that you have....I have a daughter (Aspergers) who is graduating from college, wants to get her Masters in Education so she can teach. But we are being held up by Pearson for testing which she needs to get into Grad school, won't accept her disability and give her accommodation that she has had since !st grade. |
| 343 | Behavior training. Working on that now. |
| 344 | I would like to know more about all the adult services--employment, housing, and recreation for developmentally disabled adults. |
| 345 | 1. Communication with Regional Center. 2. Communication with Day Program. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | 3. All caregivers & therapists to work together. |
| 346 | I would like more training in the various resources available to parents and students. The ease to find the resources and how they are funded along with clear purpose. |
| 347 | As a treating physician of child with disability, I noticed that families need workshops for behavior management, medication treatment, coping with a disable person, stress management and access to resources available through regional center, public school system, IHSS etc. specially for non English speaking community. |
| 348 | Every things. |
| 349 | Services, Education, Health, Employment |
| 350 | ALL resources offered to me/us not just a social worker/service coordinator's "choice FOR me/us." Where are the lists or guides of ALL services and supports? If 211 can compile resources for an entire county or state, why can't DDS or Regional Centers put our MORE information so that families can make their OWN decisions? Too much power in the hands of Regional Center staff that does not get out to families and no internal (or external quality control.) |
| 351 | A database to show, describe and outline all available options that everyone can use. |
| 352 | More information/education and support for people dealing with PTSD. |
| 353 | job training for a real outcome, housing in good communities(low income), increases for service providers, |
| 354 | How to find schools that fit the needs of students with I/D |
| 355 | More training on self-determination, facilitating person-driven planning, supporting meaningful employment that is more individualized. |
| 356 | I would like to participate in trainings that will help families bridge the gap between available services and actually receiving services. I would like a better understanding of the law relating to our disabled population, for services required. |
| 357 | Parent Training and Community training regarding activities and places that are fully accessible for those with severe intellectual and developmental disabilities. |
| 358 | I don't need training, I need funding to help my son - because the system is set up to fail these children and their families/caregivers. We feel like we're running a separate corporation just for our 3 1/2 year old son to get the critical services he uniquely needs to give him a chance at a joyful childhood and a self-sustaining life when he reaches adulthood. |
| 359 | A guidebook to services and supports available. |
| 360 | I provide these services. |
| 361 | see previous answer |
| 362 | Training pn determining what computer /technology may be appropriate for assistance /recreation. |
| 363 | Names of employers that would consider internshios |
| 364 | information about co-mornmid conditions |
| 365 | Please tell me about the areas that I referenced above and how the State Council is working to enhance them. |
| 366 | I let my Group Home Administrator training certificate lapse because I found it impossible to find 40 hours of training for Group Home Administrators. Our lone group home was one of the homes that we closed, so I no longer need it, but there is very little training available for Group Home Administrators. CCL has a list of vendors, but when you actually start calling or emailing them to sign up for training, they really only do trainings for ARF or RCFE administrators. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 367 | Housing. Medical issues. |
| 368 | The organizations we support, e.g. HICAPs, could benefit from more information on how people with intellectual/developmental disabilities get their supports and how. In other words, what is the hierarchy of organizations that support them. |
| 369 | Keep regional center updated. |
| 370 | support group for families of adult consumers |
| 371 | How to advocate better to regional center as a client |
| 372 | I'd like to know how the level of training I suggested above is being implemented and when it will be completed. |
| 373 | I don't need any more training. I need advocacy support in IEPs. |
| 374 | Community jobs that are available to developmental disabilities. |
| 375 | Everything! |
| 376 | Develop exercise programs for the disabled and programs designed to help the disabled make friends with people on a similar functioning level. My Son doesn't have any friends, which breaks my heart. He relates more with the job coaches than he does with the other participants in the programs that he has been involved in. My Son is too high functioning for the Regional Center Programs he has participated in but not high functioning enough to be independent. |
| 377 | self advocacy training and disabled community networking |
| 378 | Parent skills for ongoing ADHD age milestone issues. |
| 379 | information on how we are improving. |
| 380 | self initiation training |
| 381 | Training on better ways to support adults with developmental disabilities as well as training in the areas of sensitivity towards adults with developmental disabilities. |
| 382 | Individuals with d.d. need additional supports and training during their school years so that when they leave at either age 18 or 22, they will be better equipped to connect with the right kinds of supports. |
| 383 | More training directed to new parents for newly diagnosed children, specifically teaching them principles and practices of ABA to better inform them. Allow them to be the driver's of their ships so that when funding ends (i.e. ABA insurance funded programs), they will have the education and resources to sustain their children's programs and progress. |
| 384 | Information about how to be a better advocate for our child. |
| 385 | What services are out there, support groups, networking, seminars |
| 386 | Updates on State Council Activities |
| 387 | Lanterman Law training, IEP training, training regarding how agencies that work with DD work within the system |
| 388 | See above |
| 389 | Information sharing. Even information on how to get information. |
| 390 | Mandated supports and services, appeals process. |
| 391 | Medicare eligibility for SSI recipients & employers who offers on the job trainings in the lower SES communities of Orange County. |
| 392 | I want to better understand the court system as it relates to special education services and why the current climate is for judges to side with school districts over parents. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 393 | If there are supports already in place, information as to where to find them so that information can be forwarded to parents/caregivers. |
| 394 | How to teach my child myself. Period. No way can one parent go up against school lawyers, judges that have taken bribes, and insane education system that is below a human level of ethics. |
| 395 | Homeship programs Regional center offer loans programs that can owl or rent homes |
| 396 | How do we get the Department of Developmental Services to stop providing for unionized State Employees who have a horrible record of abuse and neglect and re-direct those funds to community based services that the State can at least hold accountable for the QUALITY of services they provide. |
| 397 | More resources |
| 398 | Better work programs that start at minimum wage and I want computer training |
| 399 | Current trends in assessment and intervention for preschoolers. Best practice strategies |
| 400 | Keep providers in loop more, with paid time to meet about consumers |
| 401 | How to talk to my teen son about sex, friendship and sustaining relationships through non-verbal cues and communication. |
| 402 | How to work with government agencies to secure land and housing monies for development of safe, secure, affordable housing for those with intellectual or developmental disabilities. |
| 403 | more coaching and apprenticeship opportunities and find out how to get around minimum wage issues which is hurting the community. |
| 404 | Self-determination |
| 405 | training on co-existing Autism and MH |
| 406 | The law and what is offered for services and support |
| 407 | College programs for our kids |
| 408 | I love any type of training. Different behaviors, diagnosis, resources etc. |
| 409 | A better understanding of what resources are out there |
| 410 | How better to get our services to the community |
| 411 | I already receive all the information I can process from many sources. |
| 412 | Housing, housing, housing... Desperate need for some sort of supported housing for Level 1. OC only has Level 2, 3 & 4. |
| 413 | Training on how to connect with other agencies and schools to support a seamless transition from one environment to another (e.g. academic and employment building blocks). |
| 414 | How to better partner with agencies consistently |
| 415 | how to ask for help how to add for medical care jobs relationships how to budget how to eat healthy food how the I you get good health how can I get a good welcome in my home how can I talk to my worker what is the State Council |
| 416 | Advocacy information designed for use by consumers and their families |
| 417 | A regular schedule of trainings regarding how a larger number of us can be of assistance at the legislative advocacy level (emailing or visiting representatives etc.) |
| 418 | Training on Autism Spectrum in adults: in education, workplace, behaviorally. Additionally, training to interact with the family, guardians, |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | caregivers of the individuals with ID. |
| 419 | transportation, medical advocacy, and employment services |
| 420 | What is the 2 year plan on spending CPP money in Southern California. |
| 421 | SB486 |
| | Financial Literacy |
| 422 | Employment Support strategies Education and training opportunities that include short term employment certification |
| 423 | transportation support and access of community resources, who can provide resources and case management that is COMPREHENSIVE across the life span not just early start, school district, regional center and insurance separately. |
| 424 | None. I think the Regional Center Staff needs more training. What more do you expect parents to take on? |
| 425 | How to support my brother to secure assistance without being seen as interfering in his life |
| 426 | What to expect at each stage of her life as far as what's available. |
| 427 | What's available? |
| 428 | Additional free workshops and training on behavior and support services. |
| 429 | 1) honest and comprehensive information - if we talk about person-centered planning then we need more then how to draw nice stick figures, but how to make it happen 2) we need training from people who understand the real world - not the world of universities and consultation |
| 430 | none |
| 431 | Supports for parents in the home with individuals with severe disabilities. |
| 432 | transition during school and school to college, school to life. School district staff need training on rights of individuals. |
| 433 | Mental illness & independent living.. Where adults with mental illness can get help as they age out of the school system (young adults) |
| 434 | Behavior training |
| 435 | Train service providers in how to be more aware of generic resources and exhausted them; allowing consumers to use their full potential. |
| 436 | more access to everything in our rural areas and not just between 8-5..I work full time. |
| 437 | Practical, what-works approaches, new theories of learning, especially with adults with autism. |
| 438 | information about available resource that can be distributed to families in our family resource center |
| 439 | Employer hiring tax credits and other on the job training hiring credits. |
| 440 | I would like regional centers to receive training on ethics and people centered practice. |
| 441 | How to respond when the schools willfully refuse to implement an IEP and how to deal with school district retaliation when one complains about the implementation not being done. |
| 442 | None anticipated for now |
| 443 | I would like to learn how to develop more resources in the community. I would like to learn how to write applications for grants to help fill in the gaps for services like social recreation opportunities. |
| 444 | how to deal with emotional meltdowns on all scales. |
| 445 | None. I want regional centers to receive training on how to work in an efficient and professional manner putting the clients needs, supports, |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | and services ahead of the cost \$\$\$\$\$. And to have them not push clients who are making the choice to live at a DC, look at other places if they don't want to until there is a closure date of the DC's announced. Lanterman act states they have a choice. Some choose the DC's. And some of their lives would be more restricted if they were moved to community. |
| 446 | more arts for children, culinary schools, sewing classes... not just train them to get a job at the local goodwill.... |
| 447 | I would like to receive training on how to better navigate the system in search of answers on how to identify and set up intervention services in my own local area. There needs to be a way for all parties to work collaboratively and efficiently. |
| 448 | I want to be educated on all the options that clients have regarding: housing, programs, funding, rights, transportation and Life skill development. |
| 449 | Training regarding Self-Determination. |
| 450 | How to obtain services for the self determination program. |
| 451 | A Training on: How to support and teach the individual with intellectual disabilities. A Training on : How to teach: Social skills for individuals with intellectual disabilities |
| 452 | IEP prep |
| 453 | Transition, self determination, options for after high school. |
| 454 | More training on the laws, and easier access to information regarding exactly what we qualify for so we are not being told different things all the time. |
| 455 | Training on how to help my child develop their speech ability. |
| 456 | Advocacy training, information regarding laws and rights of people with special needs. Services we can ask for that may benefit our kids with special needs. |
| 457 | it would be nice to have caregiver training through regional centers that helps to find out about state services & access to those opportunities. |
| 458 | How to advocate. How to file a Fair Hearing and the process. |
| 459 | social, executive functioning support, transportation, jobs, |
| 460 | Training for providers of services would be beneficial. (ABA, Functional Communication, Social Stories etc..) Training of first responders. |
| 461 | Training in the three areas I selected |
| 462 | How to successfully advocate for service needs. |
| 463 | Help on options to help person being cared for |
| 464 | I would like to know more about SCDD, what you do, and how we could improve our relationship. |
| 465 | Perhaps the CCO could become a trainer for mandated abuse reporting that providers could pay to train new staff and do refresher training every few years. The Partnership for Safe Families in Ventura County puts this kind of training on as a train-the-trainer curriculum and I have had my staff attend. It was good but not specific enough to the issues faced in our system. Here's a link to one of last year's trainings http://partnershipforsafefamilies.org/uploads/3/2/6/6/3266461/upcoming_mr_training_workshops_march-may.pdf |
| 466 | Training in how to access government programs. |
| 467 | not sure |
| 468 | Not sure at this time. |
| 469 | After 50 years of working in this field and dealing personally with a family member, I could and do frequently provide training in this field. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 470 | LEGISLATIVE |
| 471 | Need to understand why \$ per hour defines a person |
| 472 | I would like to see the SCDD dedicate a small budget to those California counties where there is currently little or no support network for parents of children with "less severe" learning disabilities, such as ADD and ADHD. I realize there are many children with more extreme needs, but certainly this issue also needs to have some importance in your 5-year planning cycle. |
| 473 | There needs to be more training on autism for service providers |
| 474 | Self advocacy, leadership, communication |
| 475 | I'd like to learn how to advocate more effectively on behalf of my disabled daughter and how to navigate the regional center's many rules and effectively appeal decisions that go against her. |
| 476 | Learn more about what services are available to developmentally disabled adults who do not live at home. |
| 477 | Laws that protect our family members that are more vulnerable |
| 478 | um really practically anything that will help us all provide better quality care but I think we need to empower individuals more and make sure those who make the funding decisions really know what is happening. |
| 479 | not sure |
| 480 | training in all above areas to professionals and families |
| 481 | Micro Enterprise |
| 482 | How to walk w/someone with limited mobility. What services are available based on need (financial, expense to cover, occupational/physical therapy. |
| 483 | work training, my daughter is turning 22 very soon and she would like to have a job where she can get pay and stop to have to depend on SSI |
| 484 | I have been on going training myself and several classes over the last ten years in the community and outside of Lake County I have a son of special needs and had to quit my job so his needs could be met in the school system here and not fall through the crack Lake County will not do an IEP unless you beg them, and have due process self advocate for parents of special needs children and ASSIST suicide prevention and a Peer Support Specialist, we need more job available in the county for our community through Behavioral Health. |
| 485 | Transportation/driving training. Training in a 'job' that will not compromise their income or health care. |
| 486 | life skills |
| 487 | We get good training. |
| 488 | Things to look for - indicators - that show we need to further explore what's going on. |
| 489 | I'm good. |
| 490 | N/A |
| 491 | I can't afford to spend time away from my program to attend training. As the administrator of this program I am fully in the ratio and I can't leave (or have staff leave) as that will leave the program short. Again, if we were properly compensated, we could afford to have more staff coverage. |
| 492 | More trainings in communities on abilities, destigmatization, and the value of persons with disabilities. |
| 493 | Additional training around Employment First and how best to access community supports to obtain employment for individuals with a disability. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 494 | I'd like to know what kids of services other communities and schools have and try to figure out why we don't have them and how we can get more. |
| 495 | How Social Security and Medical benefits are effected as people become increasingly and gainfully employed. |
| 496 | Vocational |
| 497 | Dealing with persons with developmental disabilities and their again process, it can be/is overwhelming and frustrating at times since resources aren't readily available and if they are, very limited w/minimum waged employees. |
| 498 | Becoming a better advocate, learning how to share information with other locals in similar situations so that we can help one another, more information regarding self-determination and how to help my children access it. |
| 499 | I would love to know more about what services are available to adults and how to connect my graduates with those services. |
| 500 | Advocacy for thw residents |
| 501 | specific job training skills for repetitive, labor intensive jobs |
| 502 | Autism |
| 503 | I don't know. |
| 504 | Information on parents rights. |
| 505 | Adhd. Sensory processing disorder. Recognizing and coping skills, management of anger for those. |
| 506 | My daughter is 11 years old and our #1 focus right now is getting her an appropriate/successful communication system in place. |
| 507 | continued person centered training that allows us to connect with and really be able to listen to and appreciate each individual family for their unique situation, once a year is not enough to keep us focused and enthusiastic. I'd also like small trainings on some of the most common diagnosis, or even less common. I'd love to know and understand more about some of the conditions my clients deal with. Prader-willie, early childhood cancer treatment that causes intellectual disability, Down Syndrome, McKusic Kaufman, Dandy Walker, all types of epilepsy, turrets, missing corpus callosum, dementia, etc. |
| 508 | Person centered training tools for staff to use to assist clients. |
| 509 | It would be useful for a lot of people I know to get a brief training on what the Council does, and how it connects to the rest of the system. |
| 510 | Matrix does not adequately meet the needs of local families - in terms of IEP support, local educational forums etc. We need a robust advocacy group that is collaborative, but separate from funders. The advocacy group needs to put children and families first. |
| 511 | On School Aid for Special Needs Children. |
| 512 | "Community organizing" in general |
| 513 | Grief Counseling, Coping with parent burn out, Abuse Prevention, How to navigate the system to get the supports we need, how to plan for the future or be better prepared etc. |
| 514 | Advocacy training for families. Behavior support from Regional Centers |
| 515 | I would like to be the trainer for legislatures and any other governmental representative, so they can clearly understand the needs of the client and minimize their focus on funds. |
| 516 | How to advocate strongly and learn about resources. |
| 517 | I don't news training but my child needs requires social skills and life skills training for after post secondary success in college. |
| 518 | How to perpare them to be able to work and make in it in the world. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 519 | Training about ALL programs available with in your child's needs, for example a child that is total care should be told about IHSS. A child that has parents that work and have insurance should not be told to take their kids off their insurance but they should be told about the HIPP program. I was able to save the state millions of dollars because I kept my children on my medical insurance and had the state only pay 10% of the bill vs 100% of it. My draughts have spent months in ICU and I'm proud to have kept my insurance and not rely 100% on the states budget. |
