Area Board 9 on Developmental Disabilities Board Meeting *Revised* Agenda

Posted at: http://www.scdd.ca.gov/calendar9.htm

Date: April 5, 2013

Time: 9:15 am to 1:15 pm*
*(ending time for this meeting is an estimate)

Where: Tri-Counties Regional Center
Santa Barbara Annex
505 East Montecito Street
Santa Barbara, CA 93103-3274
(805) 962-7881

You are welcome to attend our board meeting by videoconference. In order to do so, you must contact our office by **5:00 pm on Thursday, March 28th** so we can reserve your seat at the videoconference location.

***Videoconference locations by RSVP only*:**
Tri-Counties Regional Center
Atascadero
El Morro Room
7305 Morro Road, Suite 101
Atascadero, CA 93422
(805) 461-7402

Tri-Counties Regional Center
1900 E. Los Angeles Ave., 2nd Floor
Simi Valley, CA 93065
(805) 522-8030

According to Government Code Section 11123.1 and 11125(f), individuals with disabilities who need accessible alternative formats of the agenda and meeting materials and/or auxiliary aids/services to participate in the Area Board 9 general board meeting, should call Mallory Gonzales at (805) 648-0220 or send her an e-mail at: mallory.gonzales@scdd.ca.gov at least five (5) days before to the meeting.

Note: Breaks will be taken as needed. Agenda items may be taken out of order to meet the needs of board members and the public as necessary. Action may be taken under any agenda item.

A

1. Call to Order

Action Ted Martens
Welcome & Introductions
Plain Language Guide, Roberts Rules & People First Language

B

2. Approval of Meeting Minutes

Action Ted Martens

3. Public Comment on Matters not on the Agenda

Information Public

This section is for members of the public only; and is to provide the public an opportunity to comment and/or present information to the board on any matter that is not on the agenda. Each public member will be given up to five (5) minutes to speak (unless, otherwise allowed by the Chairperson). Written requests, if any, will be considered first under this section. Additionally, the board will provide a public comment period not to exceed 5 minutes total for all public comments prior to board action on each agenda item.

4. Reports from staff and/or standing committees

B

02/01/2013 Action Items	Anastasia Bacigalupo
Advocacy & Outreach	Carol Lopes
Legislative Advocacy Committee	Chairperson
Grant Committee	Ruth Vasconcellos

C

5. Report on the California State Budget

Discussion Board Members and Area Board Staff

C

6. Report on Legislation

Discussion Board Members and Area Board Staff

E

7. Report on the DDS

Discussion Board Members and Area Board Staff

E

8. Report on the Tri-Counties Regional Center
Discussion Board Members and Area Board Staff

G

9. Report on the State Council
Discussion Board Members and Area Board Staff

H

10. New Business:
Presentation: *Changes to the Diagnostic and Statistical Manual of Mental Disorders*

11. Announcements
Discussion Board Members and Area Board Staff

12. Agenda Items for Future Meetings
Discussion Board Members and Area Board Staff

13. Area Board 9 Board Member Business
Discussion Board Members and Area Board Staff

14. Adjournment
Action Ted Martens

For more information about the next meeting or anything else about Area Board 9, please give us a call at 805-648-0220. We look forward to hearing from you. Thanks for joining us today.

Area Board 9 on Developmental Disabilities
April 5, 2013 Board Meeting

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What Changes to the DSM Could Mean (article) — H

TAB A

Plain Language Guide

Area Board 9's Plain Language Guide

Plain language is plain and simple. Using plain language avoids creating barriers that set us apart from the people with whom we are communicating.

When speaking to a person or group, it is important to:

- Know your audience,
- Adapt to their needs and abilities, and
- Make your point as clearly as you can.

Complex Language	Plain Language
Passive sentences	Active sentences
Long paragraphs	Short paragraphs
Poly-syllable words	Mono or bi-syllable
Clinical language	Colloquial language
Past/mixed tense	Present tense
3rd person (they, s/he)	2nd or 1st person (you, I)

Language/Word Choice:

- No jargon or technical language.
- Use lay terms about concepts.
- If you have to use a word that is technical or complex, define the word and explain why you are using it instead of a simpler word.
- No abbreviations or acronyms unless it is commonly used by your audience.

How to Change a Sentence to Be Plain Language:

"We are disseminating the information on an annual basis."

Plain Language Version:

We are giving out the information once a year.

"The regional center terminated their contract with the vendor because they were out of compliance with their contract."

Plain Language Version:

The regional center ended its agreement with the business because they did not follow the agreement they had with the regional center.

Robert's Rules of Order Cheat Sheet

Using Robert's Rules makes our meetings run smoothly and helps make sure that we cover all the necessary items on the agenda. The rules are not that complicated, but it does help to know the basics, and how to make and handle motions according to the Rules.

Standard Order of Business According to Robert's Rules

An easy way to remember Robert's Rules' is with the mnemonic 3R-SUN — which you can see in the following list. This list is a quick reference to make it easy for you to set up a basic agenda for your meeting quickly and without much fuss.

1. **R**eading and Approval of the Minutes
2. **R**eports of Officers, Boards, and Standing Committees
3. **R**eports of Special (Select or Ad Hoc) Committees
4. **S**pecial Orders
5. **U**nfinished Business and General Orders
6. **N**ew Business

Robert's Rules: Participating in Meetings as a Member

The most important thing about participating in a meeting is knowing how to get the attention of your chairperson so you can be allowed to speak.

Addressing the Chairperson

In meetings, your chair should be addressed by a title, such as "Chairperson." Robert's Rules provides that a title should be used as defined in the *bylaws,* or the rules of order.

Speaking through the Chairperson

When addressing another member, you never go wrong by speaking through the chairperson. Refrain from using the member's name if you can avoid it. Although it may seem weird, it is more respectful to not use the member's name.

For example, "Chairperson, does the member who just spoke have information on the cost of his proposal?" works much better than, "Dang it Fred, have you thought about how much your stupid idea is gonna cost us?"

Robert's Rules of Order Cheat Sheet (continued)

Waiting for the Attention of the Chairperson Before Speaking

Before you start speaking, make sure that you have the attention of the chairperson and the chairperson has said that you can speak. When you and your fellow members get the chairperson's attention correctly and don't speak until the chairperson has given you the 'okay' to speak, you allow the chairperson to do their job. A chairperson who understands these rules and applies them correctly is able to run the meeting more smoothly.

Making and Handling Motions According to Robert's Rules

When that light bulb goes off in your head and you have a great idea, you make a motion according to Robert's Rules to get your idea talked about and a decision made by the group. The following are the important steps from start to finish to make a motion and get the group to decide whether it agrees. Each step is an important part of the process.

