



Light at the End of the Tunnel

Revealing the Hidden Truths that Impact Individuals with
Autism Spectrum Disorders and Other Developmental
Disabilities

Summary of Key Findings

December 31, 2011

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“When my son, Jared was born I realized my life would never be the same—a mother of a child with a disability. I realized that change does not happen overnight, but it’s the journey you must go through to get to the destination of “Empowerment.”

**— Tonia Ferguson,
Director, The National Autism Resource and Information Center**

THE JOURNEY

Throughout the nation, many families in isolation are finding out that their child has been diagnosed with a disability. The journey through this experience can be devastating. Often time friends and family cannot relate. Yet many families are able to find the supports necessary to navigate through the complex system and move through the journey. The National Autism Resource and Information Center’s (Autism NOW) work involves important collaborations with many partners, including self and family advocates, disability organizations, university centers for excellence in developmental disabilities (UCEDDs) and the Administration on Developmental Disabilities (ADD), all of which have helped our first year become a great success.

We are pleased to present this summary report which introduces the process for uncovering the hidden truths that often time govern our society’s behaviors in believing that individuals with disabilities still cannot live full and productive lives in their communities. Our revealing data from year one has uncovered complex elements of culture and quality of life of individuals with Autism Spectrum Disorder (ASD) and other developmental disabilities.

We’ve tried to summarize the five summits and capture a handful of stories from some of the people whose lives have been touched by Autism NOW in the first year. These families and self-advocates have journeyed down the intense road of receiving a diagnosis; their struggles and experiences have generated a direction of options, hope, and empowerment.

They realized through the many connections at the Summits that there is **LIGHT AT THE END OF THE TUNNEL!**

Struggle—to—Strength

Unveiling of the Family and Individual Needs for Disability Supports (FINDS) Survey found that despite the gains in many areas, our nation still falls short and people with intellectual and developmental disabilities (I/DD) and their families are still living in the shadows and their future is uncertain. The Autism NOW Center brings a new vision and new light where parents and individuals who live with disabilities will no longer face a confusing maze of information and service systems alone.

The Center brings added resources to expand the limited knowledge of families wondering where to go for services or whom should I contact. The impact of The Autism NOW Center, serving as the central point of entry for resources and providing a link between research and the community improves the quality of life for individuals with autism and other developmental disabilities.

Our VISION

Our vision is to be the central place to gather, organize, and disseminate high-quality resources and information to self-advocates, family, professionals, and the public.

Our MISSION

Our mission is to be a dynamic and interactive, highly visible, and effective central point of quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, and other targeted key stakeholders.

Our VALUES

- Access
- Diversity
- Empowerment
- Hope
- Inclusion
- Partnership
- High-Quality Resources and Information
- Family-Centered
- Person-Centered
- Self-Determination

Our vision, mission, and values in helping families figure it all out is reflected in the goals we pursued during year one. Autism NOW worked during the year to strengthen the advocacy skills and empower individuals with disabilities and their families through The Center's four core functions of (1) information and referral; (2) webinars; (3) website and information dissemination; and (4) exchange of knowledge events.

“Participating in the Autism NOW Center means taking an active role in a child’s life. Autism NOW has impacted our family. We feel empowered and see that we are not the only one in the fight. Families are taking the knowledge and are applying it to their own individual situations to improve their lives and the lives of their children.”

— Mother of Dave

Engagement and Empowerment — By the Numbers

\$1.8 million	Value and time of service provided by those who have engaged with the National Autism Resource & Information Center connecting through the webinars, website, call center, and regional summits.
1,000	Number of people who have contacted the Autism NOW Center and the call center powered by the Autism Society of America.
120	Hours provided by the Autism NOW Center responding, supporting, and linking resources and information to the public.
48	Percentage of callers who called the Autism NOW Center about its opportunities to learn and cultivate free webinars.
12	Percentage of callers who called about the regional summits and inquired about the cost of attendance or registration.
11	Percentage of individuals calling about services including training and education, protection and advocacy, respite, funding, and support groups.
250	Number of people who identified themselves when contacting The Center as being a professional in the disability field.
147	Number of people who identified when contacting The Center as being a family member or guardian of an individual with autism or other developmental disability.
8	Number of people who contacted the Autism NOW Center from a foreign country.
56	Number of webinars hosted by the Autism NOW Center designed for self-advocates, families, professionals, and the general public.
9,643	Number of people who attended webinars both live and on demand.
50+	Number of states as well as foreign countries (including Canada, India, Guam, Australia, Romania, and China) of the registrants and attendees on the webinars.
19,262	Number of visit to the Autism NOW website .
52,453	Number of page views that have been loaded or viewed on the website.
913	Number of people who have “liked” the Autism NOW Facebook page.
97,492	Number of posts viewed on the Autism NOW Facebook page.
216	Number of followers on Autism NOW on Twitter .
315	Number of tweets issued by Autism NOW.

Where Have We Been?

As evident throughout our society, caring for a child with a disability is challenging and a life-changing event. From the moment, there is a defined diagnosis; families need to be as informed and savvy as they can possibly be in order to negotiate through the maze of information— that too often is characterized as overwhelming.

Many families face a “learning curve” into the world of resources such as professional journals; reports; as well as educational, medical, and other alternative treatments for autism. Also, a great deal of time and effort goes into becoming knowledgeable about all the hundreds of therapies and interventions sometimes filled with false hopes and anecdotal information. Previously without a clearinghouse to evaluate the many resources and information, families faced confusion, frustration, and were generally perplexed by the vast array of information about autism.

Where Are We Now?

The clear answer is for families and individuals with I/DD to be their own expert; to be empowered to take action to ensure that they live an independent and full life in the community. The National Autism Resource and Information Center is the catalyst for change and empowerment through a new presence in the autism and I/DD community that supports the voice of individuals with autism and I/DD and their families. Also, as an agent of change — Autism NOW is here to lighten the load and ease the burden on caregivers by taking the first step of action in gathering high quality resources and information that cross the lifespan.

The future may be uncertain for those with autism and other developmental disabilities, but Autism NOW is not uncertain in its goals and vision for individuals with I/DD. We are a permanent presence working to remove any barriers of access for individuals with autism and other developmental disabilities.

“The Autism NOW Center has given our family peace of mind knowing that we are doing all we can to help our youngest child with autism. We are learning about so many resources that are available because of participation on the webinars. It has been an amazing experience for us in unimaginable ways; we hope others will join in this effort to EMPOWER!”

