



**SELF-ADVOCATES ADVISORY COMMITTEE MEETING
NOTICE /AGENDA**

Posted on www.scdd.ca.gov

THE PUBLIC MAY LISTEN IN BY CALLING:	1-800-839-9416
PARTICIPANT CODE:	2982825

DATE: Tuesday, March 24, 2015

TIME: 1:00 p.m. – 5:00 p.m.

LOCATION: DoubleTree by Hilton
2001 Point West Way
Sacramento, CA 95815
Phone: (916) 924-4900

TELECONFERENCE SITE

2118 University Park Drive
Sacramento, CA 95825
Gate Code: 075#

Pursuant to Government code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Thomas Johnson at (916) 322-8481 or email thomas.johnson@scdd.ca.gov. Requests must be received by 5:00 pm, March 16, 2016.

Page

- | | |
|-----------------------------------|--------------------|
| 1. CALL TO ORDER | D. FORDERER |
| 2. ESTABLISHMENT OF QUORUM | D. FORDERER |
| 3. WELCOME/INTRODUCTIONS | D. FORDERER |

For additional information regarding this agenda, please contact Robin Maitino, 1507 21st Street, Ste. 210, Sacramento, CA 95811, (916) 322-8481. Documents for an agenda item should be turned into SCDD no later than 12:00 p.m. the day before the meeting to give members time to review the material. The fax number is (916) 443-4957.

4. PUBLIC COMMENTS

D. FORDERER

*This item is for members of the public only to provide comments and/or present information to the Council on matters **not** on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first. The Council will provide a public comment period, not to exceed a total of seven minutes, for public comment prior to action on each agenda item.*

**5. APPROVAL OF January 21, 2015
MEETING MINUTES**

D. FORDERER 3

**6. SSAN (Statewide Self-Advocacy Network)
REPORT**

D. FORDERER 7

**7. REPORT ON EMPLOYMENT FIRST
COMMITTEE (EFC) MEETING**

K. WELLER

**8. DISCUSSION ON RESEARCH
MATERIALS FOUND**

ALL

- Abuse 9
- Deinstitutionalization 25
- Disability awareness 44

**9. BOARDS FOR ALL TRAINING
FURTHER DISCUSSION**

ALL

10. ABLE ACT INFORMATION

N. NIEBLAS/ B. GIOVATI 46

11. REVIEW COUNCIL PACKET

M. CLARK

12. TOPICS FOR FUTURE DISCUSSION

D. FORDERER

13. ADJOURNMENT

D. FORDERER



DRAFT

**SELF-ADVOCATES ADVISORY COMMITTEE MEETING MINUTES
January 21, 2015**

Members Present

Jenny Yang (Chair, SA)
Robert Taylor (SA)
Steven Kapp (SA)
Nancy Clyde (SA)
Kerstin Williams (SA)
David Forderer (SA)
Rebecca Donabed (SA)
Charles Horne-Nutt (SA)

Members Absent

Kecia Weller (SA)

Others Attending

Mary Agnes Nolan
Dena Hernandez
Thomas Johnson
Sarah May
Mike Clark
Mary Ellen Stives
Elizabeth Drake
October King
Wayne Glusker
Angela Lewis

1. CALL TO ORDER

Chairperson Jenny Yang called the meeting to order at 11:24 a.m.

2. ESTABLISHMENT OF QUORUM

A quorum was established.

3. WELCOME AND INTRODUCTIONS

Everyone present introduced themselves.

4. PUBLIC COMMENT

Council Member Robert Taylor read a letter on behalf of Joe Tichenor.

Elizabeth Drake, an employer advocate with Strategies to Empower People (STEP) gave a brief statement stating she was at the meeting to hear about employment for people with developmental disabilities and as a person with cerebral palsy, she knows how hard it is to get employment. Ms. Drake also handed out her business cards and invited members to contact her.

5. APPROVAL OF NOVEMBER 18, 2014 MINUTES

It was moved/seconded (Clyde/Horne-Nutt) and carried to approve the November 18, 2014 SAAC meeting minutes as presented. Council members Jenny Yang, Robert Taylor, Steven Kapp, Nancy Clyde, Kerstin Williams, David Forderer, Rebecca Donabed, and Charles Horne-Nutt voted 'Aye'. There were no 'Nays' or Abstentions.

6. SSAN (STATEWIDE SELF-ADVOCACY NETWORK) REPORT

Councilmember David Forderer discussed the information provided in the written report on the Statewide Self-Advocacy Network (SSAN) that is on page 6 of the SAAC packet and on page 132 of the Council packet. David will be introducing Cheryl Hewitt, SSAN Chair, tomorrow after he gives his report to the Council. Cheryl Hewitt will present the two SSAN power point presentations on Employment First and Self-Determination for approval for distribution. Councilmember Charles Horne-Nutt assisted Councilmember David Forderer with presenting the PowerPoint materials to the committee. The committee considered and voted on the following two motions:

It was moved/seconded (Forderer/Clyde) and carried to approve the Employment First PowerPoint, along with the inclusion of information of AB 1041, for the use of educational purposes throughout the State. Councilmembers Jenny Yang, Nancy Clyde, Kerstin Williams, Steven Kapp, David Forderer, Rebecca Donabed, Robert Taylor, and Charles Horne-Nutt voted 'Aye'. There were no 'Nays' or Abstentions.

It was moved/seconded (Forderer/Clyde) and carried to approve the Self Determination PowerPoint, along with the addition of Spanish translation and an implementation timeline, for the use of educational purposes throughout the State. Councilmembers Jenny Yang, Nancy Clyde, Kerstin Williams, Steven Kapp, David Forderer, Rebecca Donabed, Robert Taylor, and Charles Horne-Nutt voted 'Aye'. There were no 'Nays' or Abstentions.

7. EFC REPORT

Councilmember Kecia Weller is on leave therefore Chairperson Yang referred members to the copy of the Employment First power point presentation for the December 9, 2014 Employment First Committee meeting that was presented to SSAN members in December. The report is on pages 56-80 in the SAAC packet and on pages 117- 121 of the Council packet.

8. COUNCIL VISION

Chairperson Yang gave members the opportunity to fill out the Council Vision questionnaire located on page 82 of the SAAC packet so they could suggest additional topics for the Council vision. (All Council members were asked to do this at the last Council meeting.) The information was provided to Interim Executive Director Michal Clark who will pass them on to the SCDD Chair.

9. GOALSETTING

Members continued their Goal Setting Discussion and will be researching what materials are available to be shared at the next meeting. The 3 topics of focus are:

- Abuse
- Deinstitutionalization
- Disability Awareness

10. BOARDS FOR ALL TRAINING MATERIALS

Members viewed 4 videos regarding Board Membership titled "Boards for All". They can be viewed at the following hyperlink:

<http://www.scdd.ca.gov/boardsforall.htm>

11. REVIEW COUNCIL PACKET

Interim Executive Director Michal Clark reviewed the Council packet with committee members.