| 520 | Parents need to have training on how to implement behavior plans after they are written for their family member. |
| 521 | Parent "Bootcamp" Orientation: prviding families with community resoruces that may assit during the journey of raising a child with special health care needs. What organizations will be involved in mychild's life and what do they provide CA-LEND Family Support Training program in the SF Bay Area- Leadership Education in Neurodevelopmental and Related Disabilities (LEND), Program is to improve the health of children who have, or are at risk for, neurodevelopmental or related disabilities by preparing trainees (parents and medical providers) from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence. Tranings for In-Home Support Services providers, not just an orientation to the country program. Specifically, learning about the different demands a person in the IHSS system may require (avoiding skin ulcers, how to properly clean someone, how to transfer to and from a chair to bed, bed to chair, etc). |
| 522 | I am open to many different types of training opportunities. |
| 523 | We are always in need of up to date trainings that directly relate to providing services to our clients as it is difficult to get trainers to come in to our area, unlike bigger cities. Specifically training including working with a rural population, handling larger casloads with little resources, and working with diverse populations including indigenous people. |
| 524 | I would be interested in trainings regarding the community resources we have currently and how they work to serve our clients. It helps when I am correctly informed when I am speaking to parents. |
| 525 | What exactly does the State Council do? |
| 526 | IPP/IEP training |
| 527 | Due to the nature of my job, the training I would best benefit from would be anything around the development of services for person with developmental disabilities. However, the Regional Center system as a whole could use additional training in advocacy and inclusion so that we can better support our clients in the community. |
| 528 | How to be better at assisting people in our "system" to see their unlimited potential. How to overcome stereotypes and stigmas that people in the community have about people with a dx of an intellectual disability. |
| 529 | My caseload is so big, I don't have time for training. The people making DDS rules need to get out and observe what SC's have time to do and make things easier rather than constantly adding new documentation requirements. |
| 530 | N/A |
| 531 | No training just more help, qualified help which mandates s degree of education level to service the special needs community. |
| 532 | I would have liked to have an orientation by the regional center for my daughter and for me. I feel very strongly that communication from the regional center has been extremely poor. I had heard negative things about the regional center, but I wanted to make my own assessment. Sadly some of our first experiences were not handled as well as I would expect from an agency that was established to help people with |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | developmental disabilities. Poor communication fosters distrust and suspicion. Basic communication could eliminate all of that. |
| 533 | I feel like I have ample access to good training. I wish I had money to participate! |
| 534 | Training on any new loss that can affect the people are people |
| 535 | See above... |
| 536 | Bus, Resource use and Crisis support. |
| 537 | None at this time |
| 538 | updates on new laws to protect our person's being served |
| 539 | We are the National Center for Parents with Disabilities and their Families, federally funded, and are a source of training. |
| 540 | More self advocacy training. |
| 541 | I would like to have more training in how to have healthy relationships. How I as a person with developmental disabilities can help others with disabilities. |
| 542 | Education on available services for the disabled after they are 23. |
| 543 | anything that gives validation and certification |
| 544 | I would like to receive more training on how to deal with people with different disabilities. Training on how to communicate with certain people that I can't understand. Training on how to deal with being in public when assisting people with disabilities. |
| 545 | Reasonable estate planning. Most of the resources would be spent on an attorney. |
| 546 | Who has time for more training? Unless they come to me... |
| 547 | N/A |
| 548 | Person centered training. |
| 549 | aewrtqewrt |
| 550 | I like to know more of job training and experiences to reach out to meet new skills and objectives with perspective more goals to face head on with life to receive working with people had generous supportive life for training them how to be confident and fascinating work for more past to the future. |
| 551 | Planning for my sons future when I am not around |
| 552 | More info for parents of transition age students about employment options and planning. Also what those paths map to. |
| 553 | Management |
| 554 | an understanding of the legal rights of parents and persons with disabilities as regards to what they are entitled to under the law. |
| 555 | None. |
| 556 | Iep advocacy. Advice on what's appropriate help and progress for our child. Help with insurance billing. Help with applying for ihss and other programs to ease financial burden. Encouragement to participate in our communities despite being different. Support for inclusion. |
| 557 | I would love to help some of these clients and parents with information, regarding conservator-ship and social security difference from ssi and ssa. and organization with job information. |
| 558 | More access to resources in Sacramento County and how to ask for them. I need housing for her and all there is available seems to be in bad parts of town where she would get beat up. I need to know my rights with ALTA because they seem to not want to authorize much for her. All she has currently is PRIDE and closed transportation to and from PRIDE. I've pushed for IL,S and someone to come to the house to teach her |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | how to load a dishwasher...and I was told to attempt IHSS again before ALTA would think about authorizing ILS. I am afraid I will get turned down again because an intellectual disability is not so apparent to some as a physical disability. She's still disabled. She lives with us because she needs some extra help and Sacramento County can't seem to see that.... |
| 559 | HIPPA, all the new federal regulations on the horizon |
| 560 | Financial support and more career options. |
| 561 | transition to adult services and transition from home to a group home. |
| 562 | Social activities for children with Autism that are in their teen years. |
| 563 | Empowerment Training to train people to have more power |
| 564 | Training to get certifications to make me more employable. More support in school. It's hard to have money to even get on the bus sometimes. |
| 565 | I was a caregiver when i was 19-20 but I would have to say maybe CPR and more knowledge about medications my mother takes alot of them |
| 566 | Tech training for this population... ability to train in real work places during day programs. NOW we are limited to non profits... we have few here so the programs turn into entertainment and recreation. |
| 567 | Behavioral support at home for my son. |
| 568 | Advice about different therapies now that he is older-what is out there? |
| 569 | On what supports are available for adults that age out. |
| 570 | Parent-Advocacy and Self-Determination |
| 571 | Support training from an educated and experienced job coach to whatever career the child is capable of doing. |
| 572 | I don't need any additional training at this point, but I would like to see more education on person-centered practices in action, social role valorization, promoting awareness of whether practices match with stated values and goals, and training on how to truly include people with disabilities and their families in all aspects of the service system. |
| 573 | All parents should be given a high quality educations rights training and training on the studies showing inclusion demonstrates higher academic results for all groups of students, regardless of severity. Also, training on IEP goals. Lastly, on legal advocacy and how we can affect change at the state and federal level. |
| 574 | How to manage/use ABLE accounts. The advantages/disadvantages of Self Determination. |
| 575 | Work training |
| 576 | We have the training we need and Alpha Resource Center provides updates frequently. |
| 577 | not for me at this stage of our child's life, but for all school age parents, more IEP training |
| 578 | To get a better job. |
| 579 | n/a |
| 580 | More education provided regarding how support staff can improve our skills and understanding. How to deal with particular disabilities or stressful situations are examples of potential material to cover. |
| 581 | To train teachers, personnel, and first responders. Safety in the community. How to work w/kids w/autism and other special needs. How to help siblings of special needs. |
| 582 | Better guidance from DDS on all topics. |
| 583 | An entire 'overview' training for 'new' parents of children with developmental disabilities. Give us a longitudinal look at the system. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| | Developmental disabilities aren't new and the system of services and supports isn't rocket science, but it's complicated and daunting at the beginning of the lifelong journey facing families. If we had a global peek at what's in store, we could plan and train our children accordingly. We'd be better able to recognize and navigate the system better. We'd become better, more effective family advocates. |
| 584 | Any training that is available to the individuals to help them in knowing the sources to becoming as independent as possible. |
| 585 | I would like a clear description of what options are available for my sons as they become adults. |
| 586 | No training is needed. More programs, opportunities, etc. is what is needed. |
| 587 | I would like more information on how to advocate more effectively for the above. |
| 588 | More information about what is available. No one, even North Bay Rehab representatives, seem to know what's really out there. |
| 589 | How to support/educate students with a developmental and emotional disability (ED), when the ED portion has more impact on the success of the individual. |
| 590 | None. |
| 591 | IDK |
| 592 | Would love to see some local training opportunities in Positive Behavior Support. TCRC does great Person Centered Thinking/Planning training. If this isn't available statewide... it should be. |
| 593 | Independent living program like learning how to live independently on the weekend. |
| 594 | I am very knowledgeable. |
| 595 | ils |
| 596 | How to map the chain of decision-making controlling barriers to secure, reliable inclusion in home communities for people with developmental disabilities. How to compose an effective appeal for person-centered-performance quality. |
| 597 | Navigating the system |
| 598 | Understanding the funding vehicles available to support my son with autism. |
| 599 | Understanding the State's process to making my voice heard. |
| 600 | I am a great lobbyist. I have a professional career as a Development Director in Human Services and if there is training available on affecting policy then I would be open to it. |
| 601 | Vocational computer skills general education that is taught in a way that they learn best. |
| 602 | My son is very low functioning but is eager to do things when it is at his level. More opportunities for those who are low functioning. YES, it does require a 1-1. That's what I do everyday to move him through the day and show him how to do things, why should it be any different at an Adult Day Program. |
| 603 | How to find good facility for our sons needs after we can no longer take care of him. |
| 604 | How to sort through the housing options on behalf of my loved one ANND be able yto do that for others as well. |
| 605 | Training? How to handle the absence of adequate housing for our DD son who has no possible income source other than social security. I know in order to save money the SCDD wants adult DD children to live with their parents until the parents pass - but this is not a humane solution for the child. (Let alone the parents who didn't ask for a DD child, and the subsequent responsibility the SCDD imposes). |
| | How to work proactively with service providers; how to be an SLS provider; how to utilize self-determination; management of benefits of adult child with dev. disabilities |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 606 | As a parent I have received ample training on all issues related to caring for someone with severe autism. |
| 607 | Parental training to handle special needs kids. Respite for parents in child care of special needs kids. |
| 608 | Just require time to provide the required and appropriate training to staffing. |
| 609 | Independence with some supervision |
| 610 | Job skills: interview, on line application, social skills. |
| 611 | Cpr first aid |
| 612 | What ever I need; I especially would like to resurect the mentoring of parents who have intellectual difficulties to help them have a quality experience raising their child/children |
| 613 | How to care for kids with disability who has behaviour problems and other challenges. |
| 614 | Special education law |
| 615 | Behavioral training to learn how to encourage my son, 23 yo, to be even more independent. He rides the trolley, bus and walks in the community on his own to 3 different volunteer jobs (set up by family) working 5 days per week, 4-6 hours per day. But, he still need more skills for full independence. |
| 616 | Training on navigating the system. |
| 617 | I don't want trainings. I want direct representation |
| 618 | Self-determination research Reimbursement process for habilitative services |
| 619 | More training for whole teams on how to teach the skills needed. More coordination between regional center and schools. |
| 620 | Trainings where families understand the difference between school-based services and medically-based services. Too often, there is a misconception that therapies in the school district are the same types of supports as medically based services. Therefore, required medically-based services may be discontinued since there is a perception that school-based services are free. |
| 621 | advocacy training |
| 622 | Learn hoe to take the bus on my own more around the world. |
| 623 | None at the moment. |
| 624 | Job |
| 625 | N/A |
| 626 | My disable child would like to receive training in life skills and work. |
| 627 | Networking for job development. |
| 628 | How is the State Council addressing the crumbling Developmental Services System. |
| 629 | group home placement options |
| 630 | n/a |
| 631 | I would like to find a job. |
| 632 | Information about what is available to individuals. Regional Centers seem to offer limited services and what you get depends a lot on who your case manager is. People aren't informed about what's out there so they don't know what they can ask for. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 633 | I don't have any idea what kind of training the State Council is willing to train me for |
| 634 | any job training |
| 635 | How about a brain transplant |
| 636 | More knowledge of services available to my clients. |
| 637 | cultural competency training |
| 638 | I would like internet technology training. |
| 639 | Financial services for adults with disabilities |
| 640 | Self Determination, Advocacy and Employment. |
| 641 | Talking points in communicating with various players. Also a short class for ourselves in making our own videos. |
| 642 | How ILcs could reach out to the I/DD community, which has historically been underserved because the regional centers view I/DD as their turf and have a great deal of political clout. |
| 643 | I think it is important for each individual in whatever field they are in the importance to become more rounded of the knowledge of what is available to people to help guide them in whatever direction they are wanting to pursue. |
| 644 | as a family member I'm fine. But those who work with pwwid in homes or day centers need to be better qualified and trained initially as well as ongoing cme courses. |
| 645 | How to best prepare young adults for knowing about and accessing local resources for community support and services. How to work and keep benefits like SSI and health insurance. Strategies for friendship development and recreational activities for adults in their communities. How to access housing that has 6 to 10 year waiting lists. How to advocate and create more housing in southern Orange County. Special Needs Trusts and ABLE savings, how to most effectively establish and use them to enhance quality of life after parent's death. |
| 646 | I'd like to see training offered to RC staff and vendors that involve consumer participation and lead to insights that help RC staff and vendors work with and treat our clients with dignity. |
| 647 | Safety. Transportation. Employment options. |
| 648 | As a parent I would like to have more info on how to help get more weekend programs going. |
| 649 | I have plenty of training. Time is in short supply. Stress is in high supply. |
| 650 | I, along w/ our organization, are a part of many training opportunities, both providing training and receiving training. I wish the folks we serve could get some financial support to participate in more organized self advocacy events...helping them to see/learn about the "bigger picture" outside of their local areas. Always appreciate local, 1/2 day type trainings on best practice topics focused on inclusive opportunities. |
| 651 | Behavior Mod |
| 652 | It would be helpful for families who've just learned their child has special needs, to know where to turn for services. It would also be helpful to learn how to better manage a family, when faced with caring for a child with special needs. |
| 653 | better understanding of what services are actually available . Often, families are tod they cannot have services when in fact they can. Case managers are not all on the same page. |
| 654 | A available and affordable housing and how to research for them in San Diego county. |
| 655 | Behavioral |
| 656 | Training on what support services are available - where to get them, financial assistance, etc. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

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| 657 | n/a | |
| 658 | Computer recycling. Goodwill would not take my adult autistic son because he did not have "enough social skills". Well, then, I guess the deaf aren't employable because they can't hear -- etc! | |
| 659 | Communication on trainings available across the state/ maybe a e-letter from SCDD SCDD sponsored conferences on specific issues across the state | |
| 660 | No training need at this time. | |
| 661 | Training I don't need. I need resources and money to run the program I envision. | |
| 662 | Education regarding upcoming transitions to high school, then adult life. | |
| 663 | How to know what services are available to my daughter. | |
| 664 | Ways to help my son and stay sane | |
| 665 | Our daughter should get job coaching | |
| 666 | Employment | |
| 667 | Advocacy support and training for our son and for us. People First is fine but, its expensive. | |
| 668 | How to access the latest services for people with disabilities so that we can explain these new services or laws to the person with the disability. | |
| 669 | More ABA programs | |
| | Preparation for the transition as our child ages out of school. | |
| 670 | I also think you should give some training to the Regional Center caseworkers as the most recent bunch seem to be sweet but woefully ignorant. I wonder if there present training consists of telling them to verify how many IHSS hours we have and then call if a day. | |
| 671 | How to help my son with autism learn to work around his challenges | |
| 672 | I would love to learn even more about the self determination process, not only for my child but for other families that will one day be taking part in it. | |
| 673 | N/A | |
| 674 | Parental training, follow-up support, etc. Ways I can ensure I am providing my child with the best chance to succeed. | |
| 675 | job training. | |
| 676 | Advocacy | |
| 677 | How to navigate through the system in order for my son to have the most opportunities for success. | |
| 678 | None | |
| 679 | I was trained when I started my job. I do person centered training yearly and other trainings to best support the people that come to my Day program. | |
| 680 | direct training and supports which is individual for each person, with that said there are many subjects that are very applicable for many people. Safety in areas of internet use, money, strangers, health, community awareness, friendship boundaries etc. | |
| 681 | How to evolve from formal supports to natural supports. | |
| 682 | none | |
| 683 | How to file a complaint against a teacher, principal or district? | |
| 684 | None | |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

| | |
|-----|--|
| 685 | Successful advocacy for change. |
| 686 | how to create inclusive environments everywhere |
| 687 | IEP advocacy |
| 688 | none |
| 689 | Options counseling. Best-practice models exploration. |
| 690 | For my son, healthy living/active lifestyle trainings that encourage and inspire a life change. Training that is autism specific around sexuality and safety |
| 691 | I would like to train the state board. |
| 692 | what agencies are supposed to be doing for our adult child and how do we access them. |
| 693 | training on various disability and their effects on the person, family/care givers, employers and community. |
| 694 | government staff do not seem to be sympathetic to disabled needs. Need more training for staff that provide services tot he disabled, especially the folks that provide daily care. |
| 695 | I don't know |
| 696 | Data review as a status check on how these populations are doing. What is the growing edge of change in the service models used to support these community members with whole life and community engagement needs. |
| 697 | Preparing advanced directives, power of attorney, other documents to ensure my wishes are carried out if I am incapacitated. |

Survey Monkey Results

Question 5: What kind of training or information would you like to receive?