— Mother of John Michael

REGIONAL SUMMIT INFORMATION

Registration and Attendance

- For the five Autism NOW Regional Summits, a total of 1181 people registered to attend. Of these, 1105 registered online and 76 registered on the day of the Regional Summit.
- Overall, approximately 650 attended the Autism NOW Regional Summits. The average attendance rate for these Summits was approximately 56 percent.

Autism NOW Regional Summit Attendance

	Attendees	Total Registrants	Attendance Rate
Washington, DC <i>(Metropolitan Area)</i>	115	215	53%
Indiana	120	213	56%
Florida	90	138	65%
California	205	399	51%
Texas	120	216	56%
TOTALS	650	1181	56%

Demographic Details: Geographic Breakdown

- Autism NOW Regional Summit registrants hailed from all around the country and world. Registrants represented all 10 ADD Regions; 24 states (AL, CA, CO, DC, DE, FL, IA, ID, IL, IN, KY, MA, MD, MI, NJ, NY, OR, PA, TN, TX, VA, VT, WA, and WI); and three foreign countries (Canada, the United Kingdom, and Bangladesh).
- While registrants came from around the country, the overwhelming majority of registrants, over 93 percent, came from the same region of the country as the Summit they attended (specifically ADD Regions four, six, three, five, and nine).
- There was one exception to this trend. For the Florida Regional Summit, only 43 percent of registrants came from ADD Region 4 and 7; other regions, and 3 other countries, were also represented in registrations. This greater diversity is most likely a result of the fact that the Florida Regional Summit occurred in partnership with the Autism Society of America's National Conference, which had over 800 participants from around the world.

Stakeholders Representation

- Registrants could identify what their interest was in attending the Autism NOW Regional Summit. Registrants selected as many categories as relevant to them and could write in additional reasons for attending. The 1105 registrants provided 1262 responses total.

- Of these responses, a great majority of people who registered for the Autism NOW Regional Summits were a family member of a person with autism or I/DD (45 percent), or a professional working with/for people with autism or I/DD (34 percent).
- Fourteen percent of the registrants for the Autism NOW Regional Summits were people with autism or I/DD. Of these, 82 percent were people with autism and 18 percent were people with I/DD.
- Seven percent of registrants were people who identified as another stakeholder, including friends of people with autism or I/DD, advocates, and students studying disability issues.
- Of the family members of people with autism or I/DD: 83 percent were parents of people with autism or I/DD; 10 percent were siblings; 3 percent were grandparents; and 2 percent were spouses.
- The Florida Autism NOW Regional Summit had an abnormally large number of people who were identified as “others”. This abnormality likely occurred because 26 percent of registrants were Autism Society of America (ASA) National Conference attendees. These participants were never further identified. However, it is likely, given that most participants of the ASA Conference are professionals and parents, that these “others” would be members of these two stakeholder categories.

Regional Summit Outreach

- Autism NOW Regional Summit registrants heard about the regional summits from a diverse array of sources, including the Administration on Developmental Disabilities, church groups, support groups, schools, presenters, Facebook and other social media outlets, local chapters of The Arc, emails, notices from Autism NOW’s national partners, The Arc, and Autism NOW directly.
- However, a great majority of people (48 percent) heard about the regional summits directly from Autism NOW (26 percent), The Arc (17 percent), and The Arc’s national network (5 percent).
- Hearing about the regional summits through colleagues (15 percent) and regional autism resource centers (11 percent) were the third and fourth most popular ways of hearing about the regional summits.
- About six percent of regional summit attendees heard about regional summits through notices from national partners, and one percent of attendees heard about the regional summits from the Administration on Developmental Disabilities.

Variation Between Summits: Outreach

The following table displays raw demographic information from responses to the Regional Summits' survey.

Category	DC	IN	FL	CA	TX	Average	SD1	SD2
STAKEHOLDER INTEREST								
Family of a person with autism or I/DD	112	102	54	176	122	125.87	45.00	90.00
Person with autism or I/DD	34	31	22	58	13	36.09	18.89	37.78
Professional working with people with autism or I/DD	68	91	39	162	74	100.85	50.68	101.37
Other	3	4	38*	9	12	11.17	11.89	23.78
OUTREACH								
ADD	0	0	0	1	5	1.23	2.01	4.03
Church Group	0	0	0	5	2	2.09	2.50	5.01
Local School District	2	4	0	7	7	4.72	2.93	5.86
Presenter Email	2	5	0	11	3	5.58	4.68	9.36
Local Support Group	0	5	0	1	18	4.41	7.29	14.58
Facebook	7	15	7	6	6	7.90	3.72	7.44
Other	3	9	4	21	4	10.60	8.75	17.49
Local Arc Contact	18	10	0	4	19	9.69	7.93	15.86
Email	15	7	4	28	8	15.50	10.79	21.59
National Partner Notice	2	3	43*	18	4	13.12	14.70	29.39
Regional Autism Resource Centers	20	21	0	65	21	33.49	26.68	53.36
Word of Mouth: Colleague	17	36	12	75	28	41.80	28.27	56.54
The Arc Website	53	52	2*	42	35	39.56	17.27	34.55
The Autism NOW Center	56	29	64	99	35	63.39	31.65	63.29
TOTAL RESPONSES	195	196	136	383	195			

*Starred items are outliers appearing over 2 standard deviations (SD) away from the weighted average of the data.

This information shows that, though each Summit had variations in terms of how the people heard about the Summit, the make-up of stakeholders there were very similar. In fact, only three distinct outliers are evident; each surrounds the Florida Regional Summit.

First, the Florida Autism NOW Regional Summit had an abnormally large number of people who were identified as "others". This abnormality likely occurred because 26 percent of registrants were Autism Society of America National Conference attendees. These participants were never further identified.

However, it is likely, given that most participants of the ASA Conference are professionals and parents, that these “others” would be members of these two stakeholder categories.

Second, at the Florida Autism NOW Regional Summit, a greater proportion (32 percent) of registrants heard about the Regional Summit through the national partners. A small minority of registrants (1 percent) heard about the Regional Summit through The Arc’s network. It is likely that these two outliers can be explained as a result of the planning and partnership between Autism NOW and the Autism Society of America (ASA). For the Regional Summit, Autism NOW (along with The Arc) and the ASA forged a partnership for the Florida Regional Summit. As a result of this partnership, the ASA was paid to market the event. Accordingly, their increased efforts explain why there were more notices sent out from their organization about the event. Also, because of this partnership, The Arc did not partner with a local chapter of The Arc. Accordingly, there was less use of The Arc’s network to drive publicity to the registration website.