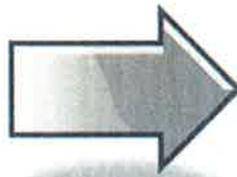
12. TOPICS FOR FUTURE DISCUSSION

Members mentioned that they would like to discuss the ABLE Act.

13. ADJOURNMENT

The meeting was adjourned at 2:55 p.m.

DRAFT



Report from SSAN Meeting TO SCDD by David Forderer
Highlights from the March 4-5, 2015 SSAN Meeting in Sacramento

Reports were given by the following individuals:

- Tony Anderson from the Lanterman Coalition gave a talk on the need for a 10% increase in funds from DDS and the need to talk with your legislators about how important the additional money would be to the disability system.
- Mike Clark (SCDD Interim Director) gave a talk: Asked the SSAN members to complete the 5 year plan survey and he shared a story about his disabled daughter being approached to do a reality TV show.
- A discussion was held related to SSAN joining the Lanterman Coalition as a separate entity. David Forderer said he would ask the SCDD Council how they felt about that.
- An election was held for the vacated position of secretary of SSAN since Charles Horne-Nutt resigned. Desiree Boykin was elected as the new secretary.

- Bob Giovati (SCDD Deputy Director of Policy and Planning) and Nelly Nieblas (SCDD Legislation and Communication Manager) gave the SSAN members a legislative overview of the bills (important to the disability community) that are before the legislature.
- Jake Atteberry and Kirk Aranda from YO (“Youth Organizing: Disabled and Proud”) gave a talk about their organization.
- SSAN members broke out into committee work groups to discuss issues pertinent to each group and then reported back to the SSAN body with any plans they set up.
- SSAN members viewed an Anti-Bullying video.

The next SSAN meeting is on June 24-25, 2015 in Sacramento.



ASAN

AUTISTIC SELF ADVOCACY NETWORK

Anti-Filicide Toolkit

Foreword: Killing Words

by Zoe Gross

April 10, 2012

Let me present to you a sequence of events.

On March 6th, a 22-year-old autistic man named George Hodgins was murdered in Sunnyvale, California. His mother, Elizabeth pulled out a gun, shot him point-blank, and then killed herself.

In the following days and weeks, journalists wrote about George Hodgins' murder. In their articles they called him "low functioning and high maintenance,"¹ and called Elizabeth Hodgins "a devoted and loving mother."² They sought out quotes from other parents of autistic children, who normalized the crime by saying things like "every mother I know who has a child with special needs has a moment just like that."³

People came to comment on these articles. They said that they felt sympathy for the mother. They called her George's "guardian angel." They said no one should judge her unless they had walked in her shoes. They said that it wasn't wrong because he was autistic, and autistic children are hell to raise. They said that it wasn't wrong because she was obviously responding to a lack of services. (In fact, she had refused services.) They said that it wasn't wrong because he was disabled, so and his life couldn't have been very good anyway.

On March 8th, Robert Latimer went on television to talk about how loving and compassionate it was when he gassed his disabled daughter Tracy. He called for "euthanasia" – the murder of disabled children by their parents – to be legalized in Canada. A woman who appeared with him agreed. She has two disabled children who she would like to kill, but she can't because it is against the law. No opposing viewpoints were presented.

On March 17th, the Autism Society released a statement about "the tragic story of Elizabeth Hodgins," which "shows that high stress on parents is very common in the autism community." The statement, signed by both Autism Society presidents, blamed her actions on a lack of services. They also noted that "the divorce rate among parents with a child with autism is as high as 70 percent due to the pressure," (this is actually a myth that was debunked in 2010⁴). They never even mentioned George's name.

On March 31st, Patricia Corby drowned her 4 year old autistic son Daniel in the bathtub, in San Diego, California.⁵

1 http://www.mercurynews.com/opinion/ci_20249537/march-17-readers-letters

2 http://www.santacruzsentinel.com/ci_20139097

3 http://www.mercurynews.com/breaking-news/ci_20133088/parents-autistic-children-speak-out-sunnyvale-murder-suicide

4 <http://www.kennedykrieger.org/overview/news/80-percent-autism-divorce-rate-debunked-first-its-kind-scientific-study>

5 <http://www.utsandiego.com/news/2012/apr/04/mother-pleads-not-guilty-killing-son/>

We need to start looking at these murders as copycat crimes, which are encouraged when murders of disabled people receive positive press coverage. Just as Katie McCarron's murder followed "Autism Every Day,"⁶ Daniel Corby's murder follows George Hodgins' murder, and subsequent media coverage which excused, explained away, or even promoted the murder of disabled people by our parents.

When journalists call murderers "loving and devoted parents," when television shows give Robert Latimer airtime, when parents normalize murder by saying that all special-needs parents have murderous thoughts, the result is an environment in which these murders are seen as acceptable. Media coverage like this sends a message that homicide is a normal, understandable response to any discomfort one might experience while parenting a disabled child, and we can't pretend that other parents of disabled kids aren't hearing that message.

Let me present to you a sequence of events.

If you wrote an article about George Hodgins' murder, or if you gave a quote for one, or if you covered it on television, or if you blogged about it, or if you commented on it,

and

if you said that no one should "judge" the murder as wrong,

if you said that Elizabeth Hodgins was "driven to murder" by George's autism or by "lack of services,"

if you called the murder "understandable,"

if you said "it wasn't a murder, it was a mercy killing,"

if you said "all parents of special-needs children have felt this way,"

please take a minute to wonder if Patricia Corby heard you.

6 <http://archive.blisstree.com/feel/may-9th-may-13th-autism-every-day-katherine-mccarron/>

What is filicide?

In the past five years, over fifty people with disabilities have been murdered by their parents, relatives or caregivers in the United States alone.

These acts are horrific enough on their own. But they exist in the context of a larger pattern:

1. A parent kills their disabled child.
2. The media portrays these murders as justifiable and inevitable due to the “burden” of having a disabled person in the family.
3. If the parent stands trial, they are given sympathy and comparatively lighter sentences, if they are sentenced at all.
4. The victim is disregarded, blamed for their own murder at the hands of the person they should have been able to trust the most, and ultimately forgotten.
5. The media sends a message that if you kill your disabled child, you will receive attention and sympathy. The justice system sends a message that if you kill your disabled child, your punishment will likely be minimal.
6. Parents of kids with disabilities see these messages.
7. A parent kills their disabled child.

What does the term “filicide” mean?

“Filicide” is the legal term for a parent murdering their child. In the disability community, “filicide” is used when talking about a parent or other relative murdering a child or adult relative with a disability. This toolkit is specifically about filicide in the disability community. When we say “filicide,” we are talking about a pattern of violence that starts when a parent or caregiver murders their child or adult relative with a disability and continues in how these murders are reported, discussed, justified, excused, and replicated.