Steps	What to Say
1. The member gets the attention of the chairperson.	"Chairperson. . . ."
2. The chairperson recognizes the member.	"The chairperson recognizes Mr. Barak Obama."
3. The member makes a motion.	"I move to send the Area Board staff on an all expenses paid trip to Tahiti."
4. Another member seconds the motion.	"Second."
5. The chairperson repeats the motion.	"It is moved and seconded that we send the Area Board staff on an all expenses paid trip to Tahiti. Are you ready for the discussion?"
6. The members discuss (or talk about) the motion.	"The chairperson recognizes Mr. Obama to speak to about his motion. . . ."
7. The chairperson asks the members to vote and the members vote.	"All those in favor of adopting the motion to send the Area Board staff on an all expenses paid trip to Tahiti please will say 'aye,' [pause] those opposed will say 'no'."
8. The chairperson says the result of the vote.	"The ayes have it and the motion carries, and we will send the Area Board staff on an all expenses paid trip to Tahiti."

People First Language

What do you call a person with a disability? *A person.*

What words define who you are? The color of your skin or hair? Your age? Your weight? Of course not.

When words alone define a person, the result is a label—a label that often reinforces barriers created by negative and stereotypical attitudes. Every individual deserves to be treated with dignity and respect—regardless of gender, ethnicity, religion, sexual orientation, hair color, or anything else.

People First Language

People First Language is an objective and respectful way to speak about people with disabilities by emphasizing the person first, rather than the disability. It acknowledges what a person *has*, and recognizes that a person *is not* the disability. In putting the person before the disability, People First Language highlights a person's value, individuality and capabilities.

What should you say?

When referring to individuals with disabilities, be considerate when choosing your words. Focus on the person—and never use terms that label, generalize, stereotype, devalue or discriminate. Unless it is relevant to the conversation, you don't even need to refer to or mention the disability.

The following chart has some examples of People First Language.

Say This	Not This
people with disabilities	the handicapped, the disabled
people without disabilities	normal, healthy, whole or typical people
person who has a congenital disability	person with a birth defect
person who has (or has been diagnosed with)...	person afflicted with, suffers from, a victim of...
person who has Down syndrome	Downs person, mongoloid, mongol
person who has (or has been diagnosed with) autism	the autistic
person with quadriplegia, person with paraplegia, person diagnosed with a physical disability	a quadriplegic, a paraplegic
person with a physical disability	a cripple
person of short stature, little person	a dwarf, a midget
person who is unable to speak, person who uses a communication device	dumb, mute
people who are blind, person who is visually impaired	the blind
person with a learning disability	learning disabled
person diagnosed with a mental health condition	crazy, insane, psycho, mentally ill, emotionally disturbed, demented
person diagnosed with a cognitive disability or with an intellectual and developmental disability	mentally retarded, retarded, slow, idiot, moron
student who receives special education services	special ed student, special education student
person who uses a wheelchair or a mobility chair	confined to a wheelchair; wheelchair bound
accessible parking, bathrooms, etc.	handicapped parking, bathrooms, etc.

TEXAS COUNCIL *for* DEVELOPMENTAL DISABILITIES

6201 East Oltorf, Suite 600 • Austin, TX 78741
1.800.262.0334 • 512.437.5432 • www.txddc.state.tx.us

December 2011

Idioma de las Personas Primero

¿Cómo se le llama a una persona con una discapacidad? *Una persona.*

¿Cuáles son las palabras que lo definen a usted cómo es? ¿El color de su piel o de su cabello? ¿Su edad? ¿Su peso? Claro que no.

Cuando sólo se usan palabras para definir a una persona, el resultado es una etiqueta (una etiqueta refuerza las barreas que se crean por actitudes negativas y estereotípicas). Cada individuo merece ser tratado con dignidad y respecto, sin importar su sexo, origen étnico, religión, orientación sexual, color de su cabello, o ninguna otra cosa.

Idioma de las Personas Primero

El Idioma de las Personas Primero es una forma objetiva y respetuosa de hablar acerca de las personas con discapacidades al hacer énfasis en la persona primero, en vez de su discapacidad. Reconoce lo que la persona tiene, y reconoce que una persona no es la discapacidad. Al poner a la persona antes de la discapacidad, el Idioma de las Personas Primero destaca el valor, la individualidad y las capacidades de una persona.

¿Qué debe decir?

Cuando se dirige a individuos con discapacidades sea cuidadoso con las palabras que selecciona. Enfóquese en la persona (y nunca use palabras que etiquetan, generalizan, encasillan o discriminan). No necesita hacer referencia o mencionar la discapacidad, salvo que sea relevante para la conversación.

La siguiente tabla muestra algunos ejemplos del Idioma de las Personas Primero.

Diga esto	No esto
personas con discapacidades	los discapacitados, los inválidos
personas sin discapacidades	personas normales, sanas, enteras o típicas
personas que tienen una discapacidad congénita	personas con un defecto de nacimiento
persona que tiene (o ha sido diagnosticada con)...	persona aquejada con, sufre de, una víctima de...
persona que tiene síndrome de Down	persona Down, mongólico
persona que tiene (o ha sido diagnosticada con) autismo	el autista
persona con tetraplejia, persona con paraplejia, persona diagnosticada con una discapacidad física	una tetrapléjico, un parapléjico
persona con una discapacidad física	un tullido
persona de estatura corta, persona pequeña	un enano
persona incapaz de hablar, persona que usa un dispositivo de comunicación	tonto, mudo
personas que están ciegas, personas con problemas de la vista	los ciegos
persona con una discapacidad del aprendizaje	discapacitado en el aprendizaje
persona diagnosticada con una condición de salud mental	loco, psicópata, enfermo mental, trastornado emocional, demente
persona diagnosticada con una discapacidad cognitiva o con una discapacidad intelectual o en el desarrollo	retardado mental, retardado, lento, idiota, tarado
estudiante que recibe servicios educativos especiales	estudiante de educación especial, estudiante "special ed"
persona que usa una silla de ruedas o silla para la movilidad	limitado a una silla de ruedas, constreñido a una silla de ruedas
estacionamiento, servicios sanitarios accesibles, etc.	estacionamiento, servicios sanitarios accesibles, etc. para discapacitados

TEXAS COUNCIL *for* DEVELOPMENTAL DISABILITIES

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diciembre 2011

TAB B

Area Board 9 Board of Directors Meeting

MINUTES 02/01/2013 OXNARD, CA

MEETING CALLED BY	Chad Skopp
TYPE OF MEETING	Board of Directors Meeting
FACILITATOR	Chad Skopp
NOTE TAKER	Mallory Gonzales
TIMEKEEPER	Mallory Gonzales
ATTENDEES	Anastasia Bacigalupo, Carol Lopes, Mallory Gonzales, Allen Barbee, Chad Skopp, Kathy Speer, Ron Vasconcellos, Ruth Vasconcellos

Agenda Topics

CALL TO ORDER

CONCLUSIONS	Meeting called to order by Mr. Skopp at 9:37 AM.