Survey Feedback

During the Autism NOW Regional Summits, participants were asked about the quality of the Summit and for additional demographic information. Out of the 650 attendees, we received 202 responses (31 percent). While this information represents a sample of the Autism NOW Regional Summit attendees, this can help provide a clearer picture of who Autism NOW served during the Summits.

Demographic Details: Comparison of Survey Feedback and Registrant Data

Demographic data was recorded and compared between registrant information and survey feedback. This comparison suggests that the respondents to the survey represented a similar breakdown of stakeholders from the regional summits.

Initial Results			
Stakeholder Category	Registration Response %	Survey Response %	Difference
Family of a person with autism or I/DD	45	46	+1
Person with autism or I/DD	14	12	-2
Professional working with people with autism or I/DD	34	28	-6
Other stakeholder category	7	1	-6
Not Specified	13	0	+13

The three differences between the survey responders and all Autism NOW registrants are the lower amount of professionals and other stakeholders, and the significantly higher number of people who are “Not Specified”. The reason for the numbers not specified is that some survey responders did not identify their names; so, their feedback could not be attached with a constituent category.

Below, are the adjusted results percentages to account for the responses labeled “Not Specified”. These numbers were adjusted by breaking up the 13 “Not Specified” responses proportionately based upon the demographic data found in the registration information.

Adjusted Results			
Stakeholder Category	Registration Response %	ADJUSTED Survey Response %	Difference
Family of a person with autism or I/DD	45	52	+7
Person with autism or I/DD	14	14	0
Professional working with people with autism or I/DD	34	32	-2
Other stakeholder category	7	2	-5

This adjustments suggest that the breakdown is similar to the registration data; however, survey respondents tended to disproportionately over-represent feedback from family members and under-represent feedback from professionals and other stakeholders. It should be noted that though the sample is skewed slightly, that the information provides valuable demographic and quality control information regarding the Regional Summits.

Demographic Details: General Attendee Information

Gender

A large majority of survey responders at the Autism NOW Regional Summits were female (75 percent). The remaining 23 percent was female, and 2 percent of survey responders did not specify with which gender they identified.

Age

- Most of the survey responders were adults between the ages of 25–64. Forty-four percent of responders were ages 45–64, and 35 percent were aged 25–44.
- Five percent of the survey responders were younger than 24 years old, and only 3 percent were older than 65.
- Thirteen percent of survey responders did not specify what age they were.

Education Level

- Autism NOW attendees appeared to be well-educated. A majority (64 percent) of survey responders had at least a college degree. Of these, two percent of responders had doctoral degrees; 20 percent had graduate degrees; 38 percent had bachelor degrees; and 4 percent had associate degrees.
- Twenty-six percent of the survey responders have a high school diploma; of these, 17 percent have attended some college.

- Four percent of the responders did not receive their high school diploma or a GED.
- Of the survey responders, 2 percent did not specify their education and another 2 percent specified that they had other educational experiences.

Marital Status

- Of the 202 survey responders, 105 (52 percent) identified themselves as married. Thirty responders (15 percent) were divorced; 4 (2 percent) were separated from their current spouses; and 9 (5 percent) were widowed.
- A significant number (22 percent) of survey responders were single or never married.
- Four percent of the survey responders did not identify their marital status.

Ethnicity

- Responses from the Autism NOW Regional Summit show that attendees came from diverse backgrounds.
- 115 responders (57 percent) identified themselves as White or Caucasian.
- Twenty-four responders (12 percent) identified themselves as African American.
- Twenty-two responders (11 percent) identified themselves as Hispanic, Latino, or of Spanish origin.
- Nine responders (4 percent) identified themselves as being of Asian origin.
- Autism NOW Summits did have attendees who identified as being of some other ethnicity or race (3 percent, 6 responses) or as being multiracial (2 percent, 4 responses).
- Eleven percent of responders (22 people) did not specify their ethnicity or race.

Variation Between Summits: General Attendee Information

The following table displays raw demographic information from responses to the Regional Summits' survey.

Demographic Category	DC	Indiana	California	Texas	Average Response	SD1	SD2
GENDER							
Male	12	9	13	12	11.28	2.28	4.57
Female	30	42	34	46	38.17	8.73	17.46
Not Specified	0	1	0	0	0.26	0.49	0.98
AGE							
18 and under	1	2	0	0	0.72	0.95	1.89
18-24	2	0	1	4	1.80	1.74	3.49
25-44	17	18	17	19	17.58	2.59	5.18
45-64	16	23	22	29	22.69	5.97	11.94

Demographic Category	DC	Indiana	California	Texas	Average Response	SD1	SD2
65 and older	1	3	2	1	1.73	0.96	1.92
Not Specified	5	6	5	7	5.76	1.23	2.45
EDUCATIONAL BACKGROUND							
Some High School	1	2	5	1	2.17	1.81	3.62
High School Diploma/GED	4	5	4	6	4.77	1.14	2.29
Some College	9	8	2	15	8.70	5.37	10.75
2-year Degree	1	3	2	3	2.31	0.95	1.89
4-year Degree	13	17	22	24	19.09	5.38	10.76
Graduate Degree	12	13	9	7	9.95	3.05	6.10
Doctoral Degree	1	1	2	0	0.93	0.81	1.63
Other	0	0	0	2	0.57	1.01	2.02
Not Specified	0	1	1	0	0.49	0.56	1.12
MARITAL STATUS							
Single, Never Married	15	4	17	9	10.69	5.83	11.65
Married	20	37	14	34	26.70	11.18	22.37
Separated	0	1	1	2	1.06	0.80	1.59
Divorced	5	9	8	8	7.51	1.89	3.77
Widowed	1	0	5	3	2.23	2.13	4.26
Not Specified	1	1	2	2	1.50	0.59	1.18
ETHNICITY							
African-American	17	2	1	4	5.43	6.75	13.50
Asian	2	0	6	1	2.10	2.52	5.04
Hispanic, Latino, or Spanish Origin	3	0	6	13	5.75	5.67	11.33
Multiracial	2	2	0	0	0.93	1.12	2.23
Some Other Race	0	0	5	1	1.45	2.24	4.47
White	17	44	20	34	29.28	12.56	25.13
Not Specified	1	4	9	5	4.77	3.09	6.17
CONSTITUENCY							
Family of a person with autism or I/DD	23	28	17	32	25.13	7.19	14.38
Person with autism or I/DD	10	6	10	1	6.24	4.29	8.57
Professional working with people with autism or I/DD	8	18	13	21	15.35	5.81	11.62
Not Specified	4	4	7	10	6.36	2.98	5.95
Other	0	0	1	1	0.52	0.56	1.12
Number of Survey Responses	42	52	47	58			

This table shows that there were no outliers or significant differences between regional summits. In this case, outliers were determined to be any amount more than 2 standard deviations from the average.