How common is it?

We don’t know. Filicide in general is very difficult to track, and filicide in the disability community is notoriously underreported. We are aware of over 50 filicides in the United States from the last 5 years where the victim was disabled. We know that the numbers we know of are much smaller than the reality.

Why are we only talking about filicide against people with disabilities?

Typically, when a child without a disability is murdered by their parents, everyone stands united in condemnation. No one attempts to understand, justify, or explain the murder. No one expresses sympathy for the murderer. No one argues that every parent has had moments or thoughts like that. No one understands. No one suggests that if the child had been easier or the family had had more support, this could have been avoided. The crime is punished harshly, and the victim is remembered and mourned.

When someone with a disability is murdered by their parents, the opposite happens.

Why does it happen?

Because we live in a world where disabled lives are valued less than the lives of people without disabilities.

Because we live in a world where people think it is better to be dead than to be disabled.

Because we live in a world where killing your disabled child is excused, minimized, and normalized.

Because we live in a world where this is okay.

Frequently Asked Questions About Filicide

Isn't this caused by lack of services?

It's absolutely true that people with disabilities and our families don't get enough services. But that's not what causes these murders.

There are thousands of families across the country with insufficient or nonexistent services who refrain from murdering their disabled family members. In addition, most high-profile cases have occurred in upper-middle-class communities and have been committed by parents who either refused services, or had more family services than is typical. This is not about services. Suggesting that murders could be prevented with more funding holds people with disabilities hostage: ***give us what we want, or the kid gets it!***

When disgruntled employees take guns into their workplaces and murder their colleagues, we don't use that as a launching point for a conversation about how Americans need better employee benefits or more paid leave. When students shoot people in their schools, we don't use this as a launching point for a conversation about anti-bullying policies. This doesn't mean that we don't care about worker's rights or student safety; it means that these are separate conversations, and combining them makes excuses for murderers. We feel that drawing a line between filicide and lack of services is equally inappropriate.

Is it a hate crime?

Yes and no. A hate crime is a crime that is motivated by bias; disability hate crimes are defined as crimes that are committed because of a bias or prejudice against disability. Filicide in the disability community is almost always about the person's disability, so in that sense, yes, this is a hate crime.

Legally, disability-related hate crime can only be persecuted on the federal level if it is inter-state, and individual states vary in their state-based hate crimes laws. Check your state to see if filicide related to disability can be considered a hate crime under state law; if not, consider lobbying your state legislature to include disability in your state's hate crimes statute, or to adopt one if your state does not have one.

Why is it bad to try to understand why someone might do this?

Filicide is a horrifying act, and wondering how someone could do this is a natural response. But when we progress to saying "I understand why someone would do this," or "but you have to understand," we are not just saying that we have thought about what motivated the killer - we are saying that the killer's actions make sense to us.

Our society's reactions to filicide reflect our beliefs about disability. When parents of kids without disabilities murder their children, we are universally united in condemnation. It is only when the victim is disabled that we pause. It is only when the victim is disabled that we are encouraged to understand.

This is a double standard, and it reveals dangerous things about our beliefs.

When we say *every parent of a disabled child has had moments like this* or *walk a mile in our shoes* or *the system failed everyone* or *but you have to understand how hard it is*, we are excusing a parent murdering their child. It does not matter how many times we say *not that I would ever condone this*: if we attempt to make a parent murdering their child understandable, if we ever attempt to position it as a comprehensible or inevitable or *normal* thing, if we take and normalize the perspective and the side of abusers and murderers, we are minimizing and excusing this act. Doing so puts the lives of disabled people everywhere in danger.

There are absolutely things we should understand about filicide. There are absolutely people with whom we should empathize. We should understand that filicide is not committed by loving parents. We should empathize with the victims. But to say, "I don't condone the murder but I understand it," is to say, "This is bad, but it isn't *so* bad if we put it in context."

We do not believe that this is a good way to talk about murder.

But anyone who would kill their child, or try to kill their child, must have a mental illness. Doesn't that change how we should think about this?

Filicide is not a symptom of mental illness. Filicide indicates a decision to murder. These decisions are deliberate and often premeditated for days or weeks. The perpetrators of filicides are often evaluated and found competent to stand trial.

Saying that only mentally ill people would commit a murder can make some people feel better, but it's not true. People with mental illness are no more violent than the general population - but, like people with developmental disabilities, they are often the targets of violent crimes. When we're talking about cases where people with disabilities are murdered by parents, invoking mental illness is just a way of blaming one group of people with disabilities for the murders of other people with disabilities, and shifting the blame away from the person who is actually responsible - the murderer.

How do we talk about this?

Names: to discourage copycats, **don't** use the full name of the murderer. **Do** use the name of the victim.

Sympathy: as with any other murder, **do** humanize the victim. **Do** unequivocally condemn the murder. **Do** mourn the victim. **Don't** sympathize with the murderer.

Be mindful of anti-disability bias: **don't** imply that it is better to be dead than disabled, that disabled people experience a lower quality of life, or that we cause other people to suffer. **Do** use respectful language, and **do** consult with people with disabilities.

Focus: **don't** give the murderer a platform. **Do** center the victim.

Don't refer to filicide as mercy-killing.

Don't talk about services in the context of filicide.

Do be mindful of the potential for copycat murders:

- avoid using the killer's name or giving them a platform
- focus on the victim, and
- avoid grisly sensationalism.

Do write about filicide against a disabled victim the same way you write about any other filicide.

How Can We Prevent This?

1. Change the conversation

Center the victim. Condemn the murderer. Refuse to “understand,” excuse, justify, minimize, or normalize a parent killing their child. Refuse to accept this. Refuse to allow this to become our new normal.

2. Prosecute

Call for these crimes to be prosecuted to the fullest extent of the law, similarly to other filicides. Demand that people with disabilities have equal protection under the law. Consider lobbying your state legislature to include disability in your state’s hate crimes statute, or to adopt one if your state does not have one.

3. End ableism

Challenge ableism (anti-disability bias and prejudice) everywhere you see it. Challenge the idea that it is better to be dead than disabled, that disabled people are a drain on society, that disability means suffering, and that disabled lives are not worth living. Promote inclusion, community integration, and acceptance.

4. Self-report

If you think you are going to harm your child or adult relative, turn yourself in. Call 911 or child protective services and say “I am thinking about killing my child.”

5. Community reporting

If someone you know is talking about killing their child, turn them in. Often in the wake of a filicide people come forward to say that days or months before the murder, the perpetrator made a comment to them suggesting that they were contemplating homicide: “I’m despairing about my child’s condition - I think this is the end for him,” or “kids like mine should be put down,” or even “I am thinking about killing my child.” In addition, report any indications you might see of child abuse or child neglect. Abuse and neglect of children and adults with disabilities is very common and extremely under-reported, and many filicides are preventable escalations.