California State Council on Developmental Disabilities Survey Monkey Results: 5-year State Plan Needs Assessment

| | | Response Count |
|---|--|----------------|
| <i>answered question</i> | | 668 |
| <i>skipped question</i> | | 444 |
| 6: What else would you like the State Council to know? | | |
| # | Response Text | |
| 1 | The housing situation for people with disabilities is terrible! | |
| 2 | I'm hearing impaired. | |
| 3 | To have more visibility in regular places in the community like groceries or department stores or clinics with the use of posters or flyers so that more people in the community would be aware of the state council, what it does and how it can help people and families with disabilities. | |
| 4 | More to bring attention the needs of the ID community to the general public. | |
| 5 | the system is broken. Lanterman Act has been abandoned. | |
| 6 | I feel that there is so much overlapping of information. Such a waste of paper with several confidential files out there for one individual. Why cant we streamline by When an IPP is started by SDRC have a format that all providers could access under a secure program and post the necessary updates and confidential we all could access. Just an idea. Then all the program would need is a primary face sheets and providers could access the one confidential files to print out any pertinent information and print as needed. | |
| 7 | Keep doing what you do. It's helping! | |
| 8 | I would like the state to be more aware of the use of developmental therapies (Eg. Relationship Development Intervention) for individuals with special needs in addition to parental choice. Some regional centers value and support developmental therapies, and others do not. It is unfair and unjust for some families to have choice over the support their family receives and for others to not based on where they live. The families deserve the right to choose which approach makes sense for their family's beliefs, philosophy and way of life. | |
| 9 | Postsecondary education as a path to employment is something that should be given greater consideration. RC staff, community providers, etc., do not fully utilize the resources that exist at the community college level, nor do they understand the way we operate. But this is a generic resource that could lead to more training, skills, and a lot of efforts and dollars are being placed to bridge the gap between community college and workforce. Worth exploring and making a connection to provider more options to those with IDD. | |
| 10 | Advocate for the regional centers to increase employment options in the community and also improve the regional center staff;s Dept of Rehab referral process. | |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 11 | I am a strong advocate In my community and always willing to help please let me know if I will be needed in any capAcity thank you. Robert |
| 12 | There needs to be services continuously for people with disabilities. They need to be supported because they are an important part of society too. |
| 13 | We need to somehow find more money to help adults with DD transition into becoming productive, working members of our society -- the more they can work the less SSI they'll need for their lifetimes -- plus think of their self-esteem!! |
| 14 | My son has been in a group home for the last year, a group home run by a BCBA, his behaviors has gone down, he is thriving, the persons that work with him believe that he can learn and he is. Every child can learn despite of his label. I have data to show the improvement, and i my self got my masters and i am accruing hours to be a BCBA. I want to open a center where parents can leave their child and know that they are not only learning but well taken care of, like a day care. Contact me 209-922-5651 Thanks for caring |
| 15 | Services are there but very hard to get. There are lots of stumbling blocks. |
| 16 | More behavioral intervention for teenagers turning adults and who have still behavior that needs to be eradicated |
| 17 | I am a single mother with autistic 11 yr old. I am a professional with a graduate degree. I have quit full time job 6yrs ago to care for my child. I have filed bankruptcy. Downsized.living in 1br granny flat...working per diem while child in school. Receive 60 hrs ihss..cant get protective sup. approved..because of age and no 911 calls..bcuz I'm always there!!! We are barely getting by..I can't afford dental work...loosing teeth! Soo much more support is neededwe need real help with childcare..i can't find agency that has respite provs that are available! School cuts mean she can't go to summer school this year!! Last summer I had to apply for food stamps!!! I can't think of anything else to do!! |
| 18 | All people with I/DD need access to individualized advocacy services for complex meetings and for due process -- not just those who can pay the expensive fees. Helping one individual has the ripple effect of helping many. |
| 19 | Parents need help. We need knowledge, information as to what is available. We need access to free or low cost advocates when we disagree with the school district, because they have unlimited legal budgets vs. our sad incomes, mostly spent trying to give our kids the services they're supposed to get but aren't. We need teachers and providers who actually care more about the kids than the district's budget and fear of losing their jobs if they speak up. |
| 20 | There are so many Autistic young adults need independent living skill & job training!!!!!! |
| 21 | That even though there have been great advancements for those with special needs this group still remains one of the most marginalized and neglected in our communities. Please help us to give our children and adults with disabilities the chance to have a safe, successful, and productive environment to lead rich and fulfilling lives. |
| 22 | Alta Regional Center makes getting any service for your child a BATTLE. Fair hearing is required everytime a simple request is made. |
| 23 | I would like to see parents or their responsible advocate to have more input about their child's needs and future once the parents are no longer alive. |
| 24 | respite is critical for families caring for children and adults with disabilities yet it is difficult to get or when you do have it, they can't drive the client, so there is no community access. This needs to change. |
| 25 | We have to navigate several bureaucracies at all times, and it feels like there are no resources to help when problems with them arise (other |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | than hiring private advocates or attorneys). Social groups for disabled and support groups for parents are few and far between. |
| 26 | Would like more awareness of what disable people need. |
| 27 | It real heartbreaker for consumers Relatives to find out you have to fight for services need it to improve their way to lives A lot of us have to wish they die Before us we have to be fitting all the time what will happen when we won t be here |
| 28 | I just want them to know how scary it is to be in my shoes. To have a child that will never be able to go the bathroom on his own, or get his own glass of water and that one day I won't be here to take care of him. |
| 29 | unsure |
| 30 | After three years |
| 31 | It's extremely difficult to get services if your child is high functioning- public Ed necessary regarding assessment and services |
| 32 | IDEA and FAPE need an overhaul. Take a look at the kids in "emotionally disturbed" programs at public school- aspergers kids can't be appropriately treated by sitting at a desk in a corner surrounded by a cardboard box. True story- this is "discipline" and "therapeutic behavior services" in the el dorado Union high school district. A shame booth. These kids didn't CHOOSE their disabilities. Get them the support and services they NEED. |
| 33 | Unsure |
| 34 | Our Orange County Area Board has been one of the key resources for families/consumers to turn to when other doors have closed. It is disappointing to learn that this 1:1 advocacy will not be available going forward. I think this should be reconsidered; oftentimes, a single incident can set a precedent and change policy/procedure. |
| 35 | These systems need to start talking to each other immediately and develop effective, meaningful programs with providers that understand the population they are working with. |
| 36 | Include a range of all ID/IDD, not just ones that are verbal, and also reflect this in their families. Reflect those w/moderate and severe disabilities and their families. We always hear from those who are capable of traditional everyday things, as NT do, but rarely if ever do we hear about those that need the services the most. Opportunities for them will be different, we need more real life role models there and less Bill Gates and Mark Zuckerberg. Thank you. |
| 37 | That the disability program that I am in is helping me fulfill the goals as a person with disabilities in education and in life skills. |
| 38 | The State Council should advocate for statewide rates for services that are all the same like how the Department of Rehabilitation looked at all services and determined a rate. |
| 39 | There are people with disabilities and they are not just foster youth. There seems to be many more opportunities for foster youth(18+) than there is for say kids who are privately adopted or birth children who cannot live at home. There needs to be supports in place for people who fall into the mild to medium range of disabilities as well as those who are severe. I would have loved form my son to be living down here but there was no way this was possible due to the resources available to him. |
| 40 | They need a lot more help advocates to help kids get out of regular schools that are failing kids. My daughter spent 5 years in regular ed. Teased bullied it was hell. If special ed kids r kept in regl large ed teachers need to educate teachers regarding students a bit autism. Understanding brings success, ignorance doesnt. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 41 | The system is hard to navigate, and parents end up learning through parent groups and Facebook! More help to navigate this stuff, please! |
| 42 | employers need incentives to hire people with disabilities. The ADA has made them afraid of law suits and expensive accommodations. |
| 43 | Keep asking questions. |
| 44 | Denti-Cal lack of funding is causing un-necessary pain and suffering |
| 45 | having information on helping people live on their own |
| 46 | a membership/ or comprehensive unity of complaints, or request for more interaction with local CACs, Advisory committees to ensure that all complaints, concerns are heard and considered in policy/procedure writing. |
| 47 | Nothing at this time |
| 48 | I am available to help assist. |
| 49 | The Regional offices are an important component of the advocacy and safety network for people with DD. The importance of people to people contact at the local level cannot be over emphasized as a means of offering individualized resources and smoothing transitions for people with DD. |
| 50 | Nevada County Special Education Program needs to improve in many areas: have in place a special ed preschool program where the children learn and thrive mainstreaming is important for all grades in the county program certain special ed students need to be in a learning based program, where some of the other students could thrive on a motorskill/OT environment.....yet these 2 types of students are being put in the same classroom and it takes away from the special ed kids that can learn. Also, Teachers assistants are hired with no experience and they are left to teach these special ed children while the main special ed teacher is overwhelmed with IEP's and trying to figure out schedules for everyone and I see the special ed teachers burnt out not wanting to teach. Our county hires substitute teachers to teach special ed children because they can not find qualified experienced special ed teachers. Our system has failed!!!! |
| 51 | Programs vendored 20 plus years ago are just hanging in their. They have not received any cost of living increase since the 1980's. This is making it more and more challenging for us to keep qualified staff, as the newer programs are able to provided higher wages. |
| 52 | that there are more individuals and their families that are struggling and frightened of what will happen to our kids we don't want roadblocks or lack of quality service providers and plead to have services started as soon as possible to give the individual with disability quality of life thank you for letting me speak |
| 53 | Walk a mile in my shoes. Go to an IEP meeting. Deal with insurance companies who refuse to cover services and take all the judgemental nonsense the world dishes out. Did I mention as a parent it is my job to not only negotiate educational plan for my son but it is my job to fight the district for the services he needs, even if it means due proses. If they had it their way he would still not be able to talk. Life's of families affected by disability is hard enough getting our kids what they need to function shouldn't be a battle. |
| 54 | We are all human beings. Please lets remember to have compassion. |
| 55 | Rules of Regional Center's caregivers are not realistic. Do not allow for relationship building. "We are not your friend"---how would you like your instructor to greet you with that statement? |
| 56 | Funding for all levels of the developmentally disabled should be unified. The current structure of separating "education" from other |

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| | "categories" pits school districts against the regional centers and causes undue conflict. Individuals/families should be given vouchers for them to use for education/treatments/care/etc. Unfunded services that school districts provide developmentally disabled children reduces the amounts to be spent on normal education. This is unfair to both and puts school districts in a conflict of interest. |
| 57 | Doing a good job so far :) |
| 58 | You have an important role but the average family is not aware of you. Work with local agencies and other stakeholders to increase your visibility. |
| 59 | Community support services are not in place to receive the flood of Intellectual Disabled individuals in the community or about to enter adult life |
| 60 | The education system is moving away from effective transition for the DD population to the work place. ROP is no longer being offered. Students are not served by DOR. Schools are unaware of the changes in employment programs such as DOR. Transition should begin in middle school if not in kindergarten. It's too late at 16. |
| 61 | if we can afford to increase the minimum wage for workers why can't we offer affordable payment to the group homes which do so much for these clients. |
| 62 | There are very little options for qualified child care for children with medical disabilities. Not every family personally knows someone would could be a trusted respite worker in their home. |
| 63 | There is a high need for low income accessible housing in Sonoma county. |
| 64 | Individuals with disabilities are still considered to have a lesser quality of life in the medical field and it is extremely difficult to obtain quality medical care and affordable housing in areas that are not filled with crime |
| 65 | Keep on slogging through the paperwork but at least fund people going to se:f advocay forum, conferences... |
| 66 | Things take too long to get resolved. Things go from bad to worst, which could be avoided when the need is recognized and responded to in a timely manner. |
| 67 | Parents and other caregivers of children with intellectual disabilities need all kinds of help. Every day is a challenge. We need more behaviorists to help our kids, schools such as Anova that just focus on these kids in every way. |
| 68 | I am 21-years old and graduated from Chico State with my 4 year bs in business administration. I am an educated, productive member of society. That being said, there is no goal I set above changing laws for mentally disabled people. it is essential to have better pay for the special education teachers so all of the good ones don't leave to work in administrative offices so they can support their families. These teachers had a passion to help those who were born with such unfair circumstances, then we drive them out of the system because we pay them less than a garbage collector. This is not okay. My brother is in classes with a bunch of mutes who moan or with 40 year olds with stupid people who might as well be one of the special kids because they could give a hoot about the kids!!! please help these kids. |
| 69 | That services for people with disabilities are vitally important. |
| 70 | Individuals with ID/DD should not stop learning/strengthening their skills when they exit the public school system (by 22 at the latest). These individuals need programs and opportunities to continue learning life skills related to employment and education. We need more programs that promote and/or provide internships (paid and unpaid) so that individuals can eventually gain valuable employment in the community and feel that they have a purpose. |
| 71 | I want to recognize the whole State Council body in making a difference in the lives of people with disabilities and to their families. May |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | God guide you and bless you more in each endeavor. We appreciate the effort and work you have done for our children. Thank you so much. |
| 72 | That we are working hard to provide great programs for students. |
| 73 | Know that Our people need more help, Please STOP cutting Back their benefits. |
| 74 | Thank you for your service and care. |
| 75 | Since families come in all sizes the move to REQUIRE 4-bed homes seems rigid and arbitrary. Many special needs individuals live joyfully with kinship, great care, and choices of activities in six and twelve bed homes! |
| 76 | We are being ignored and we need to do something about it |
| 77 | Focus spending more money on people with disabilities to improve their livelihood - these are people with limited capabilities and are in need of all sorts of assistance, transportation, social programs they can participate, various workshops, etc. |
| 78 | Overall the programs and supports have been very beneficial to our daughter in her growth. The program at Wylshire and Staff have been outstanding. They have been patient and understanding of our daughters needs and have tried to help her grow as a responsible adult. |
| 79 | Health care is too expensive every month for people for disabilities who qualify for medicare. |
| 80 | We need family support especially for Therapists and Psychologists who can understand our children. |
| 81 | The local Area Boards have always been the necessary impartial resource/advocate for people with disabilities when other doors have been closed. |
| 82 | Parents of those with special needs are navigating through education, medical and care with limited resources. |
| 83 | Change needs to happen NOW! My son will complete his education in 5 years. I cant wait that long. I need him in an inclusive environment with accommodations so that he can access the curriculum and be with his typical peers. He hates having his disability and wants to be like everyone else but the district keeps telling him NO. If i had the funding i would be taking this as far as i could legally but i don't and the district is well aware of it. The district calculates that into what they will provide or not, very very sad. |
| 84 | How to educate my son about learning to problem solve. |
| 85 | The school manipulates IEP's to they convenience. |
| 86 | We need more Autism Inclusion programs like Rady's Children's Hospital Alexa's Play C in San Diego for high functioning ASD kids. There has to be more Blended classes in San Diego Unified School District. How are there 1:67 boys with autism spectrum disorder and only one Autism inclusion program in San Diego with 30 available spots???? There should be Inclusion Preschools with HFA, some with LFA and more typical preschools private preschools that take a few kids that have disabilities. I separated the mild from the moderate to severe disabilities because kids imitate behaviors so better to have a severe kids with typical kids with the proper support. My son has been kicked out of 3 schools and he is only 3 years old. He attends a typical daycare with a full time one on one ABA therapist funded thru my insurance and he is still always one step away from getting kicked out. Autism is a social disorder. Why does early intervention happen in isolation in homes? Kids with autism have to be around typical peers to model language, behaviors and socialize. Why doesn't the model change for early intervention? Why not fund the same programs, but in private daycares that receive subsidies to enroll a few students with disabilities in their programs? ABA therapists could attend daycares with the kids and facilitate the goals in a social environment. The |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | <p>model of OT and PT should always be direct services not consult. In home OT and PT is not adequate. The early intervention model should make OT and PT provided in a facility with equipment and direct service not consult. Speech should follow the Hanan program or follow the child's lead. Social Thinking or theory of mind should be taught to parents in early intervention early on at a young age. Executive functioning should be fostered from the very beginning. Early intervention should promote theory of mind or social thinking, executive functioning (planning early on), socialization of kids with disabilities especially autism. Regional center should provide better case management services. The primary care taker is the case manager not the service provider thru regional center. If a parent is not organized, a researcher, educated or speak English they are not going to be a good case manager for their child. A class should be offered about case managing their child with the disability, organization skills needed for service providers, MD appointment, IEP, filing, etc, etc.....</p> <p>Regional center seems to be focused on minimizing costs/limiting budget outlays rather than serving the disabled and providing the services/coordination intended by law.</p> |
| 87 | |
| 88 | <p>Support your parents!! The school districts are not always following the laws, they are not providing services, they are NOT honest, people are tired of fighting against them.</p> |
| 89 | <p>I would have liked to have gone to college and get an art degree and there needs to be a program at the high school and at the college level that focuses on academic post secondary success for students with learning disabilities like EOP and upper bound</p> |
| 90 | <p>Tulare County has a excellent Disability advocate her name is Rebecca Donabed</p> |
| 91 | <p>I AM NOT DEAD YET</p> |
| 92 | <p>We are open to any support you can provide.</p> |
| 93 | <p>More communication is needed through the use of each school district's Community Advisory Committee. State mandated group where it's members are all families with children with disabilities. Antelope Valley needs help. The AV CAC needs help reaching parents and families.</p> |
| 94 | <p>Need some plan to work successfully with public schools to make sure that students with developmental disabilities get the education they deserve. There should be a liaison between regular classroom teachers and special education/resource teachers.</p> |
| 95 | <p>There is a huge wave of adults with autism headed to your door with no real supports for them in the community and for employment. Help new businesses fill this void and be innovative in your thinking.</p> |
| 96 | <p>they should suggest law enforcement training to better handle people with disabilities</p> |
| 97 | <p>You already know the system is underfunded.</p> |
| 98 | <p>Increased advocacy support for parents would be great. Especially for Spanish speaking parents.</p> |
| 99 | <p>Why is it that all the people that are there for support do not explain all the services that are available? We worked with our regional center since my son was an infant. I was never informed about IHSS. we didn't find out about it until my son was 7. We could have benefited greatly knowing sooner.</p> |
| 100 | <p>The amount of people with disabilities entering adulthood in increasing and there is a lack of available housing and activities/training available.</p> |
| 101 | <p>Cities should work with interested parties, like parents, to develop small community housing projects that encourage camaraderie among caregivers and residents, so they are not alone and segregated.</p> |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 102 | The regional centers are important. Reinstate the funding. |
| 103 | Residences that concentrate on abundant and effective supportive services require a focus on people with DD. We cannot achieve integration without focused supportive services. So larger, multiresidential complexes with focused services should be supported! |
| 104 | There is probably not enough information out about who you are, how do you fit into the system, what ways can you help. |
| 105 | they are cutting back on services to much, more awareness on what is available for help, more alta help. |
| 106 | Raising a special needs' child goes beyond the 24/7 clock and we need all the support we can get. Doors should be opened to us not slammed in our faces. |
| 107 | We struggle just like most families, but worse. Both parents should not have to work when they have a disabled child. We should be able to at least receive social security. |
| 108 | Improve pay rate and benefits for staff who work for people with dev disabilities Then retention is not a problem |
| 109 | It is hard sometimes being a parent of a child with an I/DD. It feels like everything is a fight to get minimal services and supports for my child. We fight with the regional center. We fight with the school district. We fight with health care service providers/insurance. We fight for her basic right to participate inclusively in community activities. Please help change this! |
| 110 | Individuals with disabilities are people just like you & me. They want what we have. It is difficult to provide a "good life" at our current rates. Many people don't believe that we should be providing so much for these individuals, that they don't contribute to society. On the contrary they contribute a lot. In my 31 years of service they have been my teachers. They have taught me patience, compassion, caring, satisfaction with what I have & I could go on & on. Let's face it, we all have one disability or another. I can't speak more that I language, have poor math skills, etc. if I were to sit by an academia at dinner, they would think I had an intellectual disability. We are all people & deserve a decent life. |
| 111 | I would like to know how was ARC Los Angeles/Orange County legally able to get rid of clients that did not meet their productivity percentage. We as parents are not looking for our children to bring in a pay check but to feel good about working and being productive even if the pay check is only \$5.00 every 2 weeks. I believe that productivity percentage belongs in companies that have normal working individuals and not imposed on persons with disability who have many challenges in life including poor health. |