While there were no outliers, there is one figure to note. When looking at the ethnic and racial breakdown across regional summits, the DC Regional Summit showed an interesting trend. The DC Summit responses came equally from people who identified themselves as white and those who identified themselves as African-American. This suggests that the attendees themselves showed greater diversity than in other regional summits.

Quality Control Information

Autism NOW attendees were asked to fill out quality control information regarding their experiences during the Summits. Specifically, attendants were asked to determine whether the Summit overall was “useful” or “not useful”; whether the topics were “useful” or “not useful”; whether the speakers were “effective” or “not effective”; and whether the networking activities were “helpful” or “not helpful”.

Across all Summits and responders, the responses were overwhelmingly positive. Over 96 percent of respondents said that the Regional Summits were useful, effective, and helpful.

Below are the raw responses about these questions. Please note that there are “very useful” categories mentioned in this data. In these instances, responders wrote in these responses unprompted.

Response	Overall Summit	Topics	Speakers	Networking Opportunities	Percent of Responses
Very useful, effective, helpful	5	5	0	0	1%
Useful, effective, helpful	194	195	195	195	96%
Not useful, effective, helpful	0	1	3	3	1%
Not Specified	3	1	4	4	2%

Using this information and the demographic information from the surveys, we were able to identify people who felt that the Regional Summits were particularly effective as well as those who felt the Summits were less effective. We have also identified the reasons for why people felt the Summits were more or less effective.

People Who Felt Summits Were Particularly Effective

There were 5 responders who felt that the Summits were particularly effective.

- There were 5 responders who felt that the Summits were particularly effective and wrote in the word “very” into one of the quality control categories.
- These responders represented a significant minority of the survey responders who identified themselves as aged 18–24 years (represents 14 percent of the 18–24 population); as having attended some college (9 percent of this population); as being either African-American (8 percent of the African-American population) or some other race/ethnicity (17 percent of this

population). In all other demographic categories, the responses represented less than 7 percent of the population. This suggests that people with these mentioned characteristics tended to find the Regional Summits more helpful and effective than other attendees.

- Of those survey responders who wrote-in additional comments on the survey, 3 people stated that they found the information presented in the Summits relevant and necessary; another 3 people felt the Summits were empowering; and 2 people enjoyed the networking opportunities available in the Regional Summits.

People Who Found Regional Summits Less Effective

- There were 10 responders who felt that the topics, speakers and/or networking at the summits were ineffective.
- These responders represented a significant minority of the survey responders who identified themselves as male (9 percent of male population); aged 25–44 years (represents 8 percent of the 25–44 population); as having attended some high school (22 percent of this population); as being divorced (10 percent of the divorced population); as being white (9 percent of the Caucasian population); as being a person with autism and/or I/DD (19 percent of this stakeholder population). In all other demographic categories, the responses represented less than 7 percent of the population. This suggests that people with these mentioned characteristics tended to find the Regional Summits disproportionately less helpful and effective than other attendees.
- Of those survey responders who wrote-in additional comments on the survey, 4 people stated that the Summit was less effective because of a perceived lack of self-advocate input and/or attendance; 3 people felt that there was not enough time for networking or speakers; 2 people felt that they already had significant experience or knowledge of autism; 1 person wanted more variety of topics; and another wanted handouts for topics.

ROUND TABLE DISCUSSIONS

Below is a sample of direct quotes from the Autism NOW Regional Summits' attendees that were given in response to questions asked in small round table formats.

“What is the most critical issue for individuals and other developmental disabilities right now?”

“...the critical issues... to reiterate, it looks like education; definitely relationships because, you know, I am a product, unfortunately, of a divorce because having a child with a disability is very tough.... Funding.... Employment...”

Medicaid

- **Female Speaker:** “I honestly think that the most critical issue right now is Medicaid. I know there are a lot—it's hard to pick; but in terms of what's most threatened right now, it's Medicaid funding.”

Education and Transition

- **Female Speaker:** “I'm in education as well, and I really would like to know how to get the funding to support the teachers in preparing them and helping them to learn how to deal with the different issues that we seem to have in the classroom...”
- **Female Speaker:** “One of the big areas I see is when the children transition into adulthood, it's like at age 18, and you kind of lose this whole kid system. And then you're like, ‘Wow. What's the next step?’”
- **Female Speaker:** “As a provider for adults with disabilities, I think what I run into the most is getting phone calls from parents that their children are transitioning out of the school system, and they don't know what the waiver is; and they don't know what supports are out there for them, and they just feel like they're left hanging.”
- **Female Speaker:** “As a parent of a younger child and with mainstreaming our children, I think that we need educated teachers who are aware of all the nuances of autism. And I think that teacher education training needs to be mandated.”

Relationships

- **Female Speaker:** “...the opportunity to have a peer group...”

Funding

- **Female Speaker:** “We're not low income, and we're not wealthy. So we kind of fall between the cracks. So that's my most critical issue right now.”

- **Female Speaker:** “If there's no way to pay for services, then sometimes they really are kind of stuck; we're trying to get them hooked up early in the process but the process is not very user friendly. And it just seems like with the current budgetary crisis, I worry about even if we get them on the list right now, eight years, ten years down the road, if those services are going to be out there for them. So with the growing population of students who are qualifying for autism spectrum disorder services, what's going to be out there for our kids as they transition from high school?”

Employment

- **Male Speaker:** “My brother is 51 and has Down Syndrome... we have to make sure our world understands that students with developmental disabilities have the ability to be productive citizen and that also includes paying taxes. That they'll have a skill level that they can go out and do competitive employment in a very productive way and be able to pay taxes, so it's not that they're just draining always, so my part of this is with adult transitions, and to understand this population is very much as valuable population as any other population in the United States of America.”
- **Male Speaker:** “Well, from my perspective being on the spectrum myself and knowing what I'm facing as an adult, I think one the biggest issue facing with people with disabilities in general is how can we become as productive members of society as possible? You know, regardless of how severely or intellectually challenged we are or severely impaired we are, we can be productive members of society as much as we possibly can, and it's what I've been trying to do for myself since the time I was little. I'm trying to get myself to a point where I can hold down a job and pay for my own services.”