What do I do if this happens in my community?

1. Get the language right

Change the conversation: challenge poisonous ideas and help prevent copycat crimes. Read “How do we talk about this?” for more.

2. Hold a vigil

Mourn the victim and call for justice. See our vigil guidebook at the end of this toolkit for more.

3. Watch the media

Encourage journalists to speak to disabled people, follow best practices for preventing copycat crimes, center the victim, and treat this filicide like all other filicides. Refer them to this toolkit. Push back when they make mistakes.

4. Push back

If someone attempts to justify, minimize, or normalize the murder, challenge them. Don't let them interpret your silence as agreement.

5. Sentencing

Call for the harshest possible sentence under the law. Emphasize that people with disabilities have a right to expect full and equal protection under the law.

6. Call for hate crimes legislation

As appropriate, advocate for expanding state and federal hate crimes legislation to include disability and filicide against disabled victims.

7. Hold the justice system accountable

Contact your local protection and advocacy agency, your local FBI field office, and your district attorney. Let them know that the disability community is watching. Let them know that we are outraged. Tell them to do their jobs.

How to Hold a Vigil: Site Coordinator's Guidebook

Choose and confirm a location

An ideal location is accessible by public transportation, in a public space, and somewhere that gets some foot traffic. It should also have some relevance to the issues we are calling attention to – **holding your event in front of a courtroom, City Hall, or your DA's office sends the message that we want the justice system to take this seriously.** However, if it is prohibitively cold in your area, try contacting local non-profits to see if you can use their space for your vigil.

If your event will be on public property (recommended), **you must get in touch with your local police department to find out if you need a permit.** Your city may not require a permit in order to hold events on public property, but you do absolutely need to have someone call the police department, using their non-emergency number, and confirm this.

Sample script for this call: “Hi, I’m planning an event at [place] at [day/time]. It’s a vigil for people who have died. We’ll be reading some statements and holding signs. I’m calling to ask whether we need a permit for this?” **If they say yes:** “Okay, could you talk me through how I can get one?”

If you want to use candles, you should ask about that during this call. Some places need it specified on the permit if you will be lighting candles, and some places will not allow it during a public event.

If you are planning a Day of Mourning vigil, you should have your location and time pinned down three weeks before the event. If you are planning a vigil in the wake of a recent murder, you will not have this kind of advance notice, but **do secure your location as soon as possible.**

Use Facebook to announce your vigil

Once you have your time and location, you can start spreading the word about your vigil. Begin by making a Facebook event page.

Savannah Nicole Logsdon-Breakstone is ASAN’s Social Media Director. Make sure to include her as a co-administrator of your Facebook event page. She will be easy to find, as no one else on Facebook has this full name.

As well as using Facebook to invite people you personally know, reach out to local organizations and ask them to send the link to their members. You don’t need to stick to disability rights organizations – other groups focused on social justice issues, such as LGBT groups, may be willing to help promote the event as well.

You can also create and spread flyers with the time and location of your event. Leave stacks of them with friendly organizations, and post flyers around your area. Email jbascom@autisticadvocacy for a customizable copy of ASAN's template, or feel free to make your own.

In the run-up to the 2013 Day of Mourning, some vigil sites received threatening, offensive comments on their pages. The commenter did not show up to any of the vigils, but ASAN's policy is to take threats seriously to ensure our members' safety. **If you receive aggressive comments on your page, especially if they mention or allude to physical violence, these are the steps to follow:**

1. Take a screen capture of the comment. If you don't know how to do this, Google "screencap+mac" or "screencap+PC," depending on which type of computer you are using.
2. Delete the comment.
3. Ban the commenter from accessing the event page.
4. Call the local police (again, using the non-emergency number) to report that an online threat has been made about an upcoming event which will take place on public property. Give them the time and location of the event. Let them know that you have a screen capture of the comment and can email it to them.
5. Get in touch with ASAN and let us know what happened. Email us your screencap as well.

Reach out to the press

Getting media presence at your vigil is very important. Our goal is not only to mourn our dead, but to send a message that our lives are equally valuable, and society should treat us as such. We are calling for states to prosecute these murders as aggressively as they prosecute the murders of non-disabled children. We are calling for journalists to write about these murders in a way that respects the victim, not in a way that excuses the murderer. These demands are more powerful if more people know about them. This is why it is **vital to maximize press presence at your vigil.**

The first step is to **create a press list.** Look up your local newspapers, radio and tv stations – they should have a "contact us" or "report a news tip" page on their website which will tell you where to send a press release. You can also contact local non-profits and ask them if they have a list of press contacts they would be willing to share with you. This may save you time if your vigil has to be planned quickly. If there has been a murder or attempted murder in your area recently, you should also contact the reporters who wrote articles or reported on TV about the case. Compile the email addresses and phone numbers you find into a list of contact information. This is your press list.

Get in touch with your Mayor and/or District Attorney's office and invite them to send a representative. If they agree, you should include this in your press release and mention it when you speak with reporters. This will give local media more incentive to attend your vigil.

If you are planning your vigil for more than two weeks out, send the first press release to everyone on your press list 1-2 weeks before the event. If your vigil will be sooner, just send the press release as soon as possible. If you do not have time to send individual emails, you can enter every email address on your list into the "BCC" field of a message, and then begin it with a generic salutation such as "To whom it may concern". If you can, follow up with another email one week before the event, or on a shorter timeline, a few days before. In the few days immediately before your vigil, you should also make some phone calls to the offices of local newspapers and TV stations.

See the next page for a template press release.

Template Press Release

NOTE: If there has been a recent murder or attempted murder case in your state, or especially in your local area, make sure to include a paragraph on this in your press release.

For Immediate Release

[the date you are sending out the press release]

Local Contact: **[your name]**

Phone: **[phone number where you can be reached during the day]**

Email: **[your email]**

Local Disability Community Commemorates Lives of Disabled Filicide Victims

[YOUR CITY] – As part of a nation-wide Day of Mourning, disability rights advocates in the **[your city]** area will be holding a vigil on **[date]** to honor the lives of disabled people murdered by their families and caretakers. **[If this vigil is for a specific incident in your community, replace “As part of a nation-wide Day of Mourning,” with “In memory of [victim]”]**

Over 50 such murders have been reported in the United States in the last five years, over 20 in the last year alone. The total number of killings is likely higher than the amount which are reported in news media. We must address violence against people with disabilities and speak out against the dangerous cultural prejudice that says a disabled life is not worth living.

The Autistic Self-Advocacy Network, Not Dead Yet, and the National Council on Independent Living held the first Day of Mourning in 2012 as a response to the murder of George Hodgins, a 22-year-old autistic man from California, by his mother. Day of Mourning is a national event, with around fifteen participating cities each year.