APPROVAL OF MINUTES

DISCUSSION	Board previously received the minutes from the November 30th, 2012 meeting in board packet.
CONCLUSIONS	Mrs. Speer motioned to approve the minutes. Motion seconded by Mr. Barbee, approved by all

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

PUBLIC COMMENT ON MATTERS NOT ON THE AGENDA

DISCUSSION	Jim White (ARC) was recently appointed to the Transportation Committee and requested that community members who are trans-dependent voice their concerns and input at their annual Unmet Needs Meeting.
CONCLUSIONS	The board received the information presented and no actions were requested.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
Mrs. Lopes will follow up with People	Carol Lopes	04/05/2013

First/Self-Advocacy groups to make sure they are aware of the Transportation Committee meeting.		

REPORTS FROM BOARD MEMBERS, STAFF, AND/OR STANDING COMMITTEES

DISCUSSION	Mr. Barbee attended two People First meetings and wrote a letter regarding plain language that was submitted to the TCADD board members. Mr. Barbee's letter requested the use of everyday language instead of business language, including use large print. Ms. Crabaugh shared the TCRC website does have the ability to change font size. Mrs. Vasconcellos shared information on Access for All and their mission. They have planned three upcoming events: including an Abilities Fair in May, a movie showing in May, and the Paul Wolff award ceremony. Access for All has also submitted a proposal for an inclusive fitness center in San Luis Obispo. Mr. Skopp is on the Oak Park Planning Commission and would like to create inclusive activities in the Oak Park community. Update on Action Items: The Executive Committee previously requested some examples of People First language which has been provided in the board packet. The board discussed which example they would prefer to use and/or adapt in future board packets. Mrs. Lopes provided the board with and advocacy and community outreach report in the packet. Area Board 9 has committed to attending a self-advocacy group meeting per quarter. Legislative Advocacy Committee: Ms. Bacigalupo shared the Legislative Committee has adopted a mission statement and a legislative advocacy plan. Legislators are in the process of turning in proposed bills, and within the next two weeks it should be apparent which ones Area Board 9

	should focus on. The committee agreed to send out welcome letters to legislators in our catchment area. The next meeting is set for March 15, 2013. Grant Committee Report: Mrs. Vasconcellos provided an update on the current grants. Mr. and Mrs. Vasconcellos recently observed one of the awarded grantees, Arts for Living, in San Luis Obispo.
CONCLUSIONS	Mr. Vasconcellos motioned to adopt the third sample provided in the packet, with some adaptations. Motion seconded by Mr. Barbee, approved by all.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
Staff will begin to use the Texas Council on Developmental Disabilities handout in board packets.	Staff	04/05/13
Staff will develop an Area Board 9 version that combines the Texas version with other versions preferred by the community.	Staff	Ongoing.

REPORT ON THE CALIFORNIA STATE BUDGET

DISCUSSION	The board was provided with an overview of the state budget outlined by Disability Rights California.
CONCLUSIONS	The board received the information presented and no actions were requested.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

REPORT ON LEGISLATION

DISCUSSION	Legislators are in the process of submitting bill proposals. Area Board 9 will review the information after the deadline for the legislators and provide that to the Legislative Committee. Area Board 9 has been given approval to use Capitol Track, which was previously requested by the board.
CONCLUSIONS	The board received the information presented and no actions were requested.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

REPORT ON DDS

DISCUSSION	The board was provided with an outline of updates of the Department of Developmental Services. DDS will be proposing a bill regarding insurance co-pays reimbursed by the regional centers.	
CONCLUSIONS	The board received the information presented and no actions were requested.	
ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

REPORT ON TRI-COUNTIES REGIONAL CENTER

DISCUSSION	Ms. Crabaugh provided an update on TCRC.	
CONCLUSIONS	The board received the information presented and no actions were requested.	
ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

REPORT ON THE STATE COUNCIL

DISCUSSION	Mr. Aguilar, State Council member, shared information about State Council activities. AIDD recently visited State Council and interviewed HQ staff in order to get a perspective on operations. There was a prior monitoring visit in 2006 and some of the concerns that were followed up with on this visit dealt with how the Council interacts with area boards throughout the state, focusing on how activities are reported and if monies funded are spent appropriately. There was also discussion regarding the process of hiring a new Executive Director for the State Council. Mr. Aguilar reported that the overall tenure of the meeting was positive. He has requested that staff at State Council HQ post the previous monitoring reports on the website.

	Mr. Aguilar expressed the concerns regarding the timeline of appointments from the Governor's office. The communication and repore with the Governor's office has been positive. There is a teleconference scheduled with the appointments secretary from the Governor's office on February 8, 2013. Area Board 9 and 13 collaborated to approach issues regarding SB 946, the autism insurance bill. There will be a survey circulated before the panel on March 20th.
CONCLUSIONS	The board received the information presented and no actions were requested.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

NEW BUSINESS

DISCUSSION	Ms. Bacigalupo provided an update on the Strategic Plan. There are some goals that have expired or are set to expire soon. The current Strategic Plan is set to expire in October 2013. Ms. Bacigalupo proposed a strategic planning process that would enable the board to come together at the October 2013 board meeting to develop a new plan. The plan would include input from the community via surveys and align closely with the State Plan.
CONCLUSIONS	Mr. Vasconcellos motioned to accept that some goals in the Strategic plan be suspended. Motion seconded by Mrs. Vasconcellos, approved by all. Mr. Barbee motioned to adopt the 2013 Strategic Planning Process. Motion seconded by Mrs. Speer, approved by all.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

ANNOUNCEMENTS

DISCUSSION	Ms. Bacigalupo announced Mr. Barbee was reappointed to serve on Area Board 9 for a three-year term. Mr. and Mrs.

	Vasconcellos also were reappointed by the Board of Supervisors in San Luis Obispo. Ms. Bacigalupo recommended the board review applications for Nick Larkin (Ventura County), Andrea Vergne (Ventura County), and Gigi Senna (San Luis Obispo County).
CONCLUSIONS	Mrs. Vasconcellos motioned to approve the applications for Mr. Larkin and Mrs. Vergne. Mr. Vasconcellos seconded the motion, approved by all.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
Staff will submit Mr. Larkin's board application to the Board of Supervisors in Ventura County. Mrs. Vergne's application will be submitted to the Governor's office.	Staff	Ongoing.

AGENDA ITEMS FOR FUTURE MEETINGS

DISCUSSION	Mrs. Lopes requested that the Coalition of Healthy Relationships present at a future board meeting.
CONCLUSIONS	The board received the information presented and no actions were requested.

ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
None at this time.	N/A	N/A

ADJOURNMENT

CONCLUSIONS	Meeting adjourned at 12:50 PM by Mr. Skopp.