Health and Medical

- **Male Speaker:** “Well, to me there are two issues that are kind of intertwined. One is has to do with getting help to such a large population of autistic people. I think the birth rate for kids with autism right now is like one in ten or something.”
- **Male Speaker:** “And the bit of an add-on issue to that for me is dealing with fake or bogus help or treatments, there are people out there who either knowingly take advantage of people looking for help or think they are helping when they're really not...And really getting it can be confusing for a parent or an adult; and the issue is being able to identify, okay, what works for my needs, for this person's needs and what does not, and what is true information and what is false.”

Social Skills

- **Male Speaker:** “And I'm going to the Indianapolis Metropolitan High School, which is in downtown Indianapolis; and I look around at a lot of the unruly students; and I ask, okay, which ones are autistic and aren't getting satisfactory help and which ones are just neurotypical and just being idiots?”
- **Female Speaker:** “I have a 21 year-old-son on the autism spectrum, and he has a disability. I'm going to have to agree with the social skills...And people definitely do look at him differently and don't talk to him, and what do I do?”

Early Childhood Education

- **Female Speaker:** “We need to make sure that those early childhood education programs are funded; and that we're giving out as much education and information to doctors, any kind of a doctor that has access to young kids so that the early intervention can take place.”

Recreation

- **Female Speaker:** “...since he's 16, he's kind of aged out of most of the after school and summer care options and so, just, that is very difficult. He just spends a lot of time at home just talking to himself and wandering around.”

Family and Caregiver Well-Being

- **Female Speaker:** “I just know in my own life I mean, just the health issues that you don't really think are kind of related to this, but they are, you know, I mean, because of the stress and all of that.”
- **Female Speaker:** “...stress is a huge part of that; and I would say probably most obvious is just depression. And about a year ago, after nine years of, trying to just stay on course and stuff, I hit a low and was diagnosed with clinical depression.”
- **Female Speaker:** “...it's kind of almost a little bit like what's that called— Post-Traumatic Stress Syndrome. You get the diagnosis and nobody ever told me this...there's the whole grief pattern and all of that which I'm not trained in that but, gosh, I wish there was more support for parents, especially even as they're diagnosed and all that. And I guess all through life I don't know. It's lifelong.”
- **Male Speaker:** Well, I think, initially, when our son was diagnosed I didn't understand why I was so sad. I didn't realize I was grieving for the lost child, the child that I lost. I mean, obviously, I still love the child that we had that was handicapped, but I'd lost that normal child.”
- **Female Speaker:** “What's difficult for me is my husband wants our son to be normal, and it's really hard for him; so I have the guilt of only having been able to have one child, and the child we have is special needs. And I suffer from chronic migraines, and they're getting worse; and I've lost a lot of weight in the last year just from stress.”

Bullying

- **Female Speaker:** “I think the number one issue for people with autism is bullying because people think we're different.”

Acceptance

- **Male Speaker:** “I'm a parent of a young, seven-year-old with autism. And I think for that, in my view, it's from that age group is in terms of most critical issues, is integration and inclusion...And so if we start, I think, inclusion early and getting students to understand one another and to build on their strengths, I think that's going to be very helpful for not just kids with autism, but all kids with different abilities and disabilities. And to kind of realize, value,

tolerate and celebrate their differences, so I think that, to me, is the most critical issue in the field.”

- **Female Speaker:** I think that one of the biggest issues is acceptance, not only in accepting your own limitations and knowing that ‘This is who I am’ and not having to say bad things about other people or about yourself; but it’s also getting acceptance from the community at large and acceptance from teachers and other people that are out there and letting them know that, ‘Hey, just because I’m different doesn’t mean I’m bad.’”
- **Female Speaker:** “I think that one of the things we need to combat in order to meet these issues is something that’s so basic, and that is removing the stigma.”
- **Male Speaker:** “About four years ago, I was diagnosed with Asperger’s [sobs]. We’re struggling.” [sobs]

Housing

- **Female Speaker:** “I also see housing is really critical. When folks are aging out how do they get some kind of housing with the supports they need and jobs.”

Access, Information and Referral

- **Female Speaker:** “So my frustration is, locally, I’m not satisfied that we have anybody that can evaluate him and tell us what his true capabilities are and how to teach him to achieve or reach those capabilities...”
- **Female Speaker:** “It’s frustrating not knowing where to go, where to start, who to talk to, because you seem to get the runaround; ‘We’ll talk to this person,’ or ‘Well, we can do that but there’s no funds’ and that’s what’s frustrating for me to not know how to help the parents as well as the teaching staff.”
- **Female Speaker:** “I feel like right now for parents in particular, where do they go? Who do they talk to? Where do they find the support that they need?”

“What would you want organizations that are advocating for people with disabilities to know as far as continuing to advocate on these critical issues?”

- **Female Speaker:** “I would just want them to know to never give up no matter how high the mountain seems and how many rocks sticking out of that mountain seem to be poking you, you’ve got keep climbing higher because if it’s not us speaking out for the kids we educate, if it’s not us parents speaking out for our children, and if it’s just not people like us who care about people with disabilities that keep climbing that mountain no matter how beat up we get, then the bottom’s going fall out and we’re going to be back to where we started. You just have to keep going and fighting the fight and having faith that something good’s going come out of it. And you just can’t let opposition or pessimism get in your way. You have to remain positive because there are people at stake.”
- **Male Speaker:** “...making people aware of always asking how we were doing. You know, “How are you guys doing?” I always appreciated them asking.”

“For you, your loved one, or the person that you know who has autism or another developmental disability: what are the three immediate goals for the next 1-5 years; and, what are three long-term goals for the next 5-10 years?”