Little public attention is paid to the disabled victims of these violent acts. Media coverage and public discourse about such killings frequently justifies them as “understandable” and sometimes “merciful,” rather than appropriately condemning these crimes and those who commit them. The national Day of Mourning is a time for the disability community to commemorate the many lives cut short. By honoring disabled victims of murder and celebrating the lives that they lived, these vigils send a message that disability is not a justification for violence.

The **[your city]** vigil will be held at **[location]**, and begins at **[time]**. Speakers will be **[if you have a list of speakers, put it here, making sure to include job titles if relevant]**.

--

Autistic Self-Advocacy Network (ASAN) is an inclusive international non-profit organization run by and for autistic people. ASAN seeks to advance the vision of the disability rights movement in the world of autism. Drawing on the principles of the cross-disability community on issues such as inclusive education and community living, ASAN focuses on organizing the community of autistic

adults and youth to have our voices heard in the national conversation about us. In addition, ASAN works to advance the idea of neurological diversity by furthering the view that the goal of autism advocacy should not be to create a world without autistic people. Instead, it should be to create a world in which autistic people enjoy the same access, rights, and opportunities as all other citizens.

Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill and disabled people. Not Dead Yet helps organize and articulate opposition to these practices based on secular social justice arguments. Not Dead Yet demands the equal protection of the law for the targets of so-called “mercy killing” whose lives are seen as worthless.

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

Materials

All you really need for a vigil is the list of names and your prepared remarks, but it can be helpful to have additional materials. You can make signs with slogans (for example, “No excuse for murder,” “Mourn for the dead and fight for the living”), or have cardstock and markers available for attendees to make their own. A display of photographs of the victims is a good way to honor them as individuals, and many people find it more moving to look at pictures of people who have died, than to hear or read their names.

You can also print out and distribute this year’s flyers and posters (available on the ASAN website), and have a sign-in sheet for attendees.

Most sites choose to incorporate candles into their vigils. If you are not allowed to have open flames at your site, or if it is very windy, consider using battery-powered candles instead.

What kinds of things to do at a vigil

- It’s a good idea for the site coordinator, or someone on your team, to prepare remarks for the event. If you can line up additional speakers in advance, this is even better. There will be some sample remarks available on the ASAN website.
- Remember, the purpose of this vigil is to remember disabled people who were killed by their parents or caregivers and to mourn our dead, but also to send a message that our lives are equally valuable, and society should treat us as such. We are calling for states to prosecute these murders as aggressively as they prosecute the murders of non-disabled children. We are calling for journalists to write about these murders in a way that respects the victim, not in a way that excuses the murderer.
- Light candles (or turn on electronic ones)
- Read the list of names. You can ask one person to read the whole thing, or pass the list in a circle, having each person read one name. Use discretion – if there are young children present at your event, consider reading only the names and ages, not the methods of killing, as these can be very disturbing.
- Moment of silence
- Invite attendees to speak if they have things to say
- Take pictures or video of your vigil and send them to ASAN

Keeping the Promise: Self Advocates Defining the Meaning of Community Living

Background

In June 2009, the Centers for Medicare and Medicaid Services (CMS) announced they would be publishing regulations defining the character of home and community-based settings. CMS acknowledged that, “some individuals who receive Home and Community Based Services in a residential setting managed or operated by a service provider have experienced a provider-centered and institution-like living arrangement, instead of a person-centered and home-like environment with the freedoms that should be characteristic of any home and community-based setting¹.” CMS stated that using such settings to provide “home and community based” services are contrary to the purpose of the 1915(c) waiver program.

The purpose of this paper is to provide CMS with a definition of "community" that captures the most vital elements of community life. In addition, we believe that these comments are important contributions to policy issues in the areas of housing, education, employment and transportation.

Introduction

Over the course of the last half century, the United States has made many important promises to its citizens with intellectual and developmental disabilities. These promises are found in the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the decisions of the Supreme Court and other federal courts, the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, and other laws, rules, decisions, and findings. Those of us on the “receiving end” of the promises have taken our Nation’s commitments seriously. We expect that when our country guarantees “access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” [as in the

¹ “Medicaid Program; Home and Community-Based Services (HCBS) Waivers; Center for Medicare and Medicaid Services. Advance notice of proposed rulemaking.” *Federal Register* 74 (June 22, 2009) Page 29453-29456

Developmental Disabilities Assistance and Bill of Rights Act] the promise will be kept. We believe that when our country recognizes “the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (as in the Rehabilitation Act of 1973 as amended, 29U.S.C.794), that we will indeed be in control of own lives.

When taken together these promises made to citizens with developmental disabilities establish a clear national purpose:

- Increasing self-determination and personal control in decisions affecting people with developmental disabilities and their families
- Providing opportunities for people with developmental disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with developmental disabilities
- Investing in each individual's developmental potential and capacity to contribute in age-related roles as productive and respected community members
- Ensuring access to sufficient, high-quality health and social supports to protect each person's health, safety, rights, and well-being
- Moving people with developmental disabilities out of poverty by significantly increasing opportunities for real work with real pay

Together these points outline a national commitment to integrated and respected community living for people with developmental disabilities. We know this national commitment can only be achieved with assistance from service and support provider agencies that are committed to and capable of delivering on these collective promises. Because these agencies are funded through the Medicaid program, the Centers for Medicare and Medicaid Services (CMS) and associated state program agencies are

responsible for the quality of service and support delivery. CMS's direction is central to setting standards and expectations for service providers.

Yet, despite this promise, many individuals who receive home and community based services do not experience genuine community settings or lifestyles. Many individuals are subjected to segregation, loss of control, lack of support, restrictions, no meaningful access to community and other challenges. Over time supporters of segregated, secluded, discriminatory or even exploitive models of care and support have adopted rhetorically the language of person-centered planning, insisting that its principles are at work in their program plans. Increasingly this has become a defense for practices that actually contradict the goals of individualized supports. Too much emphasis is being placed on the Person-Centered Planning rather than the measure of its outcomes. Did planning result in the individual having more control and choice in their life? Part of the problem is that often the choices being offered are from a profoundly limited menu.

Outcomes from self-directed lives must be the measures of success. Is the person enjoying a healthier and more satisfying life on their terms? Who is in charge? Does the individual have more control and choice? Is their participation in community genuine and meaningful? Are their relationships authentic?

To address these problems, the Autistic Self Advocacy Network (ASAN), Self-Advocates Becoming Empowered (SABE) and the National Youth Leadership Network convened a National Community Living Summit of self-advocates with developmental and intellectual disabilities. Twenty-five people attended the Summit. Immediately after the Summit, our team conducted 72 one-on-one interviews with our peers with developmental disabilities attending SABE's national self-advocacy conference. The Summit proceedings and interviews addressed three specific questions:

- What are three things that determine that a place or residential program is not part of the community?
- What are three things that determine that a place or program where a person gets residential services is truly in the community?