| 112 | Consumers who I have spoke with working in employment training programs (labeled by regional centers to be "sheltered workshops") like learning new tasks for completing business contracts. I have also heard regional center employees state that the training programs are used as social gatherings. If the regional center employees spent much time in the training programs, they will find there is very little time to be social. People are working or completing training projects. The only social time they have is either break or lunch. The training programs are authentic working and learning environments. Consumers who work one to ten hours per week are not truly engaging in an authentic working and learning environment. |
| 113 | That you work towards keeping places like the care facilities in Glen Ellen are kept open. Perhaps in combination to privately/public facilities for indigent seniors who are not necessarily intellectually or physically disabled. |
| 114 | Nothing other than the fact that I think that services for the school-age population is pretty good; but once the disabled population are not attending school, services are harder to obtain. |
| 115 | Distribute information about services that can be accessed by individual with disabilities |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 116 | It's time for politicians to invest in the people of the State of California and to stop being swayed by billionaires, large corporations, special interest, and public unions that continue writing large checks to buy votes in Sacramento. |
| 117 | Please give us the tools and guide lines to help our children lead independent and productive lives. Consider living arrangements like Eskaton or Vine Village, Sweetwater, Sun flower Hill, Meristem.....style communities. Together and safe, yet independent. To quote Hillary Clinton "It takes a Village" |
| 118 | The inconsistency of regional center management and implementation of the law has been ignored for decades, and the confusion it causes for the Consumer, their families and the service providers is vast. Consistency in the implementation of the regs is needed. |
| 119 | We appreciate all efforts that are on the behalf of individuals with I/DD. It seems to be a battle at all levels of government. Please reach out to all vendors in the state, we received this survey forwarded from our local ILC, not our service system. |
| 120 | The changes made keeping the offices from supporting families through process is a major blow. They helped people who could not afford an attorney as we could and the I forget the name of the office but think its known as DRC or DCR or something like that is no help on individual by individual cases. |
| 121 | they do no have enough people with developmental intellectual disabilities on their boards. |
| 122 | stop thinking being deaf is a sickness and this community can not learn. Don't label syndrome and intellectually handicapped people. They r not. They r so smart if u educate professionals working with these individuals. |
| 123 | Better help to get conservatorship of adult disabled child went needed without having to pay thousands of dollars. |
| 124 | It is extremely difficult for someone new to the process to even know where to apply for services. Then, one must wait a long time to even hear whether they are approved, and often they are not until second or third attempts despite great need. This is particularly true of emotionally disabled people (autism in particular) as their emotional disability is not as easily seen as those who have physical disabilities. The need is still great to attempt to keep these people off of the streets. |
| 125 | During the K-12 education years we focus on the importance that family is a vital tool towards a students education. When they turn 22 it is encouraged for a adult to leave home and live in a home. This is a personal choice. It insults me that you would pay a stranger 2000.00 to 5000.00 thousand to take care of our young adult. We should still continue to focus the importance of the family unit. Focus on giving the resources to the family to support this. |
| 126 | There is not enough support for students with disabilities and there is no oversight for service providers who provide services there must be State standards that are measured there must be success! |
| 127 | The welfare of intellectual/developmental disabled community is NOT a priority in most agencies. The State Council should consider recruiting families who are interested to organize and serve this community, as an agency does. |
| 128 | Blue Ribbon Commission on autism discussed the need for doctors to be educated and trained to work with our adults years ago. . There are very few psychiatrists who work with adults and know autism. No action has been taken and it has been years. Hospital settings are not set up to admit adults with autism in psychiatric crises. ARCA released a report on the DD system on the brink of collapse. It has not just started to collapse. Rather it has already collapsed. 1/3 of vendors have gone out of business. California is last in the USA, according to ARCA for individual funding. We need to do advocacy with our legislators differently. What we have been doing is not working. DDS Developmental services task force and Lanterman Coalition need new partners -recommend initiating a state task force composed of stakeholders, business leaders, private |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | and non profit educators, professional lobbyists dedicated to changing the deplorable lack of funding from our California legislators and governor. The state council should write up measurable actions that can be taken with a appropriate timeline to address the many issues that the DD community has. We also need to hold our legislators and ourselves accountable for the deteriorated state we now find has occurred for the California population. Lanterman Act is irrelevant without funding. There is a huge population of people with autism who will need services as they are aging out of school. Yet little or no planning has been done to address the coming tsunami of people with ASD. Every Life Matters- our legislators and governor seem to have forgotten that. We need to hold them accountable for our dismal underfunded DD budget |
| 129 | Many of our clients live on limited income and have to use public transportation. It would be great if there was a program that helped all people with intellectual disabilities with the expense of public transportation. |
| 130 | Housing, housing, housing. It is critical that people when they are ready to move out of the family home (usually in their twenties) be able to transition into living outside their family home while parents are alive to support them. It will be so hard on people with intellectual disabilities to leave home when they have lived their whole lives there, and at 40-50 years old their parents pass away and now they have to adjust to this major change. Higher quality day programs would be next on my list. Raise the bar! |
| 131 | thank you for all you do for our community, especially within the current budget constraints |
| 132 | A safe, stable source of housing for people with intellectual/developmental disabilities, will enable them to more successfully access and utilize other important quality of life services. |
| 133 | We need more adult recreational programs. Need more Adaptive college recreational classes that allow aides to attend free with client. |
| 134 | There should be more funding provided for vendors who provide group homes, employment, Adult Community Centers, ILS. |
| 135 | There is a huge need for additional housing for the clients served by DDS, including people who have autism, developmental disabilities, physical disabilities and others. So there is a need for either new government funding to build this housing, and/or a change in tax law to allow tax credits for construction of new housing, so that developers would build it. |
| 136 | Enabling complacency needs to be avoided and never rewarded. |
| 137 | We need more help. More advocacy. We trust the State Council and want this group to be with us as we make our way through life. Please don't let funding take your advocacy away! |
| 138 | The Lanterman Housing Alliance, 16 housing organizations in the State of California is focused on this issue and would love the support of the State Council. I am a co-chair and would love to be contacted, Kris McCann, 408=-438-7392. ED, Bay Area Housing Corporation. |
| 139 | There needs to be a easy path for parents to help their kids; a handbook of how to deal with regional center, how to find resources, how to make a good transition plan, how to deal with all of things that one needs to do for individuals with IDD. |
| 140 | Income should not always be the deciding factor to get or not to get help. |
| 141 | In the schools, the staff are really getting hurt from aggressive students. Of course we understand it might be part of the disability, however the issue is acute, and largely ignored, I feel. We need effective policies procedures in place. The students need to be able to function without hurting folks. We need appropriate methods. The police do not want the staff to press charges, we are not supposed to suspend students, but meanwhile staff is enduring some pretty aggressive students and no real means to deal with the issues. |
| 142 | How do you one look into possible educational opportunities outside of one's area. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 143 | schools district administration needs more training for awareness of students with disabilities and legal requirements |
| 144 | I would like him to move out and be as independent as possible, in preparation for me not being there forever to help him. He is terrified of anything changing. Our inability to find a program that would fit him also makes the future unknown and scary. We will keep looking. |
| 145 | Ask for more federal funding in the form of categorical or block grants. |
| 146 | Compliant with ADA requirement |
| 147 | You have parents and advocates working for funding restoration. We are a team. Please treat us as such. |
| 148 | Even when the kids qualify for the above services, there aren't enough human resources available to provide them. |
| 149 | Vallejo needs more services all around, provided in our hometown. |
| 150 | Early education intervention and scho support |
| 151 | Why cut to the Disables and elderly? |
| 152 | Employers need job fairs that are specific to finding those with disabilities with higher skills to perform work. Housing coalitions in S CA. have not created much for the disability community,needs grants from the Feds with leadership coordinated |
| 153 | We sincerely appreciate all the current course offerings and support as we strive to create more options for those with Developmental Disabilities. |
| 154 | I have been at meetings with Regional Centers, Dept. of Rehab, & County Office of ED where the caseworkers knew little of our local resources. My current positions as both vocational and supportive living professional, as well as self-educating, have given me an unique opportunity to learn about the various services in our area that apparently isn't shared within the organizations themselves. It amazes me how little they know of what goes on outside their own organization! |
| 155 | what happens to them as they get older |
| 156 | Let us know that you are willing to be an advocate for the developmentally disabled (who, though testing as intelligent, have their abilities to use that intelligence compromised by their emotional and social disabilities and frontal lobe brain damage. Let the agencies you work with, collaborate with , evaluate or allocate resources for know that this is a population that they need to reach out to . Note : we all that know that FAS is the leading preventable cause of intellectual problems in the USA, but that is the just the tip of the F.ASD iceberg, which has been largely ignored, because for years it wasn't a named disability or most professionals didn't know how to diagnose it until relatively recently. |
| 157 | I am a realist and know that my son is my responsibility. However, it seems the more responsibility I take for my child the more I am expected to take. However, other people who are heavily reliant on the "system" in terms of welfare, rent support, food support, qualify for more medical support, child care support etc. HMMMM |
| 158 | The State of CA has invested millions into real estate that they do not own or control. Private group home providers have historically utilized start-up funds to purchase and renovate group homes and the service rate to help them pay down their mortgage. Then, when its time to recover, the private group home providers shut down their business, force their consumers to relocate to another group home, and cash in their equity in the home in which the State of CA has invested. This is wasteful and it does not address the long-term housing needs of people with developmental disabilities. |
| 159 | ABOUT summer camps, there are for younger children, but for adolescents 15 & older you have to pay & mom is not able to afford to send him, He does go to summer school. children with this type of disability need to stay active or they isolate or withdraw, he has moderate |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | autism & ADHD he has a problem stain steel. Again thank you for your time and concern :-) |
| 160 | We need more resources for foster youth with disabilities. Simple as that! |
| 161 | I would like to emphasize that without expanded Employment, Health and Housing options, individuals with development disabilities will continue to experience disparate socioeconomic challenges. |
| 162 | Orange County office staff is very helpful but workshops fill up too quickly. Request frequent and repeated workshops. Please reinstate personal advocacy or, at least, workshops for this purpose. |
| 163 | The system is currently set up so that parents of children with disabilities, and later adults, become dependent on the money that child/adult brings into their home. If a parent is forced to stop working because there is no appropriate childcare for their child then their sole income becomes: unemployment (if they qualify and for as long as that lasts), their child's SSI and their child's IHSS. The longer a parent is unemployed the harder it is for them to get back into the job market. When their child reaches adulthood and is ready to become independent many parents simply cannot afford for their child to move out and live independently. This has left some of our adult clients trapped in dire circumstances. If the system better supported parents of children with disabilities in order to allow them to remain gainfully employed, then those children will have the opportunity to reach whatever level of independence they desire as adults. It also may inspire that adult client to want to be gainfully employed as they have observed their parent's working throughout their childhood. Their parents can then be their biggest cheerleaders, rather than the thing that holds them back. |
| 164 | Thank you for everything you do |
| 165 | We need better trained, more educated individuals to provide direct care. |
| 166 | It is hard to raise a child and keep track of all the things that are going on. I am afraid that when she is older that it will be harder to keep up and I am afraid that I become older and it will be hard for me to take care of her and who will do it. I am afraid of relaying on state help for her in her future but cannot put money away to assist with those expenses in the future that I know she will have. |
| 167 | Training for parents and educators |
| 168 | The State Council and its regional offices are currently too narrowly focused on employment first. There are lots of other critical issues that families with children and adults are dealing with and virtually no assistance or support is provided any longer by State Council. Those who are most severely impaired need to be considered. It is unrealistic to think that everyone is going to be able to work in a supported employment situation receiving competitive wages. There are other components of a quality life such as secure, safe and affordable housing, social connections, quality day programming, and desired leisure activities that need to be attended to and supported by State Council and its regional offices. |
| 169 | The SCDD cannot fulfill its legal mandate without independent communications access to consumers. If Regional Centers can screen SCDD communications to consumers, an obvious conflict of interest is occurring. This should be your top priority. |
| 170 | Many Clients need assistance with daily living tasks, home and personal care, activities for special needs. |
| 171 | ID & DD students need accommodations, but the group is a spectrum in that there is a range of skills and materials need to address the needs for INDIVIDUALS. |
| 172 | The payment received for consumers. Instead of increasing, it seems that regional centers are cutting all the necessary services for consumers - like transportation and the amount they pay. It needs to be reviewed. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 173 | As parents, are biggest fear is that we won't be around long enough to take care and advocate for our sons/daughters with special needs. It would be nice to know that there are agencies that will watch our children and support those younger generation family members who are left to advocate for their brothers/sisters/cousins/etc. |
| 174 | The state council should remember that these are peoples lives and each one of us can take the time to improve our community so it is as inclusive as possible for all of its members. |
| 175 | CIE is misguided. (Competitive integrated Employment) |
| 176 | It is my perception (and that of many others in the community) that the State of Ca (SCDD included) sees the huge numbers of people with Autism Spectrum Disorders (both children and young adults) as an expensive problem to be dodged rather than a population to be meaningfully supported with services. |
| 177 | As a parent of a child with autism, I know how critical proper medical help is at the right time. Take control away from school districts and place it in the hands of parents, medical professionals and advocates that know how to best help children with disabilities. |
| 178 | lausd is making it so they deny services at the IEP meetings, and then give it to the parents who go to mediation with a lawyer. That shouldn't be allowed when we are talking about intensely dangerous elopement issues. the child could very likely be killed. |
| 179 | The community of "disabled" people have a lot to offer. It takes an initial investment that will pay off hundreds-fold. |
| 180 | That Regional Centers are currently worthless with regard to adults with disabilities it's like after they become adults they fall off the grid and there is nothing for them...at least there is nothing offered. you are basically ignored |
| 181 | If SB 277 should pass how will my special needs children receive their specialized services, education and supports? |
| 182 | the section 8 housing provisions need to be corrected to make allowances for Intellectually Challenged Individuals. They have only one life time allowance for training dollars earned by one of these individuals to be used. If one gets a job then they are allowed to make a certain amount of money before their income is added to their benefits and then their housing goes up. This was set up for normal people. I know a number of DD individuals who went into training programs and were earning subsidized incomes, like my son at \$4.50 an hour, Only that job didn't work for them and then they no longer can try anything else or be trained without being penalized for it by having to pay more for their housing. If someone is a Regional Center client they should be allowed to earn a small amount thru out their lifetime without being penalized. We're not talking millionaires here, but persons under the poverty level who many times are making under the minimum wage and absolutely cannot understand the politics and rules surrounding why they can't spend ANY of the money they just earned as it now goes to the rent. There is no incentive to work at all. |
| 183 | Each person deserves someone to advocate on their behalf. Each person deserves someone to have as support. |
| 184 | Family mental and physical health is deeply impacted by the additional challenges that come from raising children with special needs. More affordable Access to family counselling would help families cope. Also, a tax break for families with special needs children would help tremendously. Our medical bills and special diet food bills and supplements bills pose an additional strain on American families like ours. |
| 185 | Budget cuts make it difficult for families to be able to get services that help persons with IDD become independent |
| 186 | They need to get out more in the public and let people know they are there. The school districts aren't going to let us know. If I had known about it when my children were at a younger age it might have changed the outcome of their lives. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 187 | The Trainings on IEPs and IHSS have been very helpful, I feel like this group is on our side and I feel like it is a safe place. It's been very helpful to me and my son. Thank you |
| 188 | It so very frustrating to find information for youth suffering from schizophrenia and what the future holds for them. Because it is mental illness the path is very unclear. Yet many youth with early diagnosis will need medication and family support the rest of their lives. Where do we go for help for our kid and ourselves. |
| 189 | Nothing at this time other than what was mentioned above. Thank you. |
| 190 | We need help so we can help our clients! |
| 191 | The safest place for citizens with developmental disabilities is in the DDCs because they are protected cared for and given the most normal life with friends and formular faces who they have grown to love as family |
| 192 | I would really like them to truly understand because they would know the challenges we face everyday and maybe through that they would no longer see our kids as a group or just a number but see us as human beings that need a little more help them others! |
| 193 | I am grateful for the services and know that my family would not have survived without Regional Center's help. |
| 194 | Not sure |
| 195 | I love America. I owe my life to America. God Bless America |
| 196 | A better way to follow up and those with jobs and see if they are treated respectfully and given the opportunity of promotions at jobs The job coach holds them back many times when the employer would be willing to give them a try with proper training |
| 197 | Teachers union has negatively impacted my child's education to the point of suing the school district for compensatory education and this needs immediate change |
| 198 | Providing additional support to families with children adult or youth in their homes is much cheaper than residential care. Funding for camp, respite and gap supervision is something that is needed to prevent families from burning out. |
| 199 | In Orange County we need to develop new programs and services to help adults with developmental disabilities. |
| 200 | How do we provide adequate services to these individuals if we know that some require intensive job coaching to maintain employment and we are limited in terms of extent of services and resources? |
| 201 | A staff of TWO PEOPLE is ridiculous for an area this large. HIRE MORE STAFF!!! I have been waiting 2 weeks for a call back from a specific staff member, and have yet to receive it. |
| 202 | It's difficult enough dealing with the health problems but it makes it harder when services n government resources aren't providing the services they promise. |
| 203 | Your work is appreciated by families |
| 204 | That's it. Thanks. |
| 205 | That I greatly respect your work! Thank you for this opportunity to provide feedback. -Sean Stalbaum |
| 206 | The run-around has been our greatest obstacle. A one-stop shop for resources, and resource and health care "concierge" would be a godsend! |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | Caregivers have at least two hands busy at all times! |
| 207 | That court appeals are a Waist of time with Denti-cal, if no is an automatic answer. |
| 208 | PLEASE give support to better mental health services. Our son has Aspergers, epilepsy, cerebral palsey, severely impaired vision and diabetes. None come even close to the impact on his life or future success as much as his mental illness. |
| 209 | members of the state council would benefit from spending a day with disabled adults living on a fixed income in a typical housing situation. Trying to survive on a typical social security check and live in a state like California with such high housing costs is very difficult. |
| 210 | If community residential care collapse and the institutions are closed where will these people go? They cannot suffer the same circumstances that our mentally ill are in. I believe the Administrators, Senators, Governor, Councilmen, should all take cuts in salaries. Do they really need all the money and resources that are afforded them? |
| 211 | Disabled adults need the opportunity for continuing education for self enrichment if they would like/need it. |
| 212 | i would like to see me on the council |
| 213 | Advocacy |
| 214 | We are not stupid. We are not stupid. We want jobs. We want to be helpful. We want to tow our own weight. We want to save money for retirement like everyone else. The minimum wage is likely are only wage; it should be a living wage. |
| 215 | Parents need help - especially with insurance coverage and if the schools their children are attending are following the law - lawyers cost a lot of money and many parents cannot afford it |
| 216 | Educate yourself about special needs. Come check the school. Make sure of their safety in school or anywhere else. Sometimes as a mother of 3 years old boy with autism I thought about installing camera in him to really know what people around him does behind closed door. |
| 217 | i need help. |
| 218 | That Area Board X1 Staff made my son's dream of supported living a reality! They listened, cared, and gave of their time in what would otherwise have been a helpless grief cycle, and persevered with us to reach the goal that my son was determinedly struggling to communicate. I hope other Area Boards are as dedicated as ours! |
| 219 | Support services in high need low resource communities, |
| 220 | More direct access to Area Board advocates to advise on specific client circumstances. |
| 221 | The importance of supporting non profit agencies like Ukiah Valley Association for Habilitation who serve people with developmental and physical disabilities, so that they can get up and go to their job on a daily basis and feel valued and earn a paycheck. Without funding to provide these services, you take their purpose away from them. People with developmental disabilities and physical disabilities deserve to wake up daily and feel self worth and purpose. Its your responsibility as a State Council to support and rally as hard for them as you would for your own job. Thank you for taking the time to read this. |