- **Female Speaker:** I have a son who is 12 with significant autism. He’s significantly affected by this autism. He is non-verbal and he is not completely toilet trained. So probably the short-term goals are to really get him over that hump of toilet training. As he gets older, it’s a whole lot harder to deal with that. I mean, even things like when he messes his pants I take him into the women’s restroom, there’s nowhere to lay him to clean him up to, all of that; plus the fact that he’s, at 12 he’s looking more and more like a man and it’s just, and it’s hard for him. We can’t, there are very few people that can watch him because, you know, people are not comfortable with changing a 12-year-old, which I don’t blame them but, so, in terms of goals, the toilet training. We do have an augmentative device that we’ve had for a little over a year and just really trying to figure out if that’s going to work for him or not. And then I think the third goal would be, as we talked about at the previous table, just looking for, at this next stage of life, at 12 years old, different activities and things that he can be involved with that are appropriate for him. I mean, even things like camp this summer, I really wanted to find a special needs camp for him and it was, I know we got a 20-page list from somebody emailed out, but as I really dug deep in into what all of that really looked like, there really weren’t that many options on there. So, anyway, that would be it.
- **Female Speaker:** Well, I have two kids on the spectrum. One sixteen-year-old with Asperger’s and one thirteen-year-old with autism, so you know, the Asperger’s one is much more higher function. We do have different set of goals for them and so for my autistic son, he’s just going to go to seventh grade, and really I, you know, for the next five, four to five years that goes to get him as more independent as possible. So our IEP will be really focused on the functional goals; things that he can do in the community, going to the store, and self-help skill, and keep himself safe, and that would be the goals. And in preparation for future employment, which is long-term goals you know that...
- **Female Speaker:** So that would be your long-term would be three five to ten years would be...?
- **Female Speaker:** Five to 10 for employment, yeah some never be employment. In the next one to five years we also want to find out where his strength are and what he’s good at, you know. Because that would gear toward employment, what kind of job he would perform well, and the end in preparation for employment the next five years will be something a skill he would need, like communication skill, self-advocacy, and reading skill, you know, following instruction, so that’s all prepare for being able to live with some level of independence for long term.
- **Female Speaker:** I’m a parent of a sixteen-year-old son with autism. Very low verbal communication, but one of the immediate goals we’re still working on is self-help skills: showering —we’re still having issues with that, shaving—since he’s hitting puberty. We run into issues that I’ve come to a lot of conferences and they don’t really talk about them those kind of things with boys. So space is another thing we’re working on, personal space. He’s discovered girls, so that’s one thing we have to work on is knowing keeping distance. Let’s see, a long-term goal, he’s also, we’re trying to work on what can he do as he gets older. The school now is working with him going to Goodwill on some job related things. Just hanging up clothes, sorting

clothes, so what can he do for as he gets older can he hold a job. They have some programs that they're working at school that show pictures of can we do that, can we do this, would you like to do that, but since he's non-verbal or his communication skills aren't good, I think he's just pushing the buttons saying, you know, maybe he liked the picture, not so much that's the job he likes. So we're going to find out what can he do and what would he like to do as he gets older in the job market.

- **Female Speaker:** I also have two children with autism, a six-year-old and a seven-year-old, a girl and a boy. I can relate to you Robin, because there's been there in the past they have had little communication skills. There was a time when I never thought I would ever hear them say "I love you mommy" or even say "Mommy" for that matter, and through schooling, through the support systems in the schools, and the PECs, we've done PECs and other trainings and behavior plans, they have come a long way. They've my son is starting to really communicate his needs. My daughter's behaviors are getting tolerable [laughs], I can say tolerable.

My long-term goals for them is well, short-term goals is to continue their education and to learn to interact with other people and to be able to go as a family and do things in the outside world. And we're coming along. They've actually attended regular foot baseball game. We went to a baseball game, which I didn't think we would ever we ever, ever, ever do. And they attended a movie. They went to the movies, and that was just a scary thing, a scary even a thought that that would even be a possibility, and they managed it with a little bit of support. They walked in going this is scary, this is scary, and the behaviors, and we just had to talk them through it, and they managed, and now they like going to the movies, so.

My long-term goal is just what you ladies shared, is that they would be supported in their older years. I'm not a young person, and I have little kids, and who are they going to have taking care of them when they're in their 20's, which seems like a long time, but it'll be not, and yeah, and to have those sources in place by then, what do I have to do to make sure those things happen for everybody, and it seems like an overwhelming I'm not superwoman, but I like you, I want to see that those things are in place, and how do you do that? And that's why things like this Autism Now is important because and what we're sharing here is important because they need to know what it's like. They need to know what we're dealing with every day.

- **Olga Stolga:** My name is Olga Stolga [spelled phonetically]. I'm a special education teacher. I'm a parent of two children in the spectrum and I'm also very involved in the community. I feel blessed that my kids have had such purpose, such they are doing very well, but at the same time they have very specific needs that when there's not academic need, when they're not fighting a class, or it's hard to convince their teachers that they learn differently, that they need those interventions. As a parent sometimes I feel guilty because I hear other parents saying, my child cannot speak, and that's where I started, but at the same time the challenges never end. You know, my son, the only way he could get to talk to someone in the classroom was by falling off the desk, so that's how he kept falling and falling, and I said, why do you do that? Oh, that's the only way I have to make friends, that's the only way somebody pays attention to me. So the challenges are there in the spectrum. My long-term goal is that they that they finish school, that they live as productive citizens, and my biggest fear is that I'm not going to be there, all this time, all this support that they have, they may not have it and it's...I've tried very hard to make them independent and to their ability, but not their level, but it's my goal is that they if I'm not here, they can have a productive and fulfilling life.
- **Male Speaker:** They are cutting down on the number of hours they are going to be giving her so my goal right now is to see what I have to do to make sure that she can keep getting 20

hours of service a week. That's my short-term goal. Long-term goals for both of them is that I want them graduating from college.

- **Female Speaker:** Thank you very much. I'm also a professional working for the ARC of the Capital area, but I have two children who are on the autism spectrum. One is six-years-old yesterday, the other one is seven. My short-term goal for both of them is that their speech is improved and that they continue their education. My son is learning to spell and write, and he loves numbers. He's the one who has more the autism behaviorisms. My daughter is non—my daughter also has limited speech, but she's a very social child, so I believe that she will come along and she will improve in her language skills and her education. My long-term goal is that they will be able to be self-sufficient and take care of themselves and finish high school and hopefully go onto college and do something, be a productive citizen. And that's all I think we have time for. Thank you.
- **Female Speaker:** For me, I'm Norma, I'm the mother of a 20-year-old autistic son, and right now he's focusing on those three immediate goals, the three immediate goals for the first one to five years is hard enough, I can't even think five to 10 years because I don't know how to get the first five years taken care of [laughs]. The goals are obviously just trying to find where he fits in, where he'll be happy, what kind of I'd like him to live as independently as possible, he's not going to be ever totally independent, he needs a lot of supervision. So I'm not really sure, just searching for where he fits in and he'll be happy, where he'll be loved, where he'll be cared for that is as close to a normal what you'd want for your child, like I say normal is that somewhat independent, that he's not as dependent on me, that that fades off. He's not as dependent on his sisters, they're not going to have be there to you know, include him in their as they try to go on with their lives, have their families. I don't want them to feel that he has to be living with them and they have to care for him. He needs to be able to live with supports, so that's just trying to figure out where that's going to be and how that's going to look is the next ten years actually [laughs].
- **Female Speaker:** He's how old?
- **Female Speaker:** He's 20. So he'll age out of the high school he's at. He has two more years till his birthday, but then that's the big question. So I'm trying to work right now to figure out what's out there, where does he go. I've been looking for a while and he just doesn't fit in the larger group home settings. He needs more than just one on six. He needs like one on three you know, or at the most, or maybe. But anyway, I'm not really sure, maybe we've gotta go out there and make our own place and develop it, but that's another thing in itself. Where do you get the money, where do you get the help, how do you know how to do that, that's overwhelming.
- **Female Speaker:** I'm Kim and my sister's 20, kind of the same as what Norma was saying is you know my sister has seizures and has some issues where she needs constant supervision and you know, my mom's goal is for her to go to a dayhab and then come home in the evenings. For me as a sister, you know, my mom's not getting any younger. My sister's going to be aging out of school, and trying to find a dayhab where they do more than just recycle in our community, haven't found anything yet and though my sister needs a lot of support, she's also very smart, and so just to do recycle every day for the rest of her life is not what I want. She needs to be engaged doing some activities and just can't seem to find that, and then you know, what happens when you know, my mom can no longer take care of her in the evenings, you know, what do we do then, you know.