- What does Community Living really mean?

In attempting to answer these questions, we engaged both through our summit and through our interview team and interviewees a wide array of different backgrounds, experiences and identities reflective of the broad diversity of our great nation. Our participants came from across the country and from every age group. They differed not only in the types of disabilities and accommodations, but also in their languages, their incomes, their religious beliefs, their sexual orientations, their mode of communication, their races and ethnicities and every other manner of diversity. Some came from big cities, others small towns and rural areas. Some talked about having spent time in institutions - others had grown up in the community. Some have spent many years of their adult life in a sheltered workshop or day program – others are competitively employed. While we know that no effort can capture every aspect and facet of our wide and diverse community, we believe that this report and the process that led to it was broadly inclusive and captured many voices typically left out of these discussions. We assert the need to leave no voice behind and are proud of the diverse community this report represents.

From the answers to these questions, we found that over and over again people said that “community” was more than just a place, size or numbers. We found the definition of community living to be multi-dimensional with many different levels, layers and domains. Five particular “dimensions” stood out to us:

- physical size and structure;
- rights and self-determination;
- qualities and attitudes of providers;
- access to community life; and
- the meeting of support and access needs.

Our recommendations from the Summit and interviews are categorized into these five aspects of community living stated above. **To ensure that community integration is available to all people with disabilities regardless of where they live, we recommend applying these standards broadly to all community based services**

and settings, regardless of whether or not the building in which a person lives is owned by an agency, service provider, the person themselves or other third party entity. By these standards, we commit to hold those in power accountable to the promise made to us in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Rehabilitation Act, the Individuals with Disabilities Education Act and countless other pieces of legislation as well as regulations, proclamations and other public statements. Thus, we do declare that the following principles capture the meaning of living in the community:



Physical Structure and Size:

We are not in the community when we experience:

Segregation and Isolation: No matter the size, if services support segregation and isolation of people with intellectual and developmental disabilities from the community, it is not community. Segregation includes “locking” us away and is both wrong and dangerous, as it opens up the possibility of undetected abuse.

Policy Guideline: Gated communities, farmsteads, and clusters of group homes—even those that include both people with and without disabilities—are not in the community. When we live in those settings we become segregated from the general scope of community life. One summit participant noted that community must “integrate with people who don’t have disabilities, and this does not mean staff.”

Lack of Control: It is not community when a provider, licensing authority or the physical structure of a building takes away control from the people who live there. We must be free to come and go as we please. It is also a problem when we lack the ability to control the privacy of our own lives, by limiting our ability to lock the door of our rooms or our bathrooms or by forcing us to share a room with someone we don’t know or don’t desire to live with.

Policy Guideline: Homes in our community must reflect the personal style and preferences of the people who live there. We should have a key to our homes and be able to lock our bedrooms and bathrooms for privacy. We should not be forced to share a room with an unknown or undesired roommate. We should have the right to freely access and use kitchens, laundry rooms, and other social and domestic areas of the home.

Policy Guideline: People should have the freedom to choose whether to live in a rural, urban or suburban community. People should have reasonable access to places of commerce, recreation, and other aspects of community life.

Large Size: A large congregate care facility is not a home in the community. If a half dozen or more people live in a provider-owned group home, it is almost never controlled by the people who live there.

Policy Guideline: A home should not be considered “in the community” if more than four unrelated people live there.

Policy Guideline: We should live in apartments, houses, condominiums, trailers, etc. located in rural, urban, or suburban communities with typical public resources such as shops, houses of worship, places to work, and accessible transportation systems. We have the right to live in a safe community among people with and without disabilities.



Rights and Self Determination

We are restricted from experiencing community life by:

Rules: When we have to do what we are told and staff watch our every move. When we don't get to make rules where we live.

Lack of voice: When opportunities for typical life activities are strictly limited to what the provider will allow, not our own preferences.

No ability to see friends or family: When we experience limits on our freedom of association. When we are restricted and at times punished for expressing our sexuality. There is a lack of freedom to come and go. When we feel like we are being locked in.

No say: When we feel disempowered (due to restrictions on freedom and strong self-advocacy).

No choices: When we have no or limited choices. People make decision for us - limiting choices about where to live, food, clothing, health care, and spending money.

Policy Guideline: We must have a right to privacy. We must be able to have time to ourselves and have a private space with a door that can be locked against intrusion by staff or housemates.

Policy Guideline: We must have rights of freedom of mobility, choice, and association. Staff cannot set rules about: a) where we go and when, b) when and what we eat or drink, and c) who may be invited into our home and at what time.

People are empowered to live in the community by:

Choice: We have choices about where and with whom we live, how to spend our time, what to buy, what to eat and drink, where to go, how to have fun, what to wear, where to work, who to chill with, who we date and marry. We are supported to make our own medical and sexual decisions. We choose who will give us advice.

Policy Guidelines: Meals are not brought in from a central location designed only to prepare food for people with disabilities. We have the right to choose what to eat, when to eat and where to eat. When eating at home, meals are prepared in a kitchen unless food is ordered from a restaurant or another location available to both individuals with and without disabilities. We can choose to make our own meals and use the kitchen when and how we want to.

Risk: We are supported to take risks, even if others don't approve. It is not a big deal when one of us makes a mistake. We get support to carry out a plan even when a provider does not agree with the decision being made. Service providers support us to get non-biased information when making decisions.

Policy Guidelines: We should receive value-neutral support (if requested) to make decisions about employment, spending money, diet, entertainment, travel, clothing, recreation, friendship, sexuality, relationships, medical decisions, and other relevant parts of community life. We may reject this support and choose to make a different decision; we may choose not to receive this support if we do not desire it.

Policy Guideline: We, as persons with disabilities, are required to follow one set of laws (the same as for other U.S. citizens and residents). We live free of rules established to control people with disabilities.

Qualities and Attitudes of Providers

Attitudes and qualities of providers which limit our opportunity to be a part of the community include:

Group Treatment: Agencies that operate programs of congregate care and group treatment that diminish our opportunities for a life and daily routines of our own choosing.

Power Difference: Agencies that create power differences between those providing services and those receiving service so that we are controlled, disrespected and denied a chance for self-determination.

Denial of Choice: Agencies that do not take the time or have the skill to listen for and identify our personal goals and preferred lifestyles. Agencies that are not committed or able to give us the chance to do the things and to be with the people that are most important to us.

Lack of Respect: Agencies that fail to teach their employees of the value of each person and the ability of each person to communicate his or her desires. Agencies that fail to teach their support staff to respond to us in a respectful, age-appropriate and helpful manner.

Branding: Agencies that draw attention to themselves at the cost of the persons they support by branding their homes, their vehicles, and their activities.