OBSERVERS	Richard Sochel, Caitlin Mackintosh, Natalie Martens, Cyndi McCauly, Pam Crabaugh, Michael Kaczycki, Jorge Aguilar, Colleen Duncan, Laurie Jordan, Jim White
RESOURCE PERSONS	Mallory Gonzales, Carol Lopes, Anastasia Bacigalupo
SPECIAL NOTES	N/A

Area Board 9: Update on Action Items

02/01/2013 BOARD MEETING

TELEPHONE LISTING

ISSUE	The board asked that Area Board 9 staff make sure that there is a 411 listing for the agency as it seems there is not one currently.
OUTCOME	Area Board 9 now has a listing through the telephone company. So if you call 411 and ask for Area Board 9, you should receive our phone number and address. If you do not, please let us know as soon as possible.

1-800 NUMBER

ISSUE	A community member requested that Area Board 9 have an 1-800 number. The community member was calling from Santa Barbara and was charged the long distance calling rate, which costs more money.
OUTCOME	Area Board 9 staff looked into how much it would cost to have a 1-800 number and we were told that it would cost $.21 per minute. Right now we are charged $0.008 per minute for local calls and for long distance we are charged $0.024 per minute for long distance calls. At this point it would be really expensive for Area Board 9 to have a 1-800 number since it is so much more money than what we are paying right now. A proposed solution is that if we can offer to call back anyone who calls us and then we will be paying for the cost of the call, not the caller.

AREA BOARD 9 ON DEVELOPMENTAL DISABILITIES
Serving the San Luis Obispo, Santa Barbara and Ventura Counties
200 East Santa Clara Street, Suite 210, Ventura, CA 93001
■ Telephone (805) 648-0220 ■ Fax (805) 648-0226

MEMORANDUM

TO: Area Board 9 Board of Directors

FROM: Carol Lopes, Community Program Specialist

RE: Area Board 9 Advocacy and Community Outreach Report, January 19, 2013 to March 25, 2013

DATE: March 25, 2013

Direct Advocacy for January to March 2013

100 Total cases
55 New cases
7 Monolingual Spanish speakers

35 Ventura County cases
13 Santa Barbara County cases
7 San Luis Obispo County cases

Case Highlight

A rewarding case we resolved this period involved a referral from Adult Protective Services. At age 20, our client was a young woman still living in her family home. A report had been made to Child Protective Services regarding the younger children in the home, and our client's case was sent to Adult Protective Services on account of her age. Because of her developmental disability, APS referred the case to Area Board 9 following an internal investigation.

We met this young woman in person at a post-secondary educational program where she had excelled academically, socially, and in a WorkAbility program for over a year. At the meeting, she articulately expressed her desire to live independently. Her TCRC service coordinator, also present at the meeting, stated that an out-of-home residential placement was unattainable due to our client's bi-polar diagnosis.

Recognizing that a childhood diagnosis was standing in the way of our client's independence, and finding no recent behavioral evidence of such a severe diagnosis, we advocated for a psychiatric re-evaluation. The new evaluation ultimately resulted in re-determination of our client's bi-polar diagnosis in favor of one requiring substantially less intensive services and setting.

Residential placement in her home community was quickly located, where our young client now enjoys a private room and a vegetable garden. She recently achieved permanent status in her new home following a 30-day trial period.

Community Outreach and Participation

With the Outreach/Transition Fair season upon us, we have been extremely busy! Here's what we've been doing:

- January: Transition to Adulthood parent information night in Santa Barbara.
- February: Parents Helping Parents Open House in SLO with OCRA; Presentation to TCRC Santa Maria office staff; Transition Fair in Oxnard;
- March: Transition Fair in Ventura; Transition Fair in Simi Valley; Transition Fair sponsored by the Independent Living Institute; Transition Fair sponsored by the Santa Barbara SELPA; Presentation to providers on Mandated Reporters at TCRC SLO office.

Feedback at the fairs we attended and presentations we provided reflected increased awareness of Area Board 9 as a community service agency.

Support to Self-Advocates

To equalize our support to self-advocacy groups in our catchment, we have initiated a schedule of quarterly visits to each of the groups. This quarter we met with People First of San Luis Obispo, People First of Santa Maria, Santa Barbara People First, and the Ventura County Self-Advocates. We are currently tracking the re-structuring of several Ventura County groups and will be visiting with them next quarter. As requested, we've supported self-advocates this quarter with the Consumer's Guide to the Lanterman Act, the Sexual Bill of Rights, and with plain language concepts. Next quarter we look forward to planning a tri-county-wide Self-Advocacy Conference, meeting with newly-formed groups, and continuing our schedule of regular visitations.

Our representative to the SSAN in Sacramento, Sigrid Bremer of Simi Valley, attended the statewide meeting on 3/1. In addition to her report on self-advocacy activities in the Tri-Counties, Sigrid distributed a copy of Advocating with Your Elected Officials to each of the SSAN members. It was received with great appreciation by the SSAN membership.

TAB C

Report on California Budget

Area Board 9 on Developmental Disabilities April 2013

Revenue increase in January might be an accounting anomaly

An increase of revenue that showed up unexpectedly in January may well be balanced out by a revenue dip in coming months, according to Governor Jerry Brown's office.

The surprise money has been the source of much speculation in the Legislature. Unexpected tax receipts filled state coffers with more than $5 billion beyond what was expected for January — more tax dollars than are set aside for the entire state university system in a year. The revenue increase was historic. But the question for budget experts was whether lawmakers could begin setting aside the extra money toward government programs and tax breaks — or whether the money amounted to an accounting anomaly.

Governor Brown's budget office now says in an official report that it is probably an anomaly. The report says the extra money was "likely the result of major tax law changes at the federal and state level having a big impact in the timing of revenue receipts."

-Adapted from the Los Angeles Times article 02/18/2013.

revenue: an amount of money received for the sale of goods or services or for payment of taxes.

revenue dip: when money that California thought it was going to receive turns out to be a lower amount than was originally planned.

anomaly: when something is weird or out of the ordinary; not expected.

legislature: the elected representatives from all over California who have the responsibility and power to make laws.

Budget Subcommittee Hearings & Governor's May Revised Budget

The Legislature began budget subcommittee hearings to review the details of the Governor's proposed budget and gives the public the opportunity to provide their comments on the budget proposals. The subcommittee hearings allow legislators to take action on the budget proposals and make recommendations if the Governor's proposed budget for an agency is too low or too high.

The Governor will be working on his revised budget for the next month as he gets ready to release his new budget, called the "May Revise." The Governor will include the most updated information on how much revenue California has received and how much money California has spent. The May Revise is a very important budget report because it lets everyone know whether California is on track with its budget.