- My brother and I want to have our lives too, but also know that she is well cared for and close to us so that we can go and see her on a daily basis, so it's kind of like, we're not millionaires, I don't think we're going to be winning the lottery, you know, I'm a teacher so it's kind of like yeah, you can't really afford anything expensive, so you know, and thinking along those terms, we've thought about how about well how do we start our own place? And you search and you contact people and it just feels like you get the run around, so it's like don't even really know how to get that going. You know we have the knowledge and the know-how and the personal experience from being a teacher of special needs and living with special needs, so the knowledge you want to and all that is there, but the funding and how do you get it going seems to be a big well kept secret [laughs].
- **Female Speaker:** The three immediate goals for the next one to five years, my son is 22, so it's important that he be able to have a job and support himself, but to do that he needs to find somebody who is willing to work with him and the idiosyncrasies that he has. It's important for him to find friends. He doesn't have anybody that he communicates with or hangs out with except for his sister, and his mom, and his dad, so that's a real important goal. And I think for him an important goal is that he finish college and get a college degree. For the long term goals it's the same thing: for him to find friends, to find a job where he can live by himself, be proud of himself, be happy with himself, and to enjoy life.
- **Female Speaker:** Ok, my son is four and a half, so over the next five years a lot of the skills are coming are things I'm hoping to get through school, but I'm expecting to also have to do a lot of support on my own. Social skills is really big. I need him to be set up for his future. I don't want him to be home with me every day if I can help it, you know, go out, play, have fun, do whatever, you know. Empathy is so important for him because he doesn't have it. And so he is strong, he's kind of like a bully himself, so I need him to understand how other people are feeling and that other people don't know what he knows, so he can't understand if he sees something a certain way that other people might not notice it or see it the same way, you know. He has trouble understanding other people's disabilities or even just limitations for age, like his two-year-old brother. He doesn't he can't understand that his brother jus simply cannot read so shoving a book in his face is just not going to help him, you know. And then also, his learning behaviors and because he has like an aversion to learning, because his communication skills have been difficult and everything has been therapies he doesn't want anything to do with something that looks like it's going to be difficult, so if you pull out flash cards and we've come a long way with it because of ABA, but you pull out flash cards he's like, that's too hard, you know, I can't do that, you know, I'm tired, you know, whatever, you know. And so I need to be able to get him through that and not be so resistant to learning so he can be successful in his education.
- As far as goals in the next five to 10 years, I definitely want to have him doing vocational training and learning how you're going to be able to hold down a job, and you know, being able to meet times and meet expectations. I want him to be able to set goals for himself and possibly have an idea of what he wants to do and what he wants to be and you know, start coming up with ways to plan on how to attain those things. And then probably the last thing would be ensuring that he will have the supports at that age that he would need because right now what I can get through school obviously we keep hearing it, it's going to all end. And if he does still need certain supports then we gotta start figure out now how can we get that. And I think part of it might be me being trained on how to give him that support, you know, if you know, there's no funding and you know, he can't get it, but so in that way you know, trying to cover all aspects so that he can have a regular life and not be stuck or limited because of you know, his behaviors or you know, things like that, so.

“What does self-advocacy and self-determination mean to you?”

- **Female Speaker:** Self-advocacy is people speaking up for themselves and learning what their rights are and having the opportunity to express themselves, and not only being able to speak out for themselves but also advocate for people who may not have the voice that they do. It means empowerment, it means a way of them feeling their own self power and understanding that they do have a voice and that they can make a difference in their own lives and not rely on other people.
- **Female Speaker:** Does anyone else really need to say anything else?
- **Female Speaker:** For me, as an individual, self-advocacy certainly means that I'm able to advocate for my needs. I'm able to let people know what I like and don't like. I think that when I think about self-advocacy for individuals with whom I work who have developmental disabilities, I think that self-advocacy changes to them being able to impact the environment to make it work successfully for them.
- **Female Speaker:** Self-advocacy means, you know, having power—you know not being, having the tools to not be oppressed because as we all know many people with disabilities, you know, face oppression and being part of a great civil rights movement [unintelligible] and learning to speak up for your rights.
- **Male Speaker:** Well I am a self-advocate and I am involved and I worked along with the self-advocacy movement, so when I hear the words self-advocacy what comes to mind is, you know, people with disabilities speaking up and, you know, taking charge of, you know, their lives and, you know, finding —assisting individuals with disabilities find the voice that will definitely lead them into a successful life and guide them how to take charge of, you know, what they need and what they want in life and to take command and take full control of and also take up, you know, protect their rights in terms of speaking up and to, you know, be fully included in the community in terms of, you know, work, you know, play, you know, social, you know, et cetera. But really, persons with disabilities really taking the lead, speaking up for themselves and finding that voice that will definitely help them become leaders and, you know, not only speak up for themselves but also other with developmental disabilities.
- **Male Speaker:** As a high school student thinking about college, the idea of self-advocacy, well, kind of comes crashing down on me because as pretty much for most — I've always kind of had educational resources guaranteed by the government and pretty much once I go to college, that's going to be gone. So, self-advocacy to me means I have to be able to go up to the dean, the teacher, the whoever and say, "Hi, my name is Jamie Cousins [spelled phonetically]. I am autistic and I have and I work best with X and Y parameters or settings, and I know you don't have to do this but if you do this will help me do the absolute best I can in this class," and that's what self-advocacy means to me.
- **Male Speaker:** For me, self-advocacy is, you know, speaking for myself and speaking for others, but it's truly a movement. It's not something that you can put a tag on and say, well, that's it. It's doing thing, it's a lifelong goal. I mean, it's something that you're not going to be able to leave and put on the table and say, well that's it, I finished it, I accomplished it. You know, so many times people will get their issues taken care of, whether it's, you know, moving to a new house or job or Social Security, or whatever it is, when they finish with their needs are, they figure they're done, but you're not. It's an ongoing movement, it's — you constantly have

to work on it, you constantly have to monitor what's happening and, you know, let people know that it's yours as well as, you know, making the way for other people.