Dual Loyalty: Agencies that communicate to support providers that they are working for the agency first and for us, the people they support, second.

Attitudes and qualities of providers which enhance people's opportunity to be a part of the community include:

Respect: Agencies that teach respect for each individual they support as an important person by listening, learning and responding in ways that honor us as individuals and increase our control over our own lives

Uniqueness: Agencies that teach and help support providers to know and respond in age-appropriate ways to each of us as a unique person with unique interests, preferences, needs and goals- not as a person defined by our disabilities.

Independence: Agencies that teach and expect support providers to truly support us to be more independent rather than to do things for us.

Choice: Agencies that measure how they are doing in responding to our preferences and desires for life as a community member and make changes as needed.

Equality: Agencies that respect us as having and deserving real homes that are respected in the same ways as the homes of everyone else in the community.

Person-Centered Culture: Agencies that fosters personalized services through a person-centered culture of respect for both support receivers and support providers, including value-based training, low staff turnover and choice of support providers.

Freedom from Fear: Agencies that provide us with an environment in which we can live safely and without fear of harm, neglect, or exploitation from others, including from support providers, other program participants, or others in the community.

Policy Guideline: Those of us receiving services must have control over hiring, firing, and supervising staff. This supports our right to self-determination, balances the staff/consumer relationship, and makes clear that our needs determine the type of support provided.

Policy Guideline: Staff working to support us as persons with disabilities in the community must be trained about our rights, including the right to self-determination, and how to support our exercising choice and control in our own lives. There must be trained staff to support us in our home, to work, and to participate in the life of our local community.



Access to Community:

Community living is not:

Segregation: If we are forced to literally live outside a community, it cannot be a community living setting. If we live on the outskirts of town, and lack access to the mainstream of community life, we are effectively segregated.

Lack of Transportation: When we lack accessible, affordable transportation, we are kept out of our communities. It is important for us to have access to navigational aids so we can find bus stops, as well as access to training on how to use public transit.

Segregated transportation (for example, a bus that is run by a disability provider agency just for people with disabilities) is not what we want. We must have access to transportation on a basis that is consistent with individuals without disabilities. In rural areas or other places with poor access to public transit, it is important that additional measures be taken to ensure we as people with disabilities are not isolated and thus left more vulnerable to abuse and being left out of community.

Policy Guideline: Those of us receiving home and community-based services must have access to accessible, affordable transportation.

Denial of Choice in Relationships: We should be able to spend time with who we want. All of our relationships should be respected. Services and supports should accommodate our relationships, not the other way around. Absolute rules like unreasonable sleep time restrictions or not being allowed in each other's rooms do not respect our right to be with other persons. We also believe some regulations must be changed. We should not be prevented from marrying because of guardianship, Medicaid, or Social Security rules.

Policy Guideline: We should not be forced to surrender our right to associate with who we want and when we want to communicate as a pre-condition for receiving services. In addition, changes to Medicaid, Social Security, and state guardianship laws should

ensure that people with disabilities have the right to marry and live with whom we choose.

Employment:

Whether we work in sheltered workshops, enclaves, or day habilitation centers, vocational segregation of us from people without disabilities does not count as community living. It is not gainful employment if we do not have the opportunity to make money at the same levels as other people who work in our community. We lose an important aspect of community life if we spend our time only around people with disabilities, in day habilitation centers, and are not able to be included in our broader communities.

Policy Guideline: We must have opportunities to work in jobs as part of the general work force, among people who do not have disabilities. Opportunities for earning wages and benefits should be the same as everyone else. CMS funding should be used for supported employment and not be used for sheltered workshops or settings paying sub-minimum wage for people with disabilities. CMS community funding should not be used for any segregated settings, including day habilitation centers. Anything that segregates us from our communities is not community.

Community living is:

Choice and Agency: We can do what we want when we want to do it, instead of having to decide as a big group of people and move together. This does not mean being alone in our independence, but exercising our self-determination.

Full Citizenship. We should be able to contribute fully to the community. This should include voting and participating in civic organizations.

Making a contribution. We believe in reciprocity (two-way relationships), to be able to pay forward society's support. For example, if friends drive us somewhere, we might watch their kids in return. We should have the opportunity to volunteer and participate in civic life like everyone else.

Knowing What is Going On in the Community We want to know what events and activities are happening. We want support to understand information about important community issues to make good decisions and have opinions.

Access to Community Resources. If we have a problem, we want to know where to go in the community to help us with solutions. Libraries, service systems, governments, and churches should be accessible sources of information and support for us.

Being a Part of a Neighborhood. We should live in a neighborhood where we can connect with community members who live next door. We would like to be treated like neighbors, and have the opportunity to work to make the neighborhood a better place.

Policy Guideline: State laws that prevent voting by people under guardianship must be amended to honor a person's right to vote.

Policy Guideline: Rules must not exist that restrict relationships between us as people with disabilities and our neighbors in the community. Visiting with neighbors should be routine and unobstructed by rules about privacy or liability.



Support and Access Needs:

Community living is not:

Aversives, Restraint, and Seclusion: When we are subjected to aversives, restraints, or seclusion, we are excluded from the community by abusive, inhumane violations of our rights that are sanctioned and tolerated by those in power.

Lack of Control: If we don't have control over our own personal belongings, money, or personal space, we are not in the community.

Policy Guideline: We must have the ability to hire, fire, train, and evaluate our staff without restriction or limitation—including no limitations set through options approved by an agency.

Policy Guideline: Typically systems do not separate housing from the services received by a person who needs support 24 hours a day. This creates a situation where we are not truly in charge of the place where we live. CMS must address the issue of separating housing and supports. Changing providers should not require us to leave the homes where we desire to live.

Community living is:

Control: We are in charge of our lives, which includes directing our services.

Communication: A fundamental aspect of community participation is the ability to communicate. Individuals must have access to needed augmentative and alternative communication (AAC) support, including the assessment, education, technology, and support systems needed to make aided communication meaningful.

Policy Guideline: Those of us who experience challenges in spoken communication should be supported to try various methods of alternatives and augmentative communication (AAC). As new technology becomes available, we should have the opportunity to use it to communicate. Staff should keep trying to see what might work and support our opportunities to improve our ability to communicate with modes of AAC

that progressively vary in capability. Medicaid should pay for AAC devices, including AAC provided on “dual-use” devices and systems like iPhones or iPads.

Digital Inclusion: Telecommunications is a part of the modern community. While living in the community, we should have access to a phone, a computer, the Internet, necessary assistive technology devices and, if needed, digital literacy training to make long-distance and short-distance interpersonal communication meaningful. No limits should be set by staff on when and how we access these systems or what types of content we can access.

Policy Guideline: CMS funding should support us as persons receiving services to access the Internet and learn how to use online technologies.