Report on Legislation: Federal Budget Bills

Area Board 9 on Developmental Disabilities April 2013

Congress Passes Funding Bill with Automatic Cuts

Last month, the Senate and House each passed a bill that will fund the federal government for the remaining half of the fiscal year which ends on September 30. They did this because they wanted to avoid the federal government shutting down because it ran out of money. The bill gives just enough money to most programs that so that can stay open, although some programs did receive a small increase in money, like 0.6%.

The bill also included cuts across many programs, known as "sequestration," which were required because of the Budget Control Act. Though the cuts are opposed by many in Congress, House and Senate leaders decided to include them in the bill rather than risk a government shutdown. President Obama is expected to sign the bill soon.

Proposed Cuts to Social Security Benefits

Congress is considering a budget proposal that would cut the Cost-of-Living-Adjustment, otherwise known as the "COLA" for people who receive social security and supplemental security income (SSI).

The proposal wants to substitute a different program, chained consumer price index, known as "chained CPI." The effect of the chained CPI would mean that when prices rise for goods or services, people who receive benefits will have to adjust their spending to buy cheaper goods or services instead of more expensive ones. This is different from how the COLA works- when prices rise for goods or services, the COLA requires that that social security and SSI payments increase to reflect that the cost of living has gone up.

funding bill: a proposed law that will provide money to a part of the government; in this case to provide money to the federal government to keep it running until September 30, 2013.

fiscal year: a period of time lasting a year that begins in a different month instead of January for accounting or financial purposes; state fiscal year begins July 1st and ends June 30th; federal fiscal year begins October 1st and ends September 30th.

sequestration: automatic cuts to a majority of programs and agencies within the federal government.

budget proposal: where legislators offer a possible plan for spending or cutting government money for the fiscal year.

Cuts under the chained CPI are predicted to force many people who receive benefits to make difficult choices, such as whether to buy all the food they need or refill their medicine prescription. For more information, please see the next page- a flyer from the American Association of Retired Persons (AARP) on this issue.

-Adapted from the ARC, National Policy Matters brief 03/22/2013.

TAB D

THE CHAINED CPI AND YOU

THE CHAINED CPI IS A BENEFIT CUT

The chained CPI proposal would cut the yearly cost-of-living adjustment (COLA) for Social Security and veterans benefits. That means, year after year, it will get harder for you to afford basic necessities – groceries, the heating bill and medicine.

UNDER THE CHAINED CPI, THE CUMULATIVE BENEFIT CUT FOR THE AVERAGE 65+ RETIREE WOULD BE:

A typical senior has an annual income of only **$20,000**

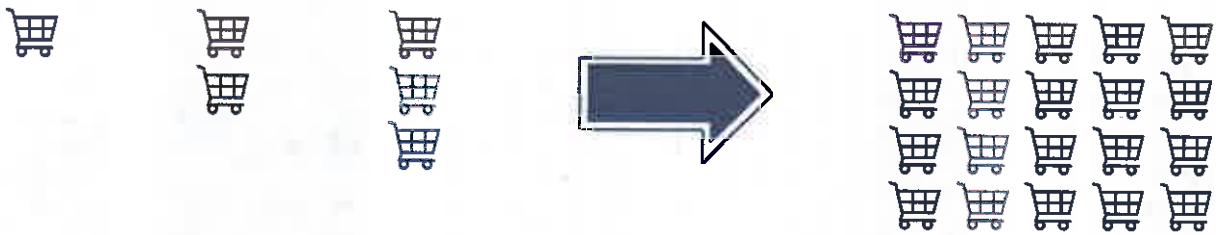
AGE 70	AGE 80	AGE 90
$662	$5,248	$14,076

THE CHAINED CPI CUTS GET DEEPER

The chained CPI benefit cuts would start small and grow larger and larger over time, costing our nation's most vulnerable thousands of dollars when they need it most.

IF YOUR BENEFITS WERE CUT BY $44 THE FIRST YEAR, YOUR ANNUAL LOSSES WOULD BE:

Year 1 $44 + Year 2 $89 + Year 3 $133 + Years 4 - 19 + Year 20 $862



= **$9,139** (Total Benefits Lost after 20 Years)

what you can do

Visit aarp.org/whatyoulose

Use the calculator to see how the chained CPI would impact you. Then send a message to your members of Congress – urge them to reject this harmful change!

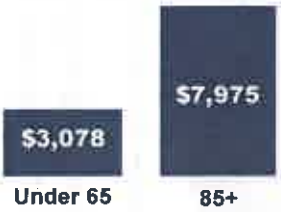
Note: The calculations above were made using the average annual Social Security benefit of $15,190.

WHAT THE CHAINED CPI MEANS FOR SOCIAL SECURITY & YOU

IT'S LESS ACCURATE FOR SENIORS

Many seniors spend much of their money on necessities like prescription drugs and health care – items that don't have lower-cost substitutes.

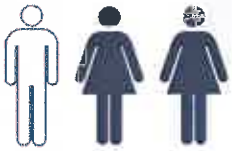
Annual Out-of-Pocket Health Care Spending



Out-of-pocket health care spending is **2.5 times** higher for those 85+ than those under 65

WOMEN WILL FEEL THE EFFECTS LONGER

Women tend to live longer and make up a larger share of the population as it ages.

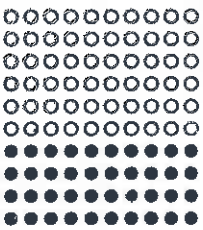


68% of Social Security recipients age 85+ are **women**

DISABLED PEOPLE HAVE A GREATER CHANCE OF FALLING INTO POVERTY

Many people with disabilities spend a large share of their income on health care, which rises faster than inflation and doesn't have lower-cost substitutes.

Disabled Population



40% of people with disabilities are kept out of poverty by Social Security

OLDER VETERANS WOULD BE HURT TWICE

Social Security **AND** veterans benefits will both be cut by the chained CPI, so every COLA dollar lost will have a huge impact.

Annual Benefits Lost at Age 90

By age 90, a 62-year-old veteran would lose **$32,000** in total benefits

BOTTOM LINE: The chained CPI proposal would slash your hard-earned Social Security and veterans benefits by $146 billion over the next 10 years alone. Washington should find more responsible ways to address our nation's budget challenges.

what you can do

Visit aarp.org/whatyoulose

Use the calculator to see how the chained CPI would impact you. Then send a message to your members of Congress – urge them to reject this harmful change!

Note: The calculations above were made using the average annual Social Security benefit of $15,190.

TAB E

Report on Dept. of Developmental Services

Area Board 9 on Developmental Disabilities April 2013

Sonoma Developmental Center Update

On March 13, 2013, the California Department of Public Health (CDPH) on announced an agreement with the Department of Developmental Services (DDS) regarding the future of the troubled Sonoma Developmental Center.