- **Ronnie Cooper:** I am Ronnie Cooper [spelled phonetically] and I am the state president of the [unintelligible] and what self-advocacy it means to me, I could sit here until 9:00 tonight and tell you. Twenty-something years ago —twenty-one years ago, I came here in Indiana and I didn't know nothing. I mean, I was like [unintelligible] I was lost. Because I grew up down south, in Georgia, and there was nothing at all for the disability kids to do. I mean, you just sat there like this here, looking, wondering. I went to school. I graduated in 1988 and I went to school where the kids did not understand. I mean, I was picked on, laughed at, scorned—don't talk to her, she's different. I [unintelligible] table and I [unintelligible] myself a [unintelligible] I mean, anything that can happen to me, happened. I mean, literally, happened.

Well when I graduated out of high school, I had dreams, hopes and dreams of going to college but my grandmother was like, no you ain't going to college. You going to stay here with me. So I stayed home for two years and took care of my grandmother. I said I was her built in nurse because at that time she was getting sick, so I just stayed at home. Well, in 1990 when she got sick, she had a stroke, and my aunt, I have a aunt that I'm real close to. She said, "Come on to Indianapolis." "Huh?" I ain't never been to no Indianapolis. I had never left the country, but I came. And the moment that I walked off that plane, I knew [unintelligible] oh boy, look where I am now.

I got here in 1990, and I mean I started working, I got my first job at Goodwill, industrial. I worked there for six years, and it was not what I wanted. No, I don't want to be here, I got to go home [unintelligible]. When I left Goodwill, I went to [unintelligible] east side. I stayed there for 12 years. No, I got to [unintelligible]. This still ain't what I want. And [unintelligible] one day. He said, Mel [spelled phonetically] do you like what you do? I said no. I said I hate it with a passion. He said well, Mel, what do you want? I said I want a career but I couldn't see myself [unintelligible] that's not no career. But I kept on. I didn't give up and so one day I was sitting [unintelligible] I said hey I want to leave this job. I'm tired now. I [unintelligible] and I've got a good support, I got a husband, my aunt, all of them, they just, Mel, whatever you want to do, do it, whatever you want to do, do it. [unintelligible]

Okay, I want to leave my [unintelligible] I left my [unintelligible] and I came back downtown, Indiana and I'm working now the Arc up in Indiana and last year got promoted to president [unintelligible] and yesterday it was a good feeling to walk into the Arc office and to walk into my office and see my name. My name. I mean, it's awesome to me and these are things that happening in my life that I—hey, I would have never dreamed. [unintelligible] coming from Georgia 20 years ago, scared to death, now walking into my own office with my name. [unintelligible] that's a blessing. I mean, it's awesome, but it wouldn't have happened to me if I wouldn't have kept on going. Because I could have just sat around and being bored and depressed. No, I want to keep on going and like I said my goal is [unintelligible] not to stop. I want to keep on keeping on and I know that one day I can [spelled phonetically]. Thanks.

- **Male Speaker:** All right, well, self-determination, let me see, for me personally, basically the word means you're determined by yourself independent of other people. So, apparently, you're basically, I suppose it could be a philosophy of life, where basically nothing will hold you back. You're basically determined to do whatever you want to do in whatever given circumstance to achieve whatever goal you've set or to reach whatever destiny you've selected. Or it can mean on a certain issue, you are just determined to accomplish whatever you've set out to accomplish in the certain issue, I guess the role of advocacy, you're determined to, I don't

know, advocate for yourself or advocate for others on whichever group you've chosen to represent or whatever selective tactic. I think that's my idea of self-determination.

- **Female Speaker:** I just, I think for me it (self determination) means having control over my life, being able to kind of live the life I want to and do the things I want to do. Have the job I want, have—live in the community I want, so I guess that's what it means for me.
- **Female Speaker:** Determine your own destiny.
- **Female Speaker:** I think that's one of the challenges with self-determination, that you want to give them access but not have them think that it's an entitlement. Make them realize that all people have to compete and qualify, you know, when someone is hired the hiring group has to balance what are the strengths and weaknesses of every individual and how can that organization accommodate or deal with, you know, you never find exactly the perfect fit, everything that you need, but just to minimize, to be able to minimize what their challenges are so that their strengths can be seen for the strengths that they have.
- **Female Speaker:** My daughter is changing my definition of self-determination. My idea of self-determination means that you become your own advocate, that you want great things for yourself. Her idea though of self-determination is, no, I'm going to do what I want to, not what Mom wants me to. And I'm learning that in the case of her autistic tendencies, that means pull up, say no, and be very, very happy just staring at the computer or at her art supplies and her beading and not doing anything that I think are important parts of society. So when you say self-determination, I think it just means doing what you really want to do, not what the rest of the world wants.
- **Female Speaker:** My daughter is 17 and we're kind of in the same thing where there's things she wants to do and activities that she's done for a long period of time that she's let us know through her behavior that she's kind of ready for a break now, so we've taken a break. But I think, and I think a big part of that is it means you have control in your life. You have choices but you have control. And sometimes we do everything for the kids and they don't actually—you can talk our kids into things sometimes that it might not be what they want to do but we can manipulate them into doing it. And that's something that you have to balance, you know. We all have the deer in the headlight look.
- **Female Speaker:** My name is Dee and self-determination means to me that every individual with a disability has the right to make their own choices, whether they're good or bad, experience failures, take risks, and just experience their own dreams and live life to the fullest. That's what it means to me. I'm not a parent, I work in a professional capacity with individuals with disabilities, but self-advocacy, self-determination are critical principles to especially people with disabilities living their own lives without—with a minimal amount of guidance.