| 222 | We need more money for these kids! We were recently able to pay for much of the support my child needs. We have had to incur significant financial difficulty to do it, forego vacations and cars and whatnot. But we consider ourselves lucky because we can pay. What about all of those kids out there whose parents simply cannot afford what they need and the state/school system does not offer it readily? We are facing a lost generation if we do not give these kids the support they desperately need. |
| 223 | As far as my daughter is concerned, she's had great services provided for her. My only issues is Day Programs |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | <p>after she turns 22. She will still need interaction with people and a structured day. But where I live there is no such place for her to go.</p> <p>There are huge deficiencies and differences from county to county for services with Regional Center (ROC) and Special Education. It is extremely complicated and severe hardship for families to navigate the system to acquire services. Sub-contracting out Regional center services to organizations that provide low to very poor quality of services for families. The quality assurance is non-existent. Many families do not even realize the services are so poor because they consider any service as great. For example, if the sub-contractor used by ROC does not meet all of the hours of service indicated in your individualize agreement due to their teachers being late, not showing up or leaving early. They make no effort to automatically make-up the time. It is the parents/guardians burden to contact the vendor to ask why the teacher did not show and if they have plans to make-up the service hours. They claim they will work with you but if it is at the end of the month the hours will not roll over therefore you loose that time and they will not offer make-up, even if they are at fault due to their staff not coming to work. This can happen often and no quality assurance is in place to mitigate these types of situations.</p> |
| 224 | <p>The parents of disable children are very overwhelming with their disable child. Without the support from the state council, they can barely survive to help their vulnerable children.</p> |
| 225 | <p>I love my job. I went to school for Graphic Design but this is the field I should have invested in school. The people who work in this field are incredibly devoted to serving this population.</p> |
| 226 | <p>Thank you for ALL that you do to make sure our children have a better quality of life in ALL areas!!</p> |
| 227 | <p>Harbor Regional Center routinely denies services that are desperately needed by the community. Children with behavioral problems are denied behavioral services based on diagnosis rather than assessment. HRC routinely denies clients services through delay tactics. They routinely lie to families about what services are available to them and give misleading information when pressed. Most services are obtained through Fair Hearing procedures which is stressful and onerous on families. HRC routinely takes advantage of families for whom English is a second language or who are under educated and lie through omission. HRC's service coordinators are not fully trained on the law and it is very common to be told conflicting information from call to call. These problems are endemic throughout the community and are not limited to one family or small group of families.</p> |
| 228 | <p>interagency cooperation is crucial - regional center, school, social services, Medi-Cal</p> |
| 229 | <p>how to best utilize the limited resources to benefit the special needs community</p> |
| 230 | <p>I really appreciate your trainings - they have been extremely insightful and full of great information I can apply right away</p> |
| 231 | <p>I would like the council to know that they have the power, the ability to affect change. You can make a difference in the quality of life for individuals with disabilities. So many of these folks do not have a voice of their own, I implore you, be their voice. Please!</p> |
| 232 | <p>I think the State Council needs to realize that by removing advocates like Area Boards - you are doing us an injustice. We haven't anyone to seek information from specific to our child's needs - Area Boards were a great comfort and clarified much information for us, but now, with them being dissolved because of lack of funding, we are left without this valuable information option. I would also like to see State Council become more involved in the issues such as Medi-Cal oversight. Every year I fill out multiple paper requests - all for the same information. Unless there is a miracle, my child's life is not going to change. And yet, when she transitions, I will have to jump through hoops again to transition her Medi-Cal and her conservatorship - this should be a simplified process.</p> |
| 233 | <p>Pay full attention and their need for the people with disability. The employment gap is my concern to get the job.</p> |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 234 | Even when there is a client rights investigation deaf clients are interviewed without an interpreter by APS this is not acceptable and the client may know how to read and write to some extent but not efficient enough to get all the facts correct. |
| 235 | Of all the things Area Boards used to do the advocates in the DC for those without viable family support was the most valuable. THat strcute should be brought to the "regional offices" but should be applied to individuals int the community who do not have viable family support. |
| 236 | support the %10 increase |
| 237 | see above |
| 238 | Just keep fighting for adults with disabilities, more housing is a must as the population is growing! Build more homes like Glennwood!!! |
| 239 | Please assist the companies that offer ABA services in being able to attain and retain employees. Pay therapist a better wage so they don't have to look for better paying jobs and we as parents and the child needing the therapy are not forced to have new therapist frequently and limit the amount of schedule changes. |
| 240 | Please focus on the moderate - severe population of students with developmental disabilities. Without subsidized employment programs opportunities will be few and far between. |
| 241 | You guys have done a great job. Thanks for asking for feedback. |
| 242 | That respite is not working for as many families as it should. Disability awareness is getting better but we still have work to do in this area. |
| 243 | Reimbursement freezes for vendors in the field are crippling many service providers. Odd considering the state ADDED 40,000 state employees between '06-'08 and between 2010-2013, while the total state employees decreased by 13,000 (net increase of 27,000 including '06-'08), the actual payroll for state employees increased from \$14.5 BILLION in 2010 to \$14.8 B in 2013, AND the employee benefits budget increased from \$14.5 B to \$14.8 BILLION in the same period. Meanwhile, our vendor reimbursement rate decreased by 4.25% in that same period of time (it has since been returned to "normal") and has been frozen at the same rate since 2008. Who is feeling the biggest economic "pinch"? |
| 244 | This is a devastating condition with little understanding or compassion from society. My children look like "spoiled brats" at stores or airports, when it is a sensory problem (noise, smells, hunger...), transitional problem(I am not doing my usual schedule) or a low toleration for frustrating situations(grocery lines, airport security lines, Disneyland lines.....Help us get more exposure of our children's DAILY life struggles out there. Give our children skills classes through out their lives so they can be a part of society because their caretakers are going to DIE at some point and these children/adults need a safety net. |
| 245 | Reinstate the funding removed from the system by the Trailer bill. Require training for people working with people with disabilities and pay a decent wage. Let's face it, its a shitty job, no wonder they are lazy. Pay for the real, actual needs of people, not the bare minimum. My son has not had a dental cleaning for six years because he requires sedation. He was able to manage with a patient dentist as a child, but now he can't sit still in the chair. His health is deteriorating. in one of the homes he was in, he even lost ten pounds in three months (he is severely underweight to begin with). My husband goes with the house twice a week to work out at the gym, because there is only one staff available for four residents. We pay his gym membership, but they should be able to staff routine outings without parents having to volunteer. My husband also goes with when they go to dances or dinners to make sure they don't feed him things he is allergic to and to manage his behavior. |
| 246 | People with Autism want to help and be needed. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 247 | You could be a force in this state, but need to get more organized. |
| 248 | The state is not doing enough to help these population be independent and productive members of the society |
| 249 | The importance of helping these young people. |
| 250 | Nothing |
| 251 | give us jobs you have |
| 252 | Special ED services in our schools for student with disabilities need help. Starting with educating teachers and aides. Administration and director receive training but the teachers and especially the aids are not being trained on some great updated special Ed training that is truly needed to help students with disabilities. As for employment : more vocational school needed or work with companies that are open to hiring people w/disabilities. Helping & supporting those companies . |
| 253 | Yearly budget cuts and inadequate funding for the care of people with disabilities make it impossible for my son and for the people who help care for him to have quality lives. His safety is compromised daily because of this. Everyone already knows this but it doesn't change. The population of DD people is doubling and the obvious unsolved problems remain the same! Affordable housing, informed health care professionals, job opportunities, reliable trained care-providers, community and social opportunities and plans for the care of aging people with disabilities are issues that need to be addressed and secured . Thank you for doing the work you do. |
| 254 | Harbor Regional Center needs to be audited. Using Facebook we are able to chat with other Down Syndrome families in other parts of California and they get loads more services. They get conferences funded, aides for camps and activities, and even ABA - yes for DS. Services should be the same for everyone in California. We are citizens and taxpayers - not charity cases. Why should a nonprofit have this power over all the families? They hold power over all the service providers and only let you use certain ones - the ones who go along with what they say. Where is the accountability? |
| 255 | The timecard processing is set up to make it nearly impossible to collect monies owed if the timecard has any mistake. It takes forever to collect, if ever. That is against the law! |
| 256 | I have been taking care of a 9 year old Severe Autistic ADHD NON VERBAL girl and only now is Regional center finally helping parents. After going into emergency room in hospital for 7 hours. No facility would regional center pay or offer her. Hospital could only do so much. Praying more help from groups to liaison for us. Please |
| 257 | This is families out there with major problem that need solution and not just a bandaid . Assisting these children now while they are young and tender can make a difference in tomorrow and through out their journey and ours . Giving them the assistance now and seeing the results as they grow to be adults walking in our shoes later . Remembering these human beings can teach us today and impact us in the future . Of we won't know unless we reach out and touch there lives to make a difference in our lives to . God made us equal and never have up on you |
| 258 | There is too much hidden abuse that goes on in these homes--residents being yelled at, punished unnecessarily, abused by people who know nothing about how to deal with people with special needs, but they have found a way to make money or get a home by signing up as residential care facilities. There is a need for more homes, but there has to be a way to monitor those who own and/or work in the homes. Most of the time, we, the family of a cognitively impaired relative, have caught many of the owners and workers of these establishments in the act of abusive behavior completely by accident--phones left on after a call without the owners knowledge, attending doctor/psychiatrist visits by surprise, etc. There are many good homes out there, but very few exceptional ones like the one our loved one is in now. It has taken |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | <p>20 years to finally find a great home with a caring, knowledgeable and understanding owner who has no hesitations about us just showing up or making surprise visits, and our loved one has never been more relaxed and open about how much he loves his new home--but this is the exception, not the norm. We want to be able to set up a monitoring system through our computer, where, at any time we can check into the common living space to see how things are going.</p> <p>Also, want to sing the praises of our local regional center in the San Fernando Valley (North Los Angeles County Regional Center--NLARCRC). Exceptional, caring people--and we're going to "name names"--who have always been there when we needed them, specifically, and especially, one rep named Anita Tinker! Too bad they can't all be like her!</p> |
| 259 | The children in autism population are growing up fast. Is the community ready for this epidemic? |
| 260 | There are not many health care providers who want to take medi-cal because the state takes too long to pay them, (3 plus months) especially with the amount of deductions they have to take and amount of paper work needed. Approvals for care takes too long. |
| 261 | Also provide more help for the middle- aged and older disabled persons. |
| 262 | Just what is stated on top. Were open to suggestions. |
| 263 | Persons with intellectual disabilities have it hard enough because they have to work at every thing 100x harder then everyone else, and they do it with a smile on their face. State needs to support the agencies that support this population and its families/ advocates in making. Sure they are safe, their over all needs are met, and they are being provided the opportunity to transition apart of their community in adulthood just like everyone else. |
| 264 | Constant changes in services are not beneficial for them. |
| 265 | Schools are not being held accountable for the IEP's so it puts parent's in a constant battle with the district. |
| 266 | my husband is a neuropsychologist and I am a pediatric nurse and with all our combined knowledge, we still find it an uphill battle with school, Regional Center, community daycares, YMCA, and others to get our daughter the services she needs to succeed in her life. Thanks for listening |
| 267 | All disabilities have a range. Please don't label and box our family members. |
| 268 | We must deal with the issue of "aging out" of the ASD population. The State Council reach out to skilled individuals working in various fields to create a new task force empowered to make changes. |
| 269 | How difficult it is for families to plan for the future after family support is gone (death of family members). |
| 270 | We have to deal with the issues related to "aging out" as it relates to the growing ASD population. The State Council needs to get creative and perhaps working with skilled individuals like Dr. Louis Vismara create new tasks forces that will be empowered to make changes. |
| 271 | We are very grateful for the services we receive. However, I believe that my child could have benefited from a few more years of the school based "transition" program (his was excellent) and maybe research can be done to see if it is feasible to extend the model of a "school based" type of program beyond age 22- especially for Autistic individuals with behaviors who can continue to learn but are not advanced enough for community college. |
| 272 | It is my opinion that there is a systemic problem with the lack of inclusion in general education classrooms in the Coachella Valley for students, like my son, with an intellectual disability. Despite bringing information from TASH and independent evaluators with expertise in |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | inclusive practices, there is this pervasive believe that a student with an intellectual disability cannot access grade level curriculum with modifications and supports. |
| 273 | Focus on developmental centers. Repurpose them rather than simply closing them. There will always still be a need for a place that is safe for short term placement for those in severe crisis. This comes from someone who has worked in the field for 20 years and a prior developmental center liaison with a regional center. |
| 274 | Empower advocates with assistance |
| 275 | That Autism has many faces |
| 276 | Take care of our providers because many have stopped supporting these services because of cutbacks. |
| 277 | Make services available to our community that is available to the typical community. |
| 278 | Appreciate the email notices of upcoming events. |
| 279 | That when they Orange County stopped healing individuals with IEP issues that hurt my family drastically. At times they were the only knowledgeable ones available to support me by providing me with information and going to IEP meetings. I would hope they would reinstate those services. Thank you. |
| 280 | I lament the destruction of the Area Boards when they were independent. |
| 281 | The school & regional center gives minimal services which are of low quality. |
| 282 | That the provider network needs nourishment and encouragement to keep on going. It is a civil rights issue. Staff shouldn't need to work 2 or 3 jobs to make ends meet. We've given lots of lip service to supporting the people in direct services who provide the care for our consumers... If we could fight for one change, it would be to prohibit the State of California to not pass on the federal cost of living increases for SSI recipients each and every year!!! |
| 283 | 1) early intervention is key 2) more state representative needs to find out about the need in the community 3) funding is necessary to address the need of the DD community. |
| 284 | Limitations with the use of IMDs, State Hospitals and limits with Developmental Centers like Porterville are a huge issue for individuals that are dually diagnosed and suffer from current and past contact with the criminal justice system. |
| 285 | the difficulty of obtaining therapy services through insurance. They are not equipped to provide the type of therapies our population needs. more training on what people with developmental disabilities need and therapists who are familiar with this population. |
| 286 | I'm a strong advocate for people with developmental disabilities because I have a family member that I grew up with that is disabled. She tells me all the time that she wishes that she can do everything that I can do; therefore, I always try to get her involved in whatever I do. She wants to be accepted like everyone else and wants people to be educated about this population. Ultimately, she wants to be viewed as just another person, not a person with disabilities. With all that being said, all of the programs that she has been involved in (such as adult day program, respite, and independent living) has helped her become more independent. |
| 287 | Competitive integrated employment for more ID/DD persons will only become a reality if we all start to ask employers what they need from us! |
| 288 | the state needs to provide more money for the services providers and non profits or there won't be places for them to go during the day. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 289 | That the regional center is useless |
| 290 | I am not happy with the cuts in programs to help the disabled. It is time to tax corporations proportionately the same way you tax the middle class. No exceptions. |
| 291 | I wish you educate the teachers who are title as a Special Education Teachers. In my area a lot of the teachers feels it is not there jobs to deal with behaviors then why did they go through schooling to be that teacher. I am lots for words. Post secondary program for my daughter was a total nightmare with teachers using hands on students my daughter was kick out of post secondary due to outages lies from some of staffs making up stories on mental disable person.How low can you get I wish they will provide spot check on classroom with children or adults with disability YOU CAN HIRE ME... |
| 292 | Congress is still talking about major cuts to Social Security, MediCare, and Medicaid. They have passed a Concurrent Budget Resolution and they have tried to cut MediCare by \$700 million as the price for them passing the Trans-Pacific Trade Agreement. If any of these cuts get approved, what are the contingency plans for regional center clients so that we can continue to live as independently as possible in the community? The disability services system needs stronger relations with city and county law enforcement to ensure better police training, better treatment in the jails, better treatment by prosecutors and judges. Such a relationship would be great for the clients who might find themselves in the criminal justice system as victims, witnesses, or accused persons. We need to make certain that women clients have the same access to services and supports as the men do; and that everyone is aware of the rights they have and how to exercise their rights when they need to. We have a problem here in Orange County where some clients live in cities that have their own city power authorities that are not under state PUC authority. This needs to be looked at as some cities like Anaheim, seem quick to want to turn the power off on clients that have fallen behind on their bills. The city power authority is under the jurisdiction of the city council and so clients may not have support programs like the state PUC CARE Program. This is an area in urgent need of investigation and implementation of support programs at the city level. |
| 293 | Expectations for our children are very low so they cannot reach their potential. See my daughter's website for an example of what can be achieved with proper supports. www.sue-rubin.org |
| 294 | We need to decrease waiting lists, and provided therapy right away. |
| 295 | The Department of Rehabilitation use to provide employment opportunities to clients that would help them obtain individual State and County jobs. This is no longer the case, DOR are placing client's in conclave type jobs in sheltered work centers and jobs requiring background checks. State employers were given incentives in the past to hire Intellectually Disabled Individuals, is that still so? Some school districts are providing transitional programs for their graduates which they are guaranteed to fail. Instead of offering a meaningful program with job coaches they are placing them in Junior Colleges with counselors who do not know how to work with our clients in main stream college level courses who have visions of becoming auto mechanics. |
| 296 | That's it. |
| 297 | Diversity |
| 298 | Thank you. |
| 299 | thank you for offering training class |
| 300 | It seems that the majority of parents dealing with RCOC Orange County are extremely frustrated and have to jump through hoops to get what is needed for their loved ones. It would be refreshing if some type of platform would exist that would lead to improvements and actual |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | reprimands for the poor quality of service provided to consumers. Parents should NOT have to employ lawyers or be able to recite the WIC to get services for their kids. |
| | The school system with the main |
| 301 | Losing side being everyone. My son was sucked into a diagnosis at three that has dragged him further and further from his peers for the past 6 years. I worried what kind of an adult he will be; he has been made to feel uncomfortable at ever level. |
| 302 | Schools are singling out and discriminating against students with disabilities. Schools are lying, doing illegal things and getting away with it. Especially charter schools: they turn away students when they are trying to enroll. They also use different reasons and tactics to drive/get families out of their program once enrolled. At the end it all comes down to using tax payers money and not wanting to spend it on special needs students. |
| 303 | That without additional financial resources the system will collapse. And the DC are not an option. |
| 304 | There are no activities for the individuals who are mildly developmentally delayed with supports. |
| | Thank you for what you DO do. |
| 305 | Also, in 2004 you awarded me/my Collaborative Autism Training & Support Program a 2 year seed grant to get started. While the NBRC partner failed to do the record keeping w/ you, unbeknownst to me, and subsequently left the Regional Center, our program is surviving as a very much valued grass roots community partnership in our three county catchment and beyond. We've won many service awards, and over 50% of our university students who are in the training (and provide services to kids/families) are hired in the field and over 50% go on for further training/certification in the field. |
| | I am totally appreciative of what you helped start!!!! |
| 306 | Please see #3 and #4 above. |
| 307 | There are way too many people earning a living, getting degrees and retiring in style off the backs of our children with no regard to the fact that they didn't do a very good job of educating the kids. They've pushed them through the system year after year and now we all have to pay for their care. |
| 308 | It's almost impossible for school districts to do all this for students when funds do not go all year around for staff that assists these students. Summer assistance with students with disabilities transitioning out of school into the work world is a huge problem... We can assist them by being able to work in summer!!! |
| 309 | The system is deeply unfair. Socio-economic unfairness. There are very well-funded clients and those that are not. Surprised this hasn't ended up in the newspapers. Regional Centers are a tale of three cities- those that are overly funded, those that are adequately funded, and those that are underfunded. They are gatekeepers for most of us, some have a welcome pass to gorge their kids on money and services galore. Deeply unfair. |
| 310 | The State Council needs to make sure that people with intellectual/developmental disabilities are safe, educated, protected, with access to leisure activities of their choice/needed services including adequate health care/resources, and with many opportunities to be fully included in their communities via schools/recreational centers/employment, etc. |
| 311 | A parent advocate can feel very alone. Any communication from the state would be welcome. |
| 312 | QUIT CUTTING HOURS |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 313 | This is a difficult question because I am not sure exactly what the State Council knows. Vickie Smith knows a lot! I just would encourage realistic options and more inclusion of rural areas that do not have an abundance of potential vendors or real estate. I feel like the governor neglects the more sparsely populated, remote counties in the State. |