CDPH and DDS have entered into a Program Improvement Plan (PIP) with an outline of improvements the Sonoma facility must meet to receive approval to operate and money from the Centers for Medicare and Medicaid (CMS). The PIP outlines several actions the Sonoma Developmental Center must take including: entering into a contract with an outside agency that will figure out what went wrong, develop action plans to correct problems found and report monthly progress to the CDPH.

CDPH is responsible for inspecting health facilities in California as well as monitoring programs that receive CMS money. An inspection in December 2012 at the Sonoma Developmental Center's Intermediate Care Facility (ICF) revealed that problems in many areas first identified last summer were not fully corrected. This required CDPH to begin steps to take away CMS approval of the entire ICF. The ICF serves approximately 290 residents with developmental disabilities.

-Adapted from an article from the Sonoma Valley Patch 03/13/2013.

developmental center: a locked facility run by the state of California, sometimes called an "institution."

centers for medicare and medicaid: a federal agency within the United States Department of Health and Human Services (DHHS) that runs the Medicare program and works in partnership with state governments to provide Medicaid, the State Children's Health Insurance Program (SCHIP), and other health insurance programs.

intermediate care facility: a facility that provides care for people with disabilities who need to receive direct care and supervision 24 hours a day.

Regional Center Purchase of Service Information

Last year, the Lanterman Act was changed to require that DDS and regional centers collect data or specific information about how they buy services and supports for the communities they serve. The data was requested because there are concerns that there are big differences in how regional centers spend their money on services and supports between diverse communities, especially racial and ethnic communities.

For more information, please see an included bulletin from Disability Rights California- about the data and posting requirements for DDS and regional center.

Regional Center's Role with the National Voter Registration Act

The National Voter Registration Act (NVRA) requires that designated agencies offer voter registration to any person who applies for new benefits or services, for renewal or for an address change. Designated agencies include:

- All offices that provide public assistance;
- All offices that provide state-funded programs primarily engaged in providing services to people with disabilities; and
- DDS/Regional Centers.

Voter registration means that the regional center must assist a person who receives services register to vote. This means regional center staff must:

- Provide persons who receive services (18 years old or older) with a voter registration card,
- Provide persons who receive services with a NVRA voter preference form,
- Help persons who receive services fill out the voter registration card,
- Send in the completed voter registration card to the election officials on behalf of the person who receives services, and
- Keep the voter registration forms on file for 2 years.

Regional center staff can assist a person served complete the voter registration forms anywhere, including at home, at their program or at their job. Regional centers are being asked to provide a link to voter registration on their website.

Also, regional centers must have a staff member act as the NVRA Voter Coordinator, to make sure that the regional center is following the requirements under the NVRA. The NVRA coordinator for Tri-Counties Regional Center is Steve Cruisinberry.

national voter regional center act: a federal law that requires state governments to allow citizens to register to vote when renewing their driver's license or applying for social services.

you may register to vote in California if:

- ✓ you are a United States citizen.
- ✓ you are a resident of California.
- ✓ you are at least 18 years old (or will be by the date of the next election).
- ✓ you are not in prison or on parole for a felony conviction.
- ✓ you have not lost your right to vote by the decision of a court.

deadline to register to vote before an election: in order to vote in an upcoming election, your completed voter registration card must be turned into your local county election office at least ***15 days before*** the election.

TAB F

Disability Rights California

California's protection and advocacy system
www.disabilityrightsca.org
Toll Free: (800) 776-5746
TTY: (800) 719-5798

Reporting of Purchase of Service Data by Various Categories by the Regional Centers and the Department of Developmental Services[1]

Effective July 1, 2012, Pub #F069.01

The State Legislature required the Department of Developmental Services (DDS) to reduce its budget by $200 million for this fiscal year, 2012-2013. This reduction is in addition to significant reductions in prior fiscal years. As a result, there are changes to the services that regional centers can purchase and how the regional centers operate. The state budget also includes a provision for an additional $50 million dollar reduction if the tax initiatives are not approved by voters in the November election plus a $100 million reduction in fiscal year 2013-2014. If the additional cuts occur, DDS is required to have the reduction affect consumer services as little as possible. DDS shall consult with stakeholders groups, including, consumers, family members, advocacy groups, service providers and staff of regional centers and developmental centers to determine how the budget reduction will be achieved.

A. How the Law Changed

The new law requires the following: 1) The Department and regional centers to collaborate with each other annually in order to compile data related to purchase of service authorization, utilization, and expenditure. 2) The Department and the regional centers to post such data on each of their

[1] The changes are part of the Budget Trailer Bill (TBL) AB 1472. You may find the law at http://www.leginfo.ca.gov/pub/11-12/bill/asm/ab_1451-1500/ab_1472_bill_20120613_amended_sen_v98.html. Changes affecting data reporting on purchase of services by regional centers and the Department of Developmental Services can be found at Welfare and Institutions Code Sec. 4519.5

respective websites. 3) The regional centers to meet with stakeholders in a public forum after posting the data on their websites. Each of the above items will be discussed in more detail below in Section B.

This new law is in response to concerns that there may be disparities in expenditure of purchase of service funds by the regional centers to diverse communities, including racial and ethnic communities. "Purchase of service" (POS) is the method used by the regional centers to buy services and supports that are in a person's Individual Program Plan (IPP). Individuals may get services such as IHSS or Medi-Cal but that is not part of the regional center's POS fund because the regional centers do not pay for these generic services. Only services and supports for which the regional centers pay are included in the POS fund.

Requiring the regional centers and the Department to compile and post POS data, and the regional centers to meet with stakeholders in a public meeting after posting the data, will assist in identifying any disparity and will lend greater transparency to the authorization, utilization, and expenditures of POS funds by each regional centers.

B. What Does the Law Require the Regional Centers And the Department to Do?

1. Collaborate and Compile Purchase of Service Data

The law requires the regional center and the Department to annually collaborate to compile data relating to POS authorization, utilization, and expenditure by each regional center with regards to all of the following:

a. The age of the consumer;

b. Race or ethnicity of the consumer;

c. Primary language spoken by the consumer; [2]

d. The specific developmental disability.[3]

e. The number and percentage of individuals, categorized by age, race or ethnicity, and disability, who are eligible for regional center

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[2] Welfare and Institutions Code Sec. 4519.5(a)(3). May also include other related details, as feasible.
[3] Welfare and Institutions Code Sec. 4519.5(a)(4). Disabilities are in accordance with Welfare and Institutions Code Sec. 4512(a), or unknown.

services but are not receiving any POS funds by the regional centers.[4]

2. Post Purchase of Service Data

By March 31, 2013, each of the 21 regional centers and the Department will have to post on their websites, information listed in Section B(1) above for fiscal year 2012. Starting December 31, 2013, and by December 31st thereafter, each regional center and the Department must post the data of the previous year. The regional center must post its own data while the Department will post data on a statewide basis. [5]

3. Meet with Stakeholders

Within three months of compiling the data with the Department, and annually thereafter, each regional center has to meet with stakeholders in a public meeting regarding the data.[6]

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[4] Welfare and Institutions Code Sec. 4519.5(b).
[5] Welfare & Institutions Code Sec. 4519.5(c)-(d).
[6] Welfare & Institutions Code Sec. 4519.5(e).