Accessibility: Homes, transportation, and other aspects of community life and methods of support must be accessible—not just within the guidelines of physical access set by the ADA, but truly accessible to us as individuals living there. This means that our broader access needs are met—even if they are non-traditional.

Policy Guideline: Wherever possible, support should be provided in ways that maximizes our use of natural and peer supports in the community, not just paid staff and providers.

Policy Guideline: The goal of support and services should be to maximize our independence and empowerment. Respect the dignity of risk—avoid making suggestions that could take control of us in the context of providing support.



Conclusion

Self-Advocates Becoming Empowered (SABE), Autistic Self Advocacy Network (ASAN) and the National Youth Leadership Network (NYLN) want to acknowledge and thank Commissioner Sharon Lewis for asking us to present this information from the stand point of self-advocates which will show how decisions impact people's lives. This is in keeping with President Obama's charge to his administration. We have jointly presented indicators of what community is and what it is not. However, people don't need special skills or education to differentiate between "genuine community" and "community-like" settings or lifestyles. Genuine community means having real choice in assistance, friends, partners, supports and living circumstances. Genuine community happens in inclusive, diverse and mixed neighborhoods. Living in genuine community means making your own decisions and being an independent and self-sufficient citizen. Living in genuine community is enjoying all the same rights, privileges and responsibilities of every other citizen. In genuine community people have names not labels, live in neighborhoods not on campuses, make their own choices, and enjoy privacy and genuine relationships of equality.

To some people, these ideas may seem radical. Some people may say that they go too far. We disagree – it is only because of the low standards that have controlled the world of disability service-provision for too long are these ideas viewed as new or unusual. We believe that we should have the same rights and opportunities as anyone else. People with disabilities should be, and are by right, equal to people without disabilities. This simple but revolutionary idea is what has guided all of our recommendations and discussions. We refuse to settle for less any longer. We demand for ourselves and for our peers a community that places us in a position of equality to our neighbors. We reject the old models of "care" and "charity" for a world that is instead ruled by rights, interdependence and true community. By these principles, we make common cause and declare to a candid world a new chapter in the disability rights struggle.

Summit participants were of leaders from the Autistic Self Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies.

Autistic Self Advocacy Network

Elesia Ashkenazy
Noranne Cochrane
Paula C. Durbin-Westby
Andrea Joyce
Shawn Kirk
Savannah Logsdon
Ari Ne'eman
Scott Michael Robertson

Self-Advocates Becoming Empowered

Max Barrows
John Britton
Cathy Enfield
Chester Finn
Erin Johnson
Tia Nelis
Victor Robinson
Eric Treat
Joe Wrinkle

National Youth Leadership Network

Micah Fialka Feldman
Reed Hahne
Betsy Valnes

Allies

George Braddock
Lucinda Griffin
Charlie Lakin
Nancy Thaler
Karen Topper

Special Thanks to the Interview Team

Elesia Ashkenazy
George Braddock
Shawn Kirk
Savannah Logsdon
Ari Ne'eman
Nancy Thaler

Photos By: Shawn Kirk

This report was written by:

Max Barrows
George Braddock
Paula C. Durbin-Westby
Shawn Kirk
Charlie Lakin
Stacey Milbern
Ari Ne'eman
Scott Michael Robertson
Nancy Thaler
Karen Topper
Betsy Valnes
Nancy Ward
Betty Williams

Editing provided by:

Paula C. Durbin-Westby
Ari Ne'eman
Karen Topper

Am I really that different ...if I am Autistic?

Being autistic means that your brain works in a different way than other people's brains do.

- **Autism is a way of thinking, gaining information, understanding information, and learning.**

You are more like everyone else than different.

- **You have your own interests and things that you like to do, just like other people do. Your interests might not be the same as other people's, but that's okay because everyone has different interests and hobbies.**
 - **You have your own goals and dreams, just like other people do. Yours might be unique and different from your friends' goals and dreams, but that's okay because that's what you want to do!**
- **You are also a person just like everyone else, and you deserve respect and love like every other person in the world.**

You do have differences, and these are shared by other autistic people; you're not alone.

- **The way you experience your senses is different from other people. You might have a harder time with the school bell or in the school cafeteria than your classmates.**
- **You might like to move in different ways than other people.**
- **You might rock side to side or front to back, or flap your arms or hands, or flick your fingers near your face, or walk differently than other people.**

This is okay.

RESOURCES:



**AUTISM
ACCEPTANCE
MONTH**

autisticadvocacy.org

autismacceptancemonth.org

Press Releases

ASSEMBLYMEMBER IRWIN INTRODUCES BILL TO HELP PEOPLE WITH DISABILITIES SAVE MONEY FOR FUTURE NEEDS

Created: Monday, 23 February 2015 10:15

SACRAMENTO – Assemblymember Jacqui Irwin (D-Thousand Oaks) introduced Assembly Bill 449 to help people with disabilities save for the future. AB 449, the Achieving a Better Life Experience (ABLE) Act, allows people with disabilities to open special accounts where they can save without risking eligibility for Social Security and other government programs. ABLE accounts are similar to the widely used 529 education savings plan but would be used for disability related expenses.

“AB 449 provides people with disabilities a path to employment and greater independence and dignity,” said Assemblymember Irwin. “The costs of caring and providing for someone with disabilities can be enormous. This bill will give families and individuals a tool to save money to support the needs of people with disabilities.”

According to the **National Down Syndrome Society**, a person diagnosed with a disability cannot have assets worth more than \$2,000 or earn more than \$680 per month without forfeiting eligibility for government programs like Medicaid and SSI. This can have the effect of discouraging people with disabilities from working and saving. The ABLE Act will allow people with disabilities to earn money and save without losing access to essential safety net programs such as Medi-Cal and Social Security.

“When my daughter was born with Down syndrome, the nurse told of the amazing potential of people like my daughter, but also of limits our government puts on their ability to contribute,” said Brad Pitzele, a proponent of AB 449. “I am excited to see Assemblymember Irwin give my daughter – and all Californians with disabilities – the opportunity to achieve and contribute to their full potential. There is great self-worth and dignity that comes from demonstrating one's capabilities and achieving for one's self.”

The **Federal ABLE Act** was signed into law by President Obama with widespread bipartisan support in December 2014. Each state must take action to be able to offer the accounts to its residents.

Money put into ABLE accounts can be used to support education, housing, transportation, employment training, health, personal support services, and other expenses approved under federal regulations to benefit the person with a disability.

Assemblymember Irwin's website: <http://asmdc.org/irwin>

Jacqui Irwin was elected in November 2014 to represent California's 44th Assembly District, which includes the communities of Camarillo, Casa Conejo, Channel Islands Beach, El Rio, Lake Sherwood, Moorpark, Oak Park, Oxnard, Port Hueneme, Santa Rosa Valley, Thousand Oaks, and Westlake Village.