| 314 | Current speech therapy provided at school is inadequate & should be handled by outside speech facilities, just as it is currently if a child is under school age. |
| 315 | These individuals, especially they young adults, want to be a part of the community. Move away from segregated living environments and work environments, and allow these individuals to show their abilities. |
| 316 | I have read that early intervention makes a bigger impact especially for the children on the autism spectrum? Also, this population is vulnerable, we need to make sure they are safe and that services are available to those who need it the most. |
| 317 | This is important work. |
| 318 | Far Norther Regional center is too big geographically. They have been consistent about telling parents in Siskiyou county that we are geographically too far to serve. I thing the RCs serving the far northern section of California need to be reconfigured. Do not base their configuration as other RCs are but on the geography of the counties involved. Because the counties are so rural w/a lower population base, the normal requirements need to become guidelines not rigid norms to follow. |
| 319 | Would like to know when grants are available to apply for. |
| 320 | The budget simply needs to increase to provide better staffing opportunities to persons served. This would allow for growth within agencies for staff and participants. It is very difficult to keep good staff when they are on the brink of making minimum wage with a state minimum wage increase. |
| 321 | I'd like the state give a chance to most of the students with disabilities as well as staff to be trained on the work sites. |
| 322 | There is a great void within our communities about awareness and education of individual rights and availability of various services. Although it is a complex and complicated situation, I would like it if the state council had more presence with the community. I understand you already conduct trainings and Awareness, it is not enough though. I think only about 15% of the disabled community and families are aware of what the state council does and it's role. Thank you |
| 323 | Care providers and service providers are burning out, year after year, after year. How can staff be paid under \$10 to provide quality services to extraordinary people? With low budgets, low wages, you get a perfect storm of a mix of employees, some of whom care and will break their backs serving others, and some of whom don't care at all... they're like vacuous droids flipping magazine pages and texting on their cell phones while the people they're 'supervising' are deficiently attended to, watching videos on a screen or not learning anything new because staff don't care. I'd like to say that managers and directors can fire terrible workers, but the reality is, there aren't many people who can work on poverty-level wages and offer their best in conditions wherein they're overworked due to imbalanced ratios and underfunded programs. I believe that TCRC & associated state district could work on allocating some of the Quality Assurance staff time towards annual re-evaluations of staff-individual ratios as "working" or "not-working" so that dynamic programs don't get stuck in the mud. |
| 324 | What happens at the school level with these children can be appalling and can cause much stress on the parents. The school and district is allowed to change rules as they see fit with no regard for the safety of the child. |
| 325 | Our area-1 board is immensely dedicated and helpful too our Regional Center. They are always available, are prompt in their response to |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | communications, and are a wealth of information. I very much value their presense and service to our community at large. |
| 326 | nothing |
| 327 | Some Regional Centers persecute the families of consumers, and the consumers. The result is often ruined lives, and sometimes worse. Often the consumers fall ill and die. |
| 328 | There should be a coordinator through day program or case worker through GGRC whose responsibility includes coordination of day program with DOR services, etc. specifically on employment training and/or employment placement opportunities. |
| 329 | You need to look at the goals of the whole person, not just let's get them out of school let's see they really have the life skills to be independent people, that is what they want, Also if a parent won't or can't advocate for child, the state steps in, and help that child. |
| 330 | Care and housing for our population as it ages is critical. Parents wish they could last forever, and our kids are 100% vulnerable. |
| 331 | Prevention and therapies are very important steps. Kids with I/DD needs to receive their needed therapies and services to help them grow out of their disabilities as well as to prepare them for future lives. |
| 332 | I intend for my daughter to live safely and have meaningful work and recreation opportunities, whatever it takes. |
| 333 | The importance to have independent vendors not connected with the Regional Center. |
| 334 | I think we have resources that help families but sometimes I feel these are abused by some that are not clearly monitored or validated. |
| 335 | the impact of emotional stress in family members, specially mothers and siblings of disable child, their mental health problem under recognized and under treated. |
| 336 | The workers need more freedom to provide personalized assistance. That's the most important thing. |
| 337 | The State Council must stay on top to see that meet the goal or not. |
| 338 | The outreach to families are done in a low scale of information either by Regional Center or other government entities, instead to reaching out to the communities in information neighborhood resources (Ex: Church, radio, communities' public parks, schools, ect) |
| 339 | Training of Regional Center staff is poor and widely varies. There are too few good social workers/service coordinators and too many to whom it is just a job. Sad state of affairs. It seems like there is no oversight of Regional Center staff. Turnover is high, morale is low and program managers are burned out. Families are then left to fend for themselves and the only families who get ahead are those who depend on networking with other families. |
| 340 | If these kids don't get the help they need in school, they will end up dead, in jail, or on the dole. These politicians need to know this problem is everyone's problem and to do something!!! |
| 341 | The state budget affects everyone. Some one with a I/DD, family, vendor's, staff and RC. I would never want to see the quality or opportunities suffer only because the funding isn't there. |
| 342 | Non-profit day programs will begin to close down due to the lack of funding and not receiving an increase in funding in over 15 years. What will be the plan then? |
| 343 | The work they currently do is appreciated |
| 344 | I find it very frustrating that the Council is in such a position that it cannot work with a Ex. Director that comes with no ties to one department and has knowledge of the DDSsystem and the needs of the people. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 345 | Continue to serve this community to the best of your ability.. they need full support |
| 346 | I have seen services in place to help our disabled population have a better way of life, i.e., work opportunities, transportation provided, social activities, and health insurance for unexpected illness, accidents. However, there is always room for improvement. As I mentioned before, with your Denti Cal system. |
| 347 | We need help to make sure our children with disabilities have the same access to things as do their typical counterparts. |
| 348 | Accessing resources is daunting. There's no way my 21yo son (high functioning autistic) could navigate this system. So many individual things by city, county, region, etc. Very difficult to navigate. |
| 349 | The system is broken, run like a business at the expense of the children and too deregulated when it comes to Regional Centers governing their own without checks and balances. It doesn't help that the top state government siphons off billions from the state special needs fund when ever they feel like it. The increase in special needs continues to grow exponentially. What will our state look like 10, 20, 30 years down the road without helping the 600,000 special needs families that are fighting a daily war to get, secure and keep critical services for their children? The state will be impacted, the question is - how severely? |
| 350 | Housing is of great need in Sonoma County, they will need a safe place. |
| 351 | We stopped all regional center support because the worker was rude and condescending. Basically we did not need any respite care because my autistic son is physically normal. It is exactly because he is physically active I need rest. I take him out every day to the park or mall. Normal kids can enjoy friends outside without supervision. My son hurts himself if he stays home all day. The regional center was obtuse and frustrating because they act as gatekeepers and administrators, not as advocates. |
| 352 | Many other agencies also are feeling your pain and also wish to help. |
| 353 | Regional Centers are problematic due to staffing. Multiple case workers and slow response times. |
| 354 | Being the parent of an adult autistic son I have little or know support for his housing or employment. after working for a company for 8 years they let him go after suffering a brain disease. Although he took some time to recover he recovered fully after a stroke and a coma. He is a miracle, he graduated college and has completed computer certificates. He would love to do an internship in a company I cannot get help with finding him an employer who would be sensitive to high functioning Autism. There are a lot of students coming up in the ranks with autism who will also need help. If you need me to help I would love to volunteer my services |
| 355 | The reimbursement level for RCFE's is way too low. |
| 356 | See question 4 |
| 357 | I think SCDD is great with the workshops but often policies that are in place are not followed though at regional center |
| 358 | Please know how far services have come in the last few decades. Thank you. |
| 359 | Please don't cut off funding for individuals with disabilities. Particularly high functioning individuals who have the capacity to develop to the point where they no longer need public benefits, but they need help to get there. There's a tidal wave of individuals with high functioning autism spectrum disorder that is going to either bankrupt the system or, if planned for wisely, can enable those less fortunate to maximize the use of public benefits by not becoming a drain on the system. |
| 360 | funding for medical equipment |
| 361 | To do a better job matching the disabled with people of a similar functioning level. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 362 | care in California is the worst in the nation, which is ridiculous considering California is the 6th largest economy on earth, the state is misguided, poorly led, and lacking in any form of realistic transportation so that people with disabilities can get to work, school, or the doctor without having to pay exorbitant transportation costs |
| 363 | Information and free resources are hard to get for low income. |
| 364 | A realistic study of how our present system can be improved. We need more brains on how to help our society accept those less fortunate than themselves. |
| 365 | I am a parent and a Service Provider for adults, recently obtained BCBA and soon to embark on childrens' services in the area of ABA. I can be reached at 760-964 4130 for more ideas or input if interested. Thanks! Therese Kragness |
| 366 | Mains! Supportive Living Services in Chico is doing a great job providing services, in spite of budget constraints. The staff works overtime, and finds ways to make do. I imagine a system where this way of serving the developmentally disabled becomes the norm, where those with disabilities are encouraged to reach their highest abilities for productivity within the community. Please support SLS. |
| 367 | Thank you for all of the work you do! |
| 368 | There needs to be more training and awareness to the growing number of children with Sensory Processing Disorder so doctors, educators, care givers and parents know the signs and what can be done to help the kids. |
| 369 | The vender community has lost (which means the people have lost) a significant number of vendors/services in the past few years (up to 33%) due to ongoing funding cuts and underfunding. Where is the string voice for the people the State Council is suppose to be serving? |
| 370 | People with DD deserve to have a life as typical and least restrictive as the rest of the population. They are worthy of our time and our tax payer dollars. |
| 371 | Self-Determination is going to change the way individuals think about and receive the services they need. Very excited this is finally going to happen in California! |
| 372 | Do more to empower the area board advocacy staff. Twice I have requested help. The first time it took 4 meetings to establish that they could not help. The second time I got 4 page list of attorneys with 1 recommendation of an experienced individual. That lawyer had no clue and wondered, as I, why they recommended him. The rest on the 4 pages.... Useless. Not knowledgeable about the players or disabled community or needs and services. |
| 373 | Regional Centers has a "Don't ask. Don't tell policy". Withholding information on supports and services which are appropriate for the consumer. Only when a caregiver/consumer/parent/attorney/advocate inquires, do those services become miraculously available. By this time, it is late. |
| 374 | I am willing to offer assistance to the State Council on disaster preparedness for individuals with disabilities in Orange County. I am bilingual in Vietnamese and have both personal and professional experience with Autism since 1998. Thank you for the survey. |
| 375 | There is a broken system here if kids with lifelong developmental disabilities are being painted as "typical" by the school districts and pushed into regular education when it is clear they will be bullied and not be able to navigate the social nuances of school. If the kid and parent wants it, then great, but it should not be pushed on a child under the fake guise of "helping" them. |
| 376 | Thank you for all that you do provide for these individuals. |
| 377 | We suffered, my child and I. Just because I believed my child could receive an education as a disabled child. I did not find one school that did not sabotage my child's education except one school, cfor homeschooling. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | <p>God bless you all ,as I hope you uncover one of California's darkest and most kept secrete. The systematic degradation of our families and children with disabilities through the educational system. I hope whom reads this is not happy about this.</p> |
| 378 | <p>More affordable programs Better medical insurance medcare</p> |
| 379 | <p>TRULY ADVOCATE FOR COMMUNITY BASED SERVICES AND THE CONSUMERS YOU GET PAID TO PROTECT AND DEFEND. Thank You for being brave enough to conduct this survey.</p> |
| 380 | <p>Help get us the funding needed to provide services.</p> |
| 381 | <p>The vendors that are contracted with the regional centers are in the business to make a profit. They are a business not a resource that is for the support of people with special needs.</p> |
| 382 | <p>Needs to be more services offered</p> |
| 383 | <p>I would like them to know how much vendors struggle to provide services to individuals with limited funding.</p> |
| 384 | <p>I think some of the plans made by legislators are just out there in left field. What will you do when sheltered workshops are gone - there are many many people with Intellectual disabilities who will never be able to work - the plans are not practical. Also programs like clients mentoring clients for life planning are not realistic - and the mentors are paid regular wages to do this? Let the legislators who make unrealistic laws consult those who work "in the trenches" with consumers. Also is a real shame that when doctors hear "medicare/medical" they do not want to see those people who have that as insurance and cannot get anything else even if they are really healthy. To me it is discrimination.</p> |
| 385 | <p>Regional center workers need to help more I am tired of talking to a wall when I ask for help</p> |
| 386 | <p>Education services (programming) differ from SELPA to SELPA. No all districts have a continuum of services for all grade levels. General Education opportunities are almost non-existent for preschool children.</p> |
| 387 | <p>Please advocate for continued IHSS funding - no cutbacks.</p> |
| 388 | <p>Having better programs in place will enable parents to advocate effectively for their child.</p> |
| 389 | <p>Keep the Promise! this should always be our slogan when things get tough as they are now.</p> |
| 390 | <p>Housing is a huge issue as you must know. Section 8 lists are closed with many years wait time if you are lucky enough to be on one. We need safe, intentional communities that support our population - there is safety in numbers - nice idea to have everyone mainstreamed, but the normal population is not interested in befriending our looking out for our population. They end up feeling and being isolated because the supports and programs are lacking, transportation is difficult. Parents and children in the community still stare and keep their distance. Criminals look to take advantage. I think our population would feel more comfortable if they lived in areas where there were many other to visit (walking) and socialize with instead of onesie twosies all spread out, feeling alone and unable to have more normal interaction because the people around them just are not interested. These days, we don't know our neighbors... it is different now, so I think that there would be better support and a better safety net if there were intentional communities establish where many or most needed supports were in walking distance.</p> |
| 391 | <p>Have me come up and meet with them. There are great needs and funding keeps getting cut</p> |

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| 392 | Thank you for the work you do. Please support our Area Boards to continue to provide individualized support where necessary. While individualized work focuses on perhaps fewer people than huge outreach services might provide, it reaches the people for whom the system is not working. Please advocate for increased rates for vendored programs so they can do their work without the constant stress of budgets that do not cover the services that people need to survive. |
| 393 | On a Whole there is no one advocating for the Disabled community. Many think, with a title they are, but our system is broken. Illegal immigrants have more rights than the disabled in California. It is a travesty! |
| 394 | Keep fighting the good fight. |
| 395 | That they should get out their and work with these kids and get to know them so they would learn how to believe it them. |
| 396 | Our people deserve the best that we can give, we have the ability, make it a priority. |
| 397 | To increase Regional Center budget for service providers |
| 398 | There is no real help for disabled adults that were injured after the age of 18 |
| 399 | I just started to work for YEOP(Youth Employment Opportunity Program) We assist 15-25 at risk youth. Would like our services to be known in our community and North County. |
| 400 | I am a parent, but also an RC vendor. California appears to be slowly, but surely, making it fiscally impossible for service providers to stay in business. No rate increase, but absorb new minimum wage costs, overtime, sick leave, etc. The State can then claim the service isn't available because no one's offering it. This in turn will save millions from the general fund, where someone can point and again proclaim that "because of THOSE people we couldn't afford to Without THOSE expenses we can ... " Similar to the blame of school districts toward special ed costs. This continuing perception keeps a wall between the average person and those who have no choice in being born who they are. |
| 401 | Absolutely wild for Scarlett and Jenny -- they are fantastic resources!!! |
| 402 | Working as a vendor there is very little consistent partnership. If we are working with individuals that are not job ready it's impossible to properly assist our clients. It would help to for these agencies to partner with us and set a strategy together for the success of the client instead of the agencies such as DOR just placing blame on the vendor. |
| 403 | Napa/Solano County losing transportation vendors due to rates paid. Limiting access to programs due to lack of transportation. |
| 404 | Funding for services is not keeping up with the cost of living or community competitive wage standards |
| 405 | if I want to plan a trip to go somewhere how do I do that just simple everyday things I go buddy else in the world dude |
| 406 | Please prioritize efforts to realign with HCBS regulations philosophy and service delivery transformation necessary to have California again take a leadership position on state of the art service models. |
| 407 | Some of our more rural areas continue to need a great deal of educational advocacy and supports. |
| 408 | The current disappointed system does not work for people with disabilities or their families which work very hard to make sure their adult children can live at home and experience happiness and satisfaction withtheir life choices. |
| 409 | Those who are currently living in DC's are the most medically fragile and extreme behavioral individuals who will need very costly services if they are to successfully transition to community living. Does the state have a plan to meet their needs? |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 410 | we need youtube videos and on-line resources so more families and professionals can access your valuable resources and presentations. I know OC Autism is interested in creating community partnership for their video library: contacts@ocautism.com |
| 411 | I worry greatly for families like my friend's. I help advocate for a friend with a very severe autistic son and cannot live at home because he can be a danger for himself and others. I watch as she struggles greatly to find good care and Regional Center folks are detached and unconcerned about it. They throw their hands up and say this is the only choice she has. The care is sub-par and they suggest she keep quiet. The home's staff is awful and they don't allow her to drop in to visit her own son. She has to make an appointment to see him - all because she complained about how they did not care for them well. I see this firsthand. I think the OC Regional Center is failing her son. I can't tell you how angry this makes me as I watch the mother suffer. Also, at the homes I have seen, I have noticed how overweight and unhealthy the clients are. No exercise, no access to sports or physical activity. They often are on diabetes medication. What's up with that? |
| 412 | We feel very isolated & unaware of what is available for support, living, the future in general. |
| 413 | With the recent budget revise, the governor has made it clear now is the time to step it up. |
| 414 | Enforce and develop individualized programs for children with Autism with in public school district by providing more services and support to children and families. |
| 415 | 1) we need leadership - we need the council to be out in front 2) we need the council to be aware of what is happening in the field today- good, bad and ugly 3) we need the council to be struggling on how to make things work better- be user friendly 4) we need the council to realize that mandating certain things is not the same to having people buy into the work |
| 416 | Teachers need to be protected better from students with severe behaviors and acting out towards staff. |
| 417 | Individuals with disabilities are capable and competent. We need to shift our expectations and allow for unique ways of demonstrating that competency. |
| 418 | Recognize that at a very young age people show signs & symptoms and this should not be dismissed as "only a kid" or "too young" . That some people can not be rehabilitated and there needs to be somewhere for those such people to go. |
| 419 | we are losing our aba..it will not be funded and our provider is out of NV. We are in CA. there are not enough services offered in our rural communities!!! |
| 420 | Our agency is 26 years old, best in our area, and at the breaking point. If it weren't for our corporate office funding ILS services we provide, we would have shut down due to lack of funds. |
| 421 | Keeping all programs available for people that want and need them is important. |
| 422 | There are enormous problems with the decisions regional centers are making in regard to their funding. Alta has a 2 year wait list for behavior services yet will not adjust their rate to something any provider could possibly work with. Tcrc denies services based on parent ability to be home, discrimination against working families. |
| 423 | Many families where I live (in Santa Barbara County) do not feel there is any assistance from the state council on disabilities. The school district constantly does not implement IEPs and harrasses parents that complain. They prefer to spend large amounts of money on legal fees to fight needed services rather than provide services or train staff. There is very little available staff for respite, child care, or any recreational or after school activities with support. There is no housing or jobs for those with disabilities. The schools and police |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | department are not willing to investigate abuse that occurs to children with disabilities. Families feel like they are on their own and the children are suffering. |
| 424 | Latino families need strong representation and that is not the case |
| 425 | The needs of clients in the rural areas of our state are just as important as clients in metro areas. Just because the population density is less, it does not negate the severity of the individual client need. |
| 426 | all levels of autism matter!!!! |
| 427 | The clients transferring from the DC's to the community should get a transition at their own pace. So many times placements are rushed and this can make it difficult for a client to assimilate to their new living environment and trust those now in charge of their care. |
| 428 | children with disabilities are special. Even though they need that extra help, their wants are just like yours and mines!! |
| 429 | I still see families with kids/adults with disabilities being discriminated against, and judged based on ethnic and economic background. |
| 430 | There seems to be a real issue with getting good people to stay at their jobs at the on-hands lower level positions. I think its the pay, lack of proper screening, ignorance and sometimes arrogance with top management at some of these non-profit organizations. Almost the right to entitlement or the status quot syndrome that comes from being in this field too long. Management becomes very passive and non-responsive to serious issues that they see as trivial and unimportant. |
| 431 | Regional Centers in California definitely need more financial support to hire more Service Coordinators which will address increasing caseloads, especially in Early Start. |