TAB G

Report on the State Council

Area Board 9 on Developmental Disabilities April 2013

Impact of Sequestration on State Council & Area Boards

Last month, the Senate and House each passed a bill that will fund the federal government for the remaining half of the fiscal year which ends on September 30. The bill also included cuts across many federal programs and agencies, known as "sequestration," which were required because of the Budget Control Act.

The State Council is a federally funded agency that supports the Area Boards in California. The State Council expects as a part of the sequestration to receive a 5% cut in its funds for this fiscal year (2012-2013) and a 9% cut for next fiscal year (2013-2014).

Luckily the State Council has already saved money for this fiscal year and there will be no additional cuts to the budgets of the State Council or Area Boards from now until September 30th. The State Council was able to save money when it ended its contract early with the Board Resource Center for support of the Self Advocate Advisory Council and the Statewide Self Advocacy Network.

For next fiscal year, there will be cuts and the cuts will be in the following areas:

- All open jobs available at Area Board offices will be eliminated and will not be re-posted.
- Each Area Board will only receive $10,000 for the Community Program Development grants.
- There will be no more self advocacy funds given to Area Boards to support self advocacy activities in their area.

The State Council is waiting to hear from its parent agency, the Administration on Intellectual and Developmental Disabilities (AIDD), to confirm whether there will be any additional cuts.

sequestration: automatic cuts to a majority of programs and agencies within the federal government.

fiscal year: a period of time lasting a year that begins in a different month instead of January for accounting or financial purposes; state fiscal year begins July 1st and ends June 30th; federal fiscal year begins October 1st and ends September 30th.

audit: a formal review of a person or agency to see if they are following the law; sometimes the review focuses on how money is being spent.

AIDD Audit Finished; Waiting for Report

The AIDD visited the State Council in January with audit of services provided by the State Council and Area Boards. AIDD also interviewed various staff at headquarters and all of the executive directors of the Area Boards. At this point, the State Council is waiting for the AIDD to send its final report on the audit and provide any recommendations or suggestions on how the State Council should be serving Californians with developmental disabilities.

AUTISM INSURANCE LAW SURVEY RESULTS

SENATE BILL 946

A statewide survey collected responses from Californians who have been impacted by the autism insurance law, otherwise known as Senate Bill 946 (SB 946). The survey was made available online in both English and Spanish. The survey results reflect responses collected from February through mid-March 2013. Below is an executive summary of the survey results.

Families who Responded to the Survey...

228 *Total Number of Families who Completed the Survey*

218 *Number of Surveys Completed in English*

10 *Number of Surveys Completed in Spanish*

90 *(%) Percent of Families Receive Regional Center Services*

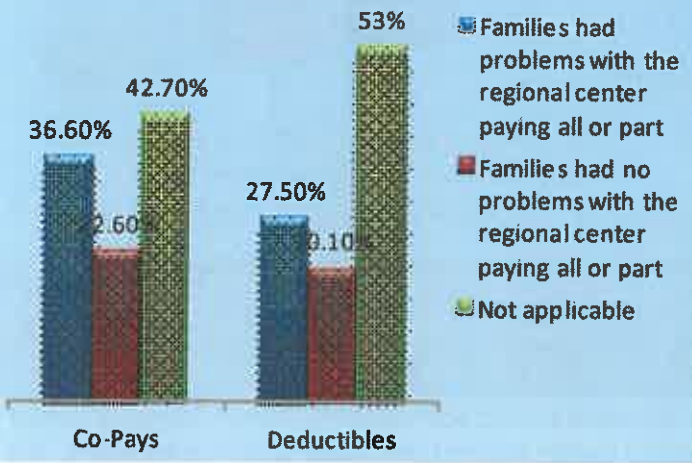
73 *(%) Percent of Families Live in Southern California*

Regional Center Assistance with Co-Pays & Deductibles

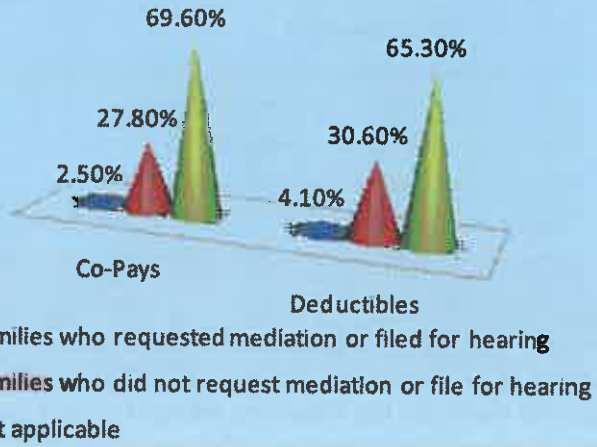
Were you aware that the regional center might be able to help you with co-pays and/or deductibles?

Sixty-six percent (66%) of families reported that they were not aware; thirty-four percent (34%) of families reported that they were aware.

Have you had any problems with the regional center paying all or part of your co-pay or deductible?



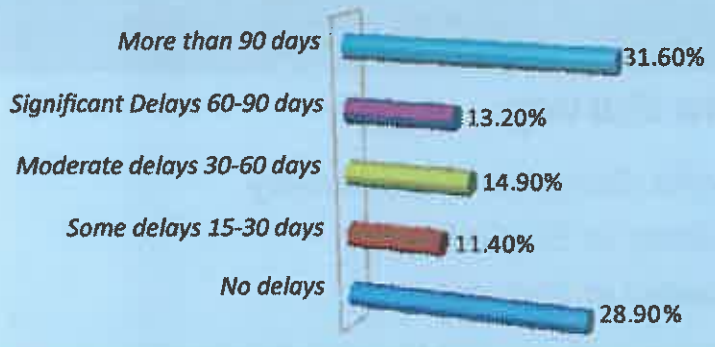
If you had problems with the regional center paying your co-pay or deductible, did you file for hearing and/or request mediation?



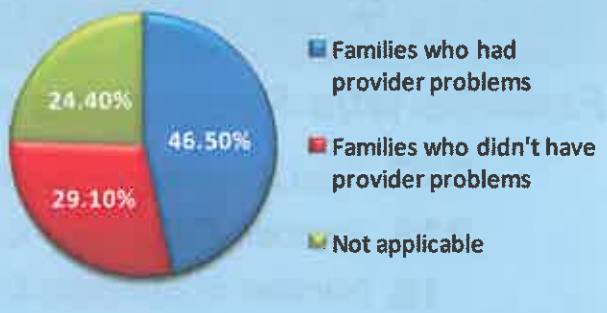
Accessing Services Through Private Insurance Plans

Delays Getting Services Started & Provider Issues

Have you experienced any delays getting behavioral services started through your private insurance plan?