| 432 | Thank you for your advocacy efforts! |
| 433 | My students enjoyed the visits that Cindy made to our classroom. Cindy, gave a wonderful, engaging presentation on Self Advocacy. In addition, she met one on one to discuss vocational options with my students that focussed on each student's skills and interests. Cindy In a short amount of time created a great rapport with my students. She brought students information that she found that related to their aspirations. Students appreciated this follow up on their behalf and were invigorated by the positive energy and information that Cindy brought to out class. Thank You Gloriana |
| 434 | I am a new mother to a beautiful two month old old baby girl that has Down Syndrome and I have been running a non-profit respite agency for 6yrs and the amount of time a parent has to spend fighting to get ANY services in California when compared to other states is such a shame. Parents are kept in the dark about what services (and especially the amount of services) that they legally qualify for, and the only way they become aware of what help they can actually get is from other parents and advocates. I now experience this first hand and have to constantly remind Regional Center staff that I am knowledgeable in what services my daughter is eligible for. That is unacceptable, I should not have to constantly argue, and speak with Supervisors in order to receive the proper amount of services. If I did not have a background with CA disability services, my daughter would suffer. I would like to help fix this in any way possible, please contact me if there is anyway I can be of assistance. |
| 435 | The quality of public school education in CA is very poor. If you have a typical child, and you are unsatisfied with that, you can send your child to a private school, but private schools don't accept delayed children, especially if they have behavioral problems, and special needs schools cost upward of 60 or 70 thousand dollars a year for one student. We are forced to send our children to public schools, and public school standards are very low. Once your child is considered to have met a certain standard, your child then loses services, and there is nothing to replace it with. Your child just becomes the struggling C student at best if they are lucky. Higher functioning children that have |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | the possibility of going to college and being independent have no real help. It's your hand writing is good enough, your behavior is good enough, your grades are good enough, but that's not fair. Why shouldn't my disabled child have the resources to make A grades instead of C and D grades?? If your child is able to meet the very low public school standards they are left there struggling with no real help. That's not competitive for college, and higher functioning children have a real chance at complete independence as adults. Public schools are run poorly and don't have enough resources. My son's school lost their speech teacher this year, and not just my son, but all the students that qualified for speech lessons went months without any speech services, and all the school would say is that they were having trouble hiring someone and would make up the missed sessions when they filled the position. There are plenty of other examples I can list of how poorly the schools are run. |
| 436 | We need better inclusive school programs for kids with special needs. They deserve to be an active part of their community just as much as the next person. |
| 437 | cutting edge practice on inclusive education has not hit the public schools in a meaningful way. They are trying, but need better guidance on how to broaden the ability of their staff to support the needs of Special Ed students in the General Ed population. |
| 438 | Bring back individual advocacy. Go to families informal meetings and mediations. |
| 439 | People are for ever growing. I think we forget this aspect and don't continue to support people as the schools supported the people. |
| 440 | Not all people with DD are able to work and they need day programs that address their needs (eg., communication, social growth and recreation). |
| 441 | Need to be more aware of a Dana life of one of its consumers |
| 442 | That they services now being offered to this population is now controlled by Department of Rehabilitation and Regional Centers. The State Council needs to step up and develop more opportunities for services other than those two. |
| 443 | Help with regional |
| 444 | I wish DDS would pull the contract at KRC. Our board, even with the recent, long-awaited resignation of our board president, I don't have confidence in our board to do the due diligence needed to properly oversee the regional center. |
| 445 | SCDD should encourage DDS to have all regional centers operate in the same manner and follow the same guidelines. |
| 446 | I would really like to see more opportunities for our adult clients to be in our community. |
| 447 | Too many families are abusing the system. There are families who make a lot of money, but ask for everything in the world. Then if they are questioned, they get loud, intimidating and bully everyone around them. More attention needs to be paid to the actual financial burden of a family, and if they can afford services or supplies, they should have to pay for it themselves. |
| 448 | Great needs of more programs and resources for young adults exiting high school |
| 449 | Regional Centers are often not responsive to needs. Unless one knows how to "work" the system, it can be quite daunting. |
| 450 | OUR SYSTEM IS NOT CONSUMER DRIVEN AND SHOULD BE. |
| 451 | You are doing more harm than good for the clients and families you should be supporting |
| 452 | I'm sure there are parents who would be willing to "step up" if there were any opportunity to organize with other parents in the same situation. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 453 | There is a dramatic shortage of supported living housing options for adults with autism |
| 454 | We appreciate your efforts and support! |
| 455 | It's difficult to find consistent quality help for my daughter (who needs an aide for all aspects of daily life) when the regional center/IHSS etc. pay such a low wage. Consistency is very important but these jobs are really only attractive to students and students move on and graduate. We are lucky if an aide stays a year with my daughter, and we supplement what they are paid by the regional center! The same problem exists in special ed programs at the public schools. There is HUGE turnover in the para jobs, HUGE. |
| 456 | Continue to provide grants to our local agencies. |
| 457 | not sure |
| 458 | day programs need a rate increase |
| 459 | Developmental disabled have come a long way and have a long to go to continue to educate themselves the their community as a whole |
| 460 | My father had a stroke (2013) while in a Board and Care Facility. The CNA's (2) were not trained to visibly recognize one symptoms, which led to him receiving care medical too late. He needs care now but can't afford anything above the minimum care allowed by Medi-Cal/Medicare. |
| 461 | have more educational services for the adults with disabilities, it's not fair that ones they age out the school system, there is nothing else for them to keep learning the basics like reading and writing. |
| 462 | Lake County has to be brought up to the current standards and laws to help everyone in our community that needs help that mean right down to the schools and administration getting trained in mental health and the BOS of Lake County they are an embarrassment to this county they all should step down. |
| 463 | Two things; First, support, and be an active participant in, the Lanternman Coalition. The unique variables of new legislators, seemingly more money in the system than originally thought and other topics make this an opportune time for advocacy that focuses on state legislators. Second: Thanks for your partnership approach with our Regional Center. I believe we have a model working relationship. This is critical, as we are both here to serve the same clients. |
| 464 | Just because they have disabilities does not mean they are not capable to doing certain areas of their lives that can work for them. Provide those things that they want and need, not just what some other group decides they need. Do not remove someone from a facility where they have lived most of their lives to a group home that speaks a foreign language just to make a certain number of placements. That is just cruel. |
| 465 | Quality assurance at least twice a year. It is important to maintain support systems and services. |
| 466 | Keep up the good work. |
| 467 | We need to address the stigmatization of people with mental illness or developmental disabilities among the population, and especially police. The way some Americans treat our most vulnerable citizens is unacceptable and must change. |
| 468 | We are seeing more individuals who have been mis-diagnosed with mental illness when indeed they are autistic. There has been great resistance on the part of Tri-Counties to re-assess |
| 469 | There is no real quality control for vendors in the system. We need a system to make sure programs are doing what they say they are doing. |
| 470 | Thank You! |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 471 | Our area, Humboldt County, is really not serving our individuals with developmental disabilities well. We need more money, personnel, and resources! |
| 472 | Housing, employment, social security, mediCal and Self-Determination training needs to begin being provided to clients, families and schools when clients are age 14. |
| 473 | This population is lonely but social!! |
| 474 | Really need to look at the aging process of this population, they need more help than to be institutionally medicated and put in group homes. I believe they too can produce something for society/limited as it might be, still a contribution and gives them a purpose. |
| 475 | I am so grateful for the services you provide!!!!!! We'd be lost without you and Disability Rights California! Thank you! |
| 476 | People with disabilities have laws protecting them, but that doesn't do a lot of good without money to back it. We do the best we can as special educators, but we often feel we could do better, especially with smaller caseloads and more aides. And in the high school end, we keep losing good people because transition programs get cut or changed or aides get cut and we lose the support that makes our job humanly possible. I also run into families doing the best they can but may have disabilities themselves, and therefore, are not in the best position to help their students. More connection with family services and schools would be great. Plus, just more consistent family services would be helpful, some of my students have had multiple counselors per year and can never really bond and the counselor barely knows the case before moving on. Thank you! |
| 477 | That the regional centers are evil and go by their own rules. |
| 478 | There needs to be self help for conserving young adults |
| 479 | Having a member from your organization present at meetings ensures people with disabilities rights are not violated. |
| 480 | That sensory processing is a real disorder. I'm sure it has to affect more than just my child here. I'm guessing it is probably overlooked or misdiagnosed and those children are being labeled as bad children, or picky children, and that's not fair to anyone. Get them the help they need now. And as a parent who struggles with a hyper sensitive easily over simulated child, I need support too! |
| 481 | It's a very lonely uncertain road for parents of special needs children and we have no idea what to do, ask for or where to go to get our children what they deserve to live a quality life. Almost everything I've learned over these past 11 years has been from other parents. There has got to be a better way so when we start this journey with a special needs child, we have appropriate help and guidance from day one. |
| 482 | There is simply not enough support for families caring for loved ones in home. The education options are lacking as well. I live with my son in Sonoma County and the more I have tried to advocate the more I learn how lacking the community really is when it comes to options for learning and therapies not to mention finding appropriate care providers for respite. |
| 483 | Can't stress enough the importance of a productive partnership with RCs in order to bring about progress. Sometimes the Council office will disagree with the RC, but being antagonistic simply doesn't work. |
| 484 | Finding good caregivers who are paid minimum wage to do the work they do being on the frontlines of our clients is difficult for our clients. It's a huge issue to find good solid caregivers to serve our clients. |
| 485 | In WA state, they have "all abilities" summer camps through their Parks and Recreation Dept. Kids in wheelchairs, limited verbal skills, seizures etc - all come together and play! What a wonderful opportunity to decrease stigma and isolation. This is a model needed in our communities too! |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | Thank you for all your work!!!! |
| 486 | If the Children (disabled/Special Needs also) our this Nations future...we need to do everything possible to help teach them how to make it better! |
| 487 | that state and regional programs are not helping as they should. The state is ignoring and having people who have needs fall between the cracks. They lack the help they should get, especially when they are not extreme cases. |
| 488 | Consensus decision-making is not easy, but can be very helpful to everyone. |
| 489 | The importance of working with families and keeping families in the know. Give families the complete budget it costs to support our family member. It is not as if families are abusing a system in fact families carry a huge load of the system. Thank you for your work and the opportunity to give input! |
| 490 | There must be a better representation of the council. The council should primarily consist of the following people: "People who actually work directly with the clients, the client, and care providers" Not people who do not have a "clue" on how to meet these clients needs. |
| 491 | Self determination should be the #1 focus going forward and making sure it is implemented. |
| 492 | As a parent it's very frustrating having to fight, push and be the bad guy making waves to get our children the services that they require. It's hard enough having this kids to take care of, that alone is exhausting, then to have to put up a fight on top of that is just too much! |
| 493 | Phone calls should be answered during regular business hours at Regional Center, even if it means to answer and ask person calling to please hold. Voice mails left should be answered within the workday or when left after hours voicemails should be listened too and responded to when the office opens on next workday. Some Regional case managers are great at responding and some aren't, hopefully this can be solved by management, ie. timeline. When Case Managers are changed at Regional Center and introductory letter from new case manager with e-mail and business card is needed. A personal appointment should be offered and scheduled within 30 days of transfer of case managers. Thank you for your review of these suggestions. |
| 494 | Employment, Training, Educational Opportunities available for parents who care for children with Special Health Care Needs. In-Home Support services is a great "hands-on" training parents/families receive (not by choice) when learning to care for the medically fragile child, but there is no ongoing employment support (CNA positions) that can further enhance a family's knowledge. |
| 495 | N/A |
| 496 | It would be beneficial for the State Council to actually meet and hear from our clients, providers, and agencies face to face in a community meeting to get a feel for the population and hear first hand people's needs and concerns. This includes meeting with people in the outlying areas and not just major cities. |
| 497 | Regional Centers are committed to providing quality services to the individuals we serve. |
| 498 | Thank you! |
| 499 | We can't get people to work at RC as wages are no longer competitive. |
| 500 | N/A |
| 501 | My daughter has a unique condition called 15q11.duplication. I would like local services to support her |
| 502 | the regional centers are not adequately providing services to those in need, but are rather distracted by funding concerns. they are not equipped to appropriately assist families with the myriad of opportunities for a meaningful adult life through access to day program |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | opportunities. |
| 503 | <p>I have three suggestions: More uniformity in the size of regional center could lead to less bureaucracy and more transparency. Reconfiguring regions could address population shifts, etc., that have occurred over time. In depth surveys independent of the NCI survey, could help assure quality of service. The results should be analyzed, concerns raised should be addressed, and corrections/solutions should be implemented. Are there any "think papers" that talk about the changes that are needed? I am sure there must be but I am out of the loop. (Mostly because I am busy working and can't always attend to all the other stuff around me.) I didn't know about this planning process, how do you get the word out? (I just happened to see a piece of paper that one of my friends had that he got at a Supported Life Institute Conference planning meeting.</p> |
| 504 | Thank you for all the advocacy you have provided in the past years I am very pleased with your services thank you |
| 505 | In-home/residential support is very concerning to those of us with 24/7 supervision-type children. I happen to have the privilege of being able to stay at home with our sons. But as I get older this will not be possible (other people in similar situations are either single and/or have to work outside of the home and care management becomes difficult). What happens to our adult children when it becomes difficult or we cannot take care of them any longer? |
| 506 | So many of the area programs are managed by individuals that will not embrace technology, nor will they branch out so individuals can be competitive in the work force, ie STEM in programs. Many individuals watch youtube videos and learn how to cook, garden, catch bussing schedules, paper is obsolete, yet many of the programs are wasting funds by pushing piece work in this area. IHSS, ILS, SLS could all be utilized to support technology. Many programs are on vary huge vast pieces of land, ie closed schools, that land could be better utilized than by losing funding on keeping them around w/in communities that are not going to be having families living in them or supporting large structures, that are costing district, aka the taxpayers an large amount of money to keep them up. They should be sold off, the money from those proceeds should be generated back into land development, senior, low income, disabled housing, w/in those communities rec rooms could be built to help the individuals w/in the development acquire career skills. |
| 507 | That the staff that serve this population are highly under paid and need support to help. |
| 508 | There are agencies that are ready and able to provide services but the funding needs to match the quality of services. |
| 509 | I would like the SC of the Central Coast to know that they have done an amazing job. Thanks to your advocacy my sister is receiving the services she deserves. Thanks |
| 510 | Is the State Council familiar with Rocking the Cradle: Ensuring the Rights of Parents with Disabilities? This is a report submitted by NCD in 2012 to President Obama, which we had a substantial role in producing. It continues to have a significant national impact and would be important for the State Council to review (on line). RE choices above, Safety/Abuse Prevention also is a priority! |
| 511 | Individual advocacy my local SCDD office provides is important to me. |
| 512 | They can continue to offer individual-advocacy to individualizes with developmental disabilities. |
| 513 | not all disabilities are big and obvious |
| 514 | People with disabilities are on the earth for a reason. They teach us more about life than were teaching them. The community needs to have |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | more awareness and understanding of people with disabilities. If everyone gets along better it will make life easier for everyone. I just want people with disabilities to be accepted in the community. |
| 516 | In the past I have needed and provided 'child care' for families who work. There is nothing out there. How about affordable day care at county education buildings & day programs. |
| 517 | see above. |
| 518 | That people with disabilities should be able to get all the support and services they need. |
| 519 | The way things are right now you wait forever for a response from the regional center because of either unanswered emails and phone calls or some committee hasn't made the decision yet. |
| 520 | Service providers give a lot of supports to individuals but the lack of sustainable salaries makes employment sketchy. |
| 521 | eratqwtwr |
| 522 | no |
| 523 | Ensuring a person has had the resent appropriate services, goals that map to outcomes for adulthood. Then to make transition more clear - with opportunities, resources, specific steps and next steps. The transition is cumbersome, vague, resources for needs are limited in recreation. |
| 524 | Have more community involvement |
| 525 | please us state funds to invest in property that could become models for integration of regular families and both families and individuals with disabilities. make them co-ops once they are established and allow people to make an investment in their own lives. require a sale to another family with similar needs when they move, limit amount of profit gained from sale to keep prices low and reasonable. |
| 526 | Shutting down self contained programs is a huge mistake. Until recently my wife worked at a self contained early intervention program, AIM, which has had to close. The clients of these programs are left without options or isolated with in home services. Now we fear this will happen with our sons program at Hope Services. |
| 527 | Financial stress on our family is significant. The schools seem to always take the cheap way out and offer the least possible help. Our doctors say our child needs a much higher level of support. We feel caught in a real bind. |
| 528 | Many are not getting the services they need and told because of cut backs. Many want to change service coordinators and are not able to, even when they call the supervision. They feel that their hands are tired and many feel frustrated. |
| 529 | we need more disabled housing in this community. it all seems to be senior housing or too scary for disabled people to live in. We finally received ALTA for my 43 year old sister in law last year after I fought for it for a few years. She was turned down as a child and again before 18. There are so many disabled people with no advocates and they get next to nothing for services. If it wasn't for me and my family, my sister in law would be homeless. |
| 530 | I would like the State Council to know that even if we are labeled as "different" we stand and speak with one voice. |
| 531 | The new name for the local offices is very confusing-----please simplify. |
| 532 | Thank you for ILS support groups. They have allowed me thrive as an individual with their support and guidance. |
| 533 | For the SCDD to continue providing grants for our local agencies. |

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| 534 | Would like teachers who are in the general educational environment receive more trainings on how to work with special needs children at all grade levels. Sometimes they come across as though their doing parents a favor, not like their in the teaching environment to help all children. |
| 535 | nothing |
| 536 | I do not understand why a child who has a chromosomal disorder with physical therapy needs similar to a child with Cerebral Palsy but does not qualify for California Children's Services. Eligibility should be based on functional levels and medical co-morbidities not just one diagnosis. |
| 537 | Better systems. It's not helping people. |
| 538 | That its hard to even think about working when my mom lives in our home and is considered a fall risk and my son is autistic and yet the hours i get to take care of my mom and the fight i have been dealing with to get my son SSI are not only stressful but they are needed in able for my family to live, they make the process so hard. |
| 539 | PLEASE focus some of your energies on less populated areas... I am one parent who has gone to SAC and sought training over the span of my childs school life. But all other parents were clueless as to what they should expect. Being in South Lake Tahoe the professionals in Sac never came here. WE get no attention.... we have valuable people here but little for them. Please Help. Regional Center offers no training to parents either. we are all expected figure it out ourselves... |
| 540 | That providing the cost of activities swim lessons, camps, tickets to museums to better support these kids with stable, structured life to bring out the best earlier intervention for healthier eating and support with functional preventative health care. |
| 541 | Our family has been incredibly lucky in many ways. Finding good programs as they were getting started, and getting our son into them. My husband's background in psychotherapy services helped him "speak the language" and advocate successfully for our son. And my work in finance helped us find funding when it's been needed. Most families don't get that lucky, and don't have the background or the personal resources they need to be effective advocates. We need to work on connecting new families with people who've been in the game for a while and can help. |
| 542 | Parents are afraid to share what resources their child is receiving for fear that there is not enough to go around. This seemed to happen with all the budget cuts a few years ago. There is no forum to really find out what Tri counties will cover and what I should be asking of them. It seems like all they want to do is continue to cut services and have no suggestions for problems. |
| 543 | There is a whole lot of money in disabilities. Follow the money. As an example, Rick Ingram of DDS is married to Jane Howard, the owner of a Regional Center vendor. This is a clear conflict of interest. Follow the money. |
| 544 | I am very concerned about my son with Autism being left to this system when my husband and I are too old or deceased. He thrives only because his parents are involved at every step and willing to fight agencies and providers for oversight and proper services. We utilize private insurance for the appropriate therapies. We are very worried about the harm that will come to our son when we are gone even provided there is a trust for him. We are highly concerned it will be misused by the system and that our son will not receive a dignified or appropriate life by way of care. |
| 545 | Protection for our children with their rights to co exist with the community and protection of parents like me who is committed lifetime to help, support and advocate for their best interest. . |
| 546 | Gone for Good is a great program that doesnt get enough funding or recognition |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 547 | I think California does a better job than most states with their programs but there is always room for improvement. |
| 548 | We need to work with our legislators to rebuild our DD system. |
| 549 | They were great before. Why did you make the changes. |
| 550 | Many good things are happening, but there are also many events of people with good intentions being beaten down by a large, unwieldy, complex system. Perhaps highlight some of the success stories while supporting people to work through the situations that are not working. |
| 551 | My fear along with many of my colleagues is that with the new regulations many people will no longer have meaningful employment. I fear that we will see a lot of people who currently work or go to Vocational training programs such as Supported Employment Groups not having that option due to Vendors closing their doors. Leaving people at home or day programs. |
| 552 | The arbitrary nature of hour limits on services or differences between regional centers (one covers a training or service while the other does not) seems unfair. |
| 553 | I think the local Regional Advisory Councils are very important and have a good pulse on the needs of the community. I think there is power in their partnering with Regional Center and other agencies with similar focus. I would like to see the Regional Advisory Councils have a strong voice in selecting membership. I further feel the Legislative Advocacy work of this group has a tremendously successful impact in awareness of the State Council through their work with local legislators and their visits to their offices; I would hate to see this relationship stop. |
| 554 | It helps so much to have companies like Goodwill helping mentally disable people get jobs. |
| 555 | To remember that the lives of folks with DD, just like those of us who don't have disabilities at the moment, are made happy and positive in many individual ways. Health, safety, food and shelter are important but it is often how well support people listen and implement programs which makes life worth living or not for our folks. Stable financial resources and respectful working conditions will really help our system of DD Supports work for all people. |
| 556 | End of life issues for aging clients |
| 557 | That I want to be on the board. |
| 558 | There are many people who might consider jobs in this sector, but with such low wages they are unable to do so or cannot stay in these roles long. |
| 559 | Can't wait for Self-Determination to take effect. Hopefully will be able to help child progress. |
| 560 | Not only are the people we serve are affected, so are the providers, direct care staff, and regional center staff. We are not able to staff the positions so projects are always delayed. We are having a hard time just keeping up. |
| 561 | You people are our 'union' and you need better marketing. Tell us what you do. Ask us what WE do and how you can help. Keep asking us. And ask our kids. Represent. |
| 562 | How wonderful it is and how much the individuals teach us in our everyday life and how they make me realize, how important and lucky each and everyone of us are to work as a whole. |
| 563 | We love our kids, but we are tired - tired of limited services, tired of always having to fight for every last crumb from every siloed agency with which we interact. |
| 564 | Do not delay! This issue must be addressed today. These young people are already in the system - we know who they are and what their |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | needs are from the regional centers and the schools. It is incredibly irresponsible to only shut down the (bad) previous options of institutionalization without creating viable alternatives for those who need help. |
| 565 | That actions, implementations of programs, etc. means more than sending a survey. Hope you'll walk the walk! |
| 566 | Sooner or later the community is going to have to take care of our adult children with disabilities, when the family members who are doing it are deceased. It would be better for everyone if you start now. Otherwise our children will be sick, hungry and homeless and someone else will have to do it for them. |
| 567 | See 3, 4 & 5. It would be great as a parent to not always feel like I'm re-inventing the wheel when it comes to my daughter's health care, work, inclusion. Thanks for "listening". |
| 568 | THE NEEDS OF THE AUTISTIC POPULATION DIFFERS FROM ANY OTHER DD DEMOGRAPHIC IN TERMS OF BEHAVIORAL SUPPORTS AND HOUSING. THE MODELS OF HOUSING AND SUPPORTS THAT WAS DEVELOPED AROUND A POPULATION HEAVILY WEIGHTED TOWARDS INTELLECTUAL DISABILITY IS NOT ADEQUATELY SERVING THE AUTISTIC COMMUNITY. NEW MODELS NEED TO BE DEVELOPED AND FUNDED WHICH REALISTICALLY ASSESS AND SERVE THOSE WITH AUTISM. |
| 569 | Training for children and family services about disabilities is needed. Many cases of abuse go unsubstantiated due to lack of sufficient assessment ("not a good witness") or lack of sufficient placement. |
| 570 | nothing at this time. |
| 571 | The Abuse Reporting rules need to be reviewed. Service Providers are inundating police departments and the Ombudsman office with meaningless reporting. It is diluting the REAL abuse reporting. |
| 572 | Recreation program on the weekend for people with disabilities. |
| 573 | That getting services from RC has been a battle, ever since my son was diagnosed. |
| 574 | It's really scary not knowing the future for my son. Please don't neglect this group of population. Please don't take advantage of them since they can't say for themselves. Please support them. |
| 575 | jobs |
| 576 | Homeless People with Developmental Disabilities is very bad on every level. No one can be for it. Use every influence on the DOJ, HUD, courts, legislatures and municipalities to lay out the extreme costs of neglecting guarantees and subsidies sufficient to assure adequate housing for people with intellectual/developmental disabilities. |
| 577 | The regional center system is flawed and broken. The basic organizational design makes them not accountable. Until they are accountable nothing is going to change |
| 578 | I had not heard of the State Council. Inform the public of the function of the State Council and how to get involved in making a difference. |
| 579 | I think at the middle school and high school level there is a real lack of peer inclusion and education on the value of inter-connectedness for the disabled. Social Capital is something to spend time on so that services don't over take community building. |
| 580 | It would be beneficial for all to know the needs of the Regional Centers, in terms of future Program Development. As a Service Provider, many of us have the expertise to facilitate others, or our own agencies, in the expansion of services. Unfortunately, there is no current EFFECTIVE mechanism in place. Regional Centers need to be inclusive and use the resources at their fingertips! |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 581 | Work with the various groups to get a real look at how desperately changes r needed |
| 582 | So much come back to the proper training of all involved. Theory is great, but so few actually know how to work effectively with this population, to help them move forward. It feels like they are just being babysat!!! Don't get me wrong. I do appreciate all the help that I have received, I'm just frustrated. Thank you for listening. |
| 583 | All the services provided are much appreciated. It greatly helps the other family members pursue normal life activities which they might otherwise be unable to do so. Jobs, School, Education, etc |
| 584 | Figure out how to streamline. Combine the parts of the puzzle that make sense. Build a website with a strong user interface. |
| 585 | Answer the elephant in the room question: Who is responsible for housing the RC defined DD adult who has no chance at earning a meaningful income. The parent or the State? If it is the State, then announce that the state has not lived up to its obligation, at the expense of the DD adult and family. |
| 586 | Am very concerned about the lack of services for adolescents with extreme behavioral needs. It seems that the entire system is dependent on families continuing to care for their adult children. If that is the case, then more services should be provided in the home, including extensive behavioral support staff who come and stay there up to several times weekly, if deemed necessary. provide support for groups of families who are trying to brainstorm solutions to the housing crisis and to the adolescence and behavioral crises. |
| 587 | The State Council has done nothing at all to point out the elephant in the room -- the state's soaring DDS autism population, a group that is intensively disabled and will require lifelong care in tailored settings and with highly trained staff. There are now about 5,000 DDS autism births per year in the state, and soon autism will be half the DDS caseload. What has the State Council in the face of this massive public health disaster, one that will require billions of dollars annually to provide the additional programs, housing and staff that will be needed? Nothing. |
| 588 | Thanks for the services. |
| 589 | Services for elderly and the unanticipated needs of increasing dementias require stability and consistency in their circle of supports. This will always be a barrier with current rates and the expectation that DAP will provide 7+ hours of service and supports within a 5 hour program design. |
| 590 | Need does not end at 22 |
| 591 | Utilize more social media to make CSCD more accessible to all families. |
| 592 | Increase the pay scale of respite care givers who are personally hired by clients through Premiere care |
| 593 | I know that budgetary restraints are involved in providing a full range of program options for individuals with intellectual/developmental disabilities. I also know that when our state legislator tried to cut budgets for our VI children's programs, we communicated with our CAPVI/NAPVI parents in the Northern California/Sacramento area about the problem and they showed up on the States Capitol lawn with their children on the day of the vote. We also contacted local news outlets about the problem. Guess what? They did not cut the budget for VI programs. |
| 594 | As a parent of two disable kids we struggle for Medical to cover prescription meds prescribe by their Psychiatrist to help them sleep and calm them down for them to focus at school.TAR send my Docs to the Insurance but still denied.Very stressful for the parent |
| 595 | Tough battle. Teachers need your help. Remember it la not about money. It's about our future. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 596 | Develop a clear vision for where SCDD can make a positive impact. Dont try to take on too many different goals. Focus |
| 597 | People with developmental disabilities need more opportunities to be part of school "life" and community "life". It is really sad to see so many youth sidelined, eating lunch alone, sitting alone, not included socially. I would like to see a "quality of life" measure checking out how "happy and fulfilled" are the students? |
| 598 | Please add more staff to advocate. |
| 599 | Students with disabilities need innovative work experiences. Being a bagger, custodian, etc is important and appropriate for many of our guys. If funding were increased for service providers like OT to engage in habilitative supports like above, individuals may be far less dependent on state services. |
| 600 | we appreciate all the help that you have given our community. With IEPs and IPPs, it has been a huge help |
| 601 | How to know how to budget so we could save money to go to confrences and spend the night at the hotel for lots of meetings like state ride go to choices for one day. |
| 602 | As a Licensed Marriage and Family Therapist with a successful private practice in Costa Mesa, I would like to see better access to quality outpatient mental health services by psychotherapists who are well-trained in working with the developmentally disabled adult population in Orange County, as many have co-morbid diagnoses. |
| 603 | Nothing |
| 604 | N/A |
| 605 | These individuals have a lot to contribute to our society, support them! |
| 606 | There is a very concerning lack of research that identifies the most efficient and effective strategies for training young adults with DD and ID. I would like to see more grant money allocated for adult-specific treatments and supports, so service providers can be more effective in creating sustainable growth and change with their clients. |
| 607 | I would like the education of parents of people with this disability to be more informed of available services in each community. I would also like more funding for accessible transport an housing that should also be affordable. |
| 608 | The recent changes to the Area Boards is appalling. The idea that Area Boards can no longer provide advocacy services to people with developmental disabilities, and shifting the burden to Disability Rights California is irresponsible. DRC will not take individual advocacy case. I believe the State Council failed. |
| 609 | Everyone that works with this community should be trained how to do it right. Services should not be based on color of skin. Get people off of the streets and into homes. |
| 610 | I could try to talk to legislators about the plight of the intellectual/developmental disabled community. |
| 611 | Thank you for all you do. |
| 612 | I have Huntingtons disease |
| 613 | Not only is it the right thing to do, but by funding programs that lead to employment and independent living for people with disabilities the government saves money in the long run because the result is less people relying on the government for their long term care |
| 614 | I would like the State Council to "listen," not just hear people with disabilities. And I request that the State Council "consider" our viewpoint(s). |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 615 | Employment assistance is one of those areas where friends/family have relatively limited ability to help the client. |
| 616 | Approach local governments to help community members aware of service for individuals with disabilities |
| 617 | Your doing wonderful work I know its very hard. |
| 618 | Working to solidify integrated (non-segregated) k-12 education environments, greater access to accommodations on college campuses, equal pay for equal work in employment and securing accommodations for everyone to cast a private ballot in elections are the keys to sustainable independence. These help all other issues succeed as well. |
| 619 | People with disabilities need the support of the State Council to help open as many doors as possible, to be as successful as the person standing next to them. We must support one another. |
| 620 | employees who provide support/assistance should be required to take yearly ongoing courses. Housing is a huge need. Successful community integration with friendship network building is needed. |
| 621 | I would like to see "green" eco friendly housing projects built with low cost building material. Straw hay bale homes can be built rapidly and extremely inexpensively. They are extremely energy efficient and last forever. People with disabilities can participate in the design and construction of their own homes. Universities can compete to build energy efficient homes on state owned land to demonstrate to the public, how to build the homes of the future. Persons with disabilities can help educate the public on energy efficient home building that is good for everyone. |
| 622 | Please research TERI in Oceanside, CA. See why it is so successful and how they can be used as a model for other group living situations throughout the state. They are doing many things right and client satisfaction and quality of life is very high there. You are important! |
| 623 | The Regional Center has been a huge help to us for years. To have the same caseworker for our daughter for more than 10 years has made all the difference to her and to us. This is truly valuable. Also, the oversight and assistance of the Area Board representative. I think even more could be done if the caseworkers had more time with each client. Make sure the number of caseworkers is kept high enough to handle all the cases and do it well. Money put into assisting the intellectually/developmentally disabled is money well spent. It's not a luxury for our communities but a necessity. Thank you. |
| 624 | We live in a great area but...we are away from the city and all the opportunities for a wider range of opportunities for work and socializing away from program. |
| 625 | What I would like to see is some sort of longer term respite so my family could take a vacation, or travel to a family event, once a year. |
| 626 | Getting respite workers is difficult at best, especially if you have an adult child with behaviors. We appreciate you and your work! |
| 627 | More money for services. |
| 628 | It is challenging enough to raise a "typical" child in today's society; but when you add the layer of a developmental/intellectual disability, it makes managing a happy, healthy family nearly impossible. Help these families, with support that will foster healthy families, as well as competent children and adults in the long run. |
| 629 | The quality of interactive training for staff in service delivery needs to be greatly improved. Last year, changes were made in that direction for residential care for the elderly. The same needs to happen for the disabled. Too much of the funds are going into the wrong pockets of |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | hospital CEOs while funds are not being allocated for residential care itself. |
| 630 | Could provide more information to conservators, especially conservators of older clients, it would be good if they would get more involved in advocacy. How to support the State Council to advocate for more public transportation on the weekends, especially Sundays. |
| 631 | Keep up the great work! |
| 632 | As the sister of a DD person it does not seem fair that my family is now responsible to care for my brother. We get only 12 Respite hours per MONTH. My dad was a veteran of 3 wars and now I can't work because I have to care for my brother. We need more help. |
| 633 | Service Coordinators often spend less than 10 minutes with the clients at quarterly meetings and often are rude toward RSPs. Service Coordinators often do not know the difference between a 4A client and a 4I client. They often mislead services a client needs for placement then make threats if the RSP doesn't take the client. Some negotiated rate homes are not being utilized for the most difficult clients and could be moved to lower level of care thereby providing available beds for those in need. |
| 634 | DDS needs to eliminate/revise the Annual Program Fee and the Parental Fee Programs. The CA State Auditor reviewed the Parental Fee Program and issued it's report on January. The filings were appalling to say the least. https://www.auditor.ca.gov/pdfs/reports/2014-118.pdf Assemblymember Eggman (Stockton) will be submitting legislation to change the Parental Fee Program based on the auditor's findings. |
| 635 | I don't know that I trust SCDD to actually become effective in the field of Developmental Disabilities- from my view- I don't see SCDD "at the table" with the mover and shakers- that needs to change. The area boards were effective tools to keep the communities engaged across the state- I hope that doesn't end. |
| 636 | Providing training programs for those with learning disabilities that do not qualify for State funded programs or Disability. I find that to be a challenge for many who have teens or adults with slower learning abilities but do not qualify for programs. |
| 637 | Our district has made huge strides in early intervention as far as life skills and job training, we are not there yet but I must say every year we get closer and closer to what our students need. More financial support would always be beneficial to our students who are needing services such as paid internships, job training, and even bus passes. |
| 638 | Providing the money to help special needs children and families should be a priority |
| 639 | Please help develop some other housing choices. The plan in Poway needs to move faster. The young adults need to find homes before their parents get to old to take care of them and their placement becomes an emergency. |
| 640 | Politicians do not understand what the local regional offices mean and what responsibilities the Regional Centers are completely ignoring. |
| 641 | Please don't cut respite hours ! |
| 642 | Taking the family out of the equation will only aggravate the current problem. A functioning family is key to success. My son has been very successful but, it took a village! |
| 643 | Is there a way to combine technology and independent skills were a game can be created to teach the skills that young adults need. They would be learning while having fun. |
| 644 | I have two special needs children at home and have fostered for 13 years. I have fought for services and especially early intervention and respite care for my children birth and foster. My Autistic son would not be high functioning if it wasn't for early intervention service, and I would be stressed if I didn't have respite. Parents need time away to relax and exhale. |
| 645 | You are fabulous and appreciated! |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| 646 | People with disabilities aren't a list cause. They just need more time and help to reach their full potential. |
| 647 | The Kern Regional Center doesn't seem to be run very well. I know that the local staff is not to blame. Last summer my son was denied a summer program that he has always participated in, the reason KRC stated that it was denied was "they don't pay for child care" the program was never called child care and it is paid for all year long. When I requested the appeal packet it was given to me in the wrong order, if I wouldn't have read through it carefully I would have submitted the page that says I don't want to file an appeal. The documents were also mostly illegible. They were copies of copies of copies that were very old. These are legal documents that are given out in a manner to confuse the parents. We won the appeal but are now being put through the wringer for services this coming summer. Why is it ok to do this to the children who are in need of help? |
| 648 | We appreciate all that our family has received! We hope this type of service to our most needy and deserving individuals and their families can be a priority in California going forward! |
| 649 | Many parents with special needs children are single parents. I am a mom and have had to quit my job to care for my disabled and now medically fragile child. How do I ensure that services won't be taken? My child cannot be left alone and it is not an option to have the state care for her. How do we live outside the poverty level? I fight for everything she gets, yet she deserves so much more. I deserve more; the option to return to work is not feasible, for my child to get the care she needs. |
| 650 | Listen to the clients more |
| 651 | Individuals with intellectual/developmental disabilities thrive on routine. The biggest disruptor in our daughter's life is when there are changes in the staff in her adult day program. There is high turnover in these positions--it is a difficult job but so very important to the people that they serve. We advocate for fair wages, continuing education and benefits for staff with direct interaction with the disabled consumers. Please restore funds that have caused cuts to day programs, IHHS, respite and transportation workers. They serve a very underserved population and our society and our state should support them adequate funding for these programs. |
| 652 | I appreciate all of your initiatives and interest in helping us with services and knowledge that is so needed. |
| 653 | Reduce the amount of money given to illegals in this state so you can better service the citizens that need assistance - those who have a legal right to be helped. |
| 654 | We are grateful to the California taxpayers for their generosity |
| 655 | People with disabilities are people, they need to keep or get more health benefits, The people that come to my Day program really enjoy them self's while they are there. We do physical therapy with them, and do all daily living activities. They really love to be integrated in to our community, buy going to parks, shopping, and just socializing with community member's. To be able to do all the things they enjoy they need to have funding for Day Programs. |
| 656 | I would like San Diego Regional Center to be accountable for giving people information out right, stop hiding services, put all information on their web site calendars, which the calendars are now empty. |
| 657 | With high turn over of Regional Center Staff and direct care staff, there is a shallow understanding of what self-advocacy is, and how professional can better support clients to be effective self-advocates. |
| 658 | local offices are the best resources for knowing what communities need - |
| 659 | Employment for persons with developmental disabilities (DD) should be meaningful and provide a living wage. Wouldn't it be wonderful if people with DD could be earning comparable wages as their coworkers. A recent program on the news spoke to an advocate in Connecticut |

Survey Monkey Results

Question 6: What else would you like the Council to know?

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| | (who found a way to have the movie theater in town be operated by persons with developmental and other disabilities). What this person said is people with disabilities need less trips to the park and other outings and more meaningful jobs. |
| 660 | Please restore cuts to Supported Employment Agencies and continue to keep this topic on the forefront. |
| 661 | great folks to work with on difficult issues. |
| 662 | Are large health and social service institutions the best providers of services? |
| 663 | Develop media relations and stand up to regional centers and the state whilst incorporating self-advocates in the day-to-day duties and processes of the state council. |
| 664 | when you do a tailored day program thru regional center, there is no support on how to set it up or any funds to purchase needed items for the program. |
| 665 | Thank you for all the efforts you have made for folks with disabilities. |
| 666 | Social Security office in Ukiah CA is not user friendly to the disabled. Long phone waits, no live person to interact with. staff not disability friendly, really a bad experience. One size does not fit all, not all folks can live safely independently and need licensed care to protect them. Not all funds should go to self determination but some to small homes that provide family setting. Many have nursing needs and with the wrong care or in home support folks who lack training it can mean hospitalization and death. Not all fish swim in same direction, there needs to be a continuum of care that meets the variety of care needed. Small homes, mentor homes, independent living. |
| 667 | Don't really know |
| 668 | Areas if advocacy that independent living centers can engage in to better support these populations of California residents. |

Survey Monkey Results

Question 6: What else would you like the Council to know?