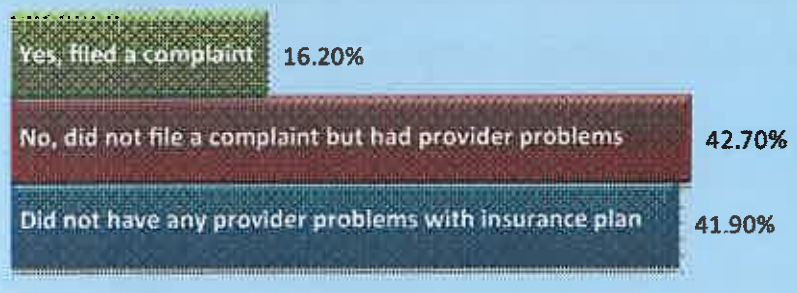


Have you experienced any problems with getting an appropriate provider through your private insurance plan?



Complaints & Independent Medical Reviews

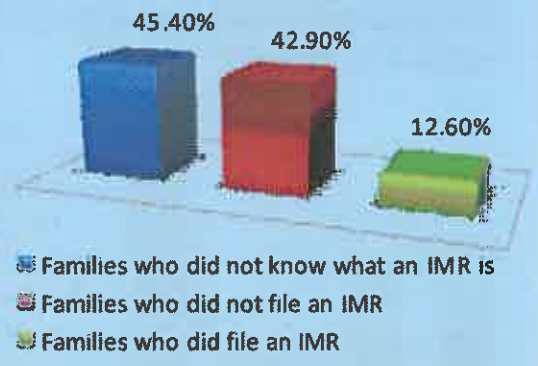
If you had problems getting an appropriate provider, did you file a complaint with your private insurance plan?



Yes, we filed a complaint but...

"They still denied coverage."
"They told us it wasn't medically necessary."
"[It was] denied on appeal. I stopped short of going to the DMHC. I was too exhausted to chase it anymore."

Besides filing a complaint against your insurance plan, have you filed an Independent Medical Review (IMR) with the Department of Managed Health Care (DMHC)?



Yes, we filed an IMR...

"IMR overturned Anthem's denial. However, Anthem is still refusing to pay for services."
"IMR agreed with our case."
"Decision overturned in our favor."
"They ruled in our favor against the insurance company."

If you are having difficulty getting your child's services funded or delivered, please contact your local Area Board office for assistance. For a listing of the Area Boards, please visit: *www.scdd.ca.gov/areaboards.htm#AB Locations* or call (866) 802-0514.

Special thanks to the following groups for their support with the survey: Area Boards/SCDD, Autism Society of California Chapters, Family Resource Centers, OCRA/DRC, ARCA, Regional Center Autism Coordinators, Service Providers, and **most importantly, all the families who completed the survey.** Survey design & analysis: Area Boards 9 & 13.

TAB H

What Changes to the DSM May Mean...

An article for Parents by Dr. Pamela Compart, M.D.

If you have a child with autism you have likely heard of the DSM-IV. The DSM-IV stands for the Diagnostic and Statistical Manual-Fourth Edition (DSM-IV). It is published by the American Psychiatric Association and it's the primary manual used by clinicians to provide a formal diagnosis of autism and related disorders. The manual outlines the specific criteria that must be met to receive a diagnosis, as well as the corresponding label and numerical code that is sometimes used by insurance companies to identify the diagnosis. The main purpose is to provide standard guidelines for clinicians to use for the diagnosis of different psychological disorders and conditions.

The DSM-IV currently identifies a set of Pervasive Developmental Disorders that are considered "autism spectrum disorders" (ASDs). These include Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The DSM-IV has been under revision for several years and a new edition, the DSM-V, will be released in 2013. Significant changes to the criteria and categories of ASDs are planned for the new edition. As a parent it is important that you be well informed, so we will review the proposed changes and their possible implications.

One of the most significant changes is that the separate diagnostic labels of Autistic Disorder, Asperger's Disorder, and PDD-NOS will be replaced by one umbrella term "Autism Spectrum Disorder." Further distinctions will be made according to severity levels. The severity levels are based on the amount of support needed, due to challenges with social communication and restricted interests and repetitive behaviors. For example, a person might be diagnosed with Autism Spectrum Disorder, Level 1, Level 2, or Level 3. The DSM-V revision website says the reasons for using the umbrella term of "Autism Spectrum Disorder" are 1) the old way isn't precise enough—different clinicians diagnose the same person with different disorders, and some change their diagnosis of the same symptoms differently from year to year, and 2) autism is defined by a common set of behaviors and it should be characterized by a single name according to severity.

The removal of the formal diagnoses of Asperger's Disorder and PDD-NOS is a major change. People who currently hold these diagnoses will likely receive a different diagnosis when re-evaluated. This has the potential to be confusing for parents of children with these diagnoses as well as children and adults who identify strongly with their diagnosis.

Revisions to the specific criteria needed for a diagnosis of Autism Spectrum Disorder have also been made. The new criteria are more thorough and strict compared to the old criteria. For example, more symptoms are needed to meet criteria within the area of fixated interests and repetitive behaviors. Other changes to the criteria include a

reorganization. Currently, the domains for Autistic Disorder include impairments in Communication, Social Interaction, and Restricted Interests and Repetitive Behaviors. In the new edition, the Communication and Social Interaction domains will be combined into one, titled "Social/Communication Deficits." Additionally, the requirement of a delay in language development is no longer necessary for a diagnosis.

These proposed changes are based on research, analysis, and expert opinion. The revisions have been made with the hope that the diagnosis of autism spectrum disorders will be more specific, reliable, and valid. Despite these positive hopes, legitimate concerns have been raised regarding how these changes might impact people on the spectrum. One of the biggest concerns is that some who are higher functioning will no longer meet the more strict diagnostic criteria and will therefore have difficulties accessing relevant services. Questions have been raised about what will happen to people currently diagnosed with Asperger's Disorder or PDD-NOS. Furthermore, there is uncertainty regarding how state and educational services and insurance companies will adopt these changes.

It is clear these changes will have an impact on families and people currently diagnosed with an autism spectrum disorder. It remains to be seen how diagnosticians and clinicians will use the new criteria in evaluating children and the impact it will have on the availability of services. Therefore, it is important to remain informed and up to date. To follow and learn more about the proposed changes, see the DSM-V revision website.

The video that accompanies this article can be found at:
http://www.autism.com/index.php/news_dsmV