



**National Council on Disability  
Live, Learn, Earn Regional Forum Series  
Portland, Oregon  
May 5-6, 2011**

**Summary of Discussion May 5, 2011**

**National Council on Disability (NCD) Welcoming Remarks**

NCD Member and Vice Chair of Engagement Ari Ne'eman welcomed the attendees and gave an overview of the forum. He stressed the value of having input from all participants and indicated that feedback will be used in preparation for a NCD Congressional forum in Washington, DC.

---

**Regional Challenges & Opportunities**

- John Agosta, Vice President, Human Services Research Institute
- Ted Lutterman, Director of Research Analysis, National Association of State Mental Health Program Directors Research Institute

The panel gave a brief summary of intellectual disability and psychiatric disability treatment beginning in 1773 with the Eastern State Hospital in Williamsburg, VA, through the 1950's to present day. The current recession has reduced services for people with disabilities at the same time that demand is increasing.

Federal and state expenditures have failed to keep up with an increased demand for services since the 1950's. There was \$3.5 billion in federal reductions to mental health services in 2010 which contributed to the shortage of psychiatric inpatient capacity. This resulted in an increase in wait times for state psychiatric beds and overcrowding in state hospitals. Even in the community, people with psychiatric disabilities still face far higher instances of homelessness and lower instances of employment than their peers without disabilities.

There tends to be a trend to separate intellectual and psychiatric disability services. Counties provide the services using federal money distributed through the States. Some states provide the services directly and others contract through private partners. While 95% of people receive community service, many of those with disabilities denied access to preventative services, instead, seek costlier critical services in hospitals, homeless shelters, and emergency rooms.

Segregated programs result in overpaying for unnecessary services, but the current Home and Community Based Service (HCBS) model is too dependent on Medicaid. Limited resources need to be leveraged better by connecting people with disabilities with their communities. Connecting households to community assets such as clubs, schools, hospitals, and recreational opportunities will result in mutual support and valued outcomes for individuals, families, and systems.

---

## **Community Living Systems Change in Oregon—Leveraging Successes for More Wins**

*Moderated by Gary Blumenthal, NCD Member*

### **Panel 1: Experiences of Parties Involved with the Legal Settlement Surrounding the Closures of Institutions**

- Kathryn Weit, Interim Director, Oregon Council on Developmental Disabilities
- Marylee Faye, Administrator, Office on Developmental Disabilities, Oregon Department of Human Services
- Margaret Theisen, CEO, Full Access; President, Oregon Support Services Association
- Judy Cunio, Self Advocacy Coordinator, Oregon Council on Developmental Disabilities

An overview of the 20-year pathway to institutional closure in Oregon was presented. There are three foundations for systems change:

- 1-Building Values of Community Inclusion
- 2-Understanding Influence and Opportunities
- 3-Long Term Strategy

In Oregon, the process was aided by a United States Department of Justice (U.S. DOJ) lawsuit where Medicaid funding of institutions was at risk of ceasing. The state stopped admission to institutions while advocates had an understanding of budget and legislative strategies. Oregon found that the benefits of inclusion far outweighed the cost of building and maintaining institutions (where 30% of the budget was supporting 3% of the population), and settling repeated Olmstead lawsuits.

Advocates partnered with labor unions, family members, and communicated messages to the community to build public support. People on seemingly endless waiting lists for services were powerful advocates. Institutional minded parents focused on individuals' deficits and vulnerabilities, but once they transitioned family members with disabilities into the community, they realized that it is far preferable to an institution. Even the strongest institutional minded parents ended up testifying in support of HCBS. A waitlist lawsuit also resulted in a better service support system.

Judy gave a personal account of her experience in an institution and working in sheltered workshops. She indicated that while she was institutionalized she didn't have the skills to take responsibility or to make decisions and had to learn them on her own. She worked on self advocacy for 35 years and saw a lot of change in that time. She stressed that everyone needs to coordinate advocacy strategies and that everyone deserves equal treatment.

Panel members highlighted the importance of being proactive rather than reactive, that outcomes differ for each individual and empowering people to be self-advocates recognizing that they have the true power. People with disabilities need to get involved in various community clubs and activities. Once advocates collectively focus on the most difficult barriers to inclusion, other barriers will be easier to overcome. Working with staff from institutions to ensure that they will have jobs is important so they will not oppose people advocating for HCBS.

**Panel 2:** *Looking at the Need for Mental Health Systems Change in Oregon and Federal Investigation*

- Bob Joondeph, Executive Director, Disability Rights Oregon
- Chris Bouneff, Executive Director, NAMI Oregon
- Jane-ellen Weidanz, Adult Mental Health Services Unit Manager, Oregon Department of Human Services / Addictions and Mental Health Division

Even with the current reduction in mental health services, the need to provide these services will continue, and working with individuals to provide flexible wraparound services is the best approach. It is essential for advocates to focus on core principles and values and to work closely with the community to ensure people get entitled services. This will help overcome the institutional based thinking associated with prisons, jails, and institutions. A treatment response service system is the most desirable approach because people with PD face a stunted system. Using the case study of a person with a PD who lived in the institution for 15 years and died two years ago as an example, there is a great need for long-term systems change.

Oregon was at risk of returning to institutional based treatment of psychiatric disabilities, but there is now hope because of recent actions taken by the Department of Justice (DOJ) to pursue Olmstead cases more actively, supporting advocacy efforts emphasizing individual rights. DOJ investigated the state of Oregon, and the state wanted to pursue the problem proactively. The state did not want to see a delay in services, so it hired an outside consultant to look at service delivery and make recommendations for improvement.

Advocates need to move the frame of the conversation to getting people the right services at the right time and ensuring that early intervention services are provided.

---

**Systems Change through Litigation**

*Moderated by Ari Ne'eman, NCD Member and Vice Chair of Engagement*

*Transitions to community from institutional care; examination of the Success at Home Program in San Francisco, CA, following the settlement in the case of Chambers v. San Francisco*

- Elissa Gershon, Senior Attorney, Disability Rights California
- Jennifer Mathis, Deputy Legal Director, Bazelon Center for Mental Health Law
- Federal Partner: Henry Claypool, Director, Office on Disability, U.S. Department of Health and Human Services

The panel began with the history of the Laguna Honda Hospital and Rehabilitation Center in San Francisco, CA. With 1,200 beds, Laguna Honda is the largest publicly funded institution in the country. It costs \$500 a day per person to live there. Laguna Honda was the source of a major Olmstead Lawsuit, which resulted in 500 community-based housing vouchers for people with disabilities.

Services for people with disabilities are provided in a silo system where services are based on disability. Change involves a paradigm shift. Advocates need to focus on what the community needs to look like – not just HCBS, but the right kind of HCBS.

External forces like parents, providers, systems, industries, and elected officials all have their own interests. These interests help drive the system, not the rationality or practicality of services provided. This results in a “meaningless” system where services are not driven by common sense and are not providing people what people with disabilities want, just what the system assumes they need. Medicaid needs to focus on the services that work and that should drive the system. The money is available; it’s just not being used appropriately.

Stressing the importance of “real choice,” advocates need to make sure that institutionalized people with disabilities are making informed decisions. People can be afraid of transitioning out of a nursing facility. They have been told for years, sometimes even decades, that they cannot leave. People need to know what services are available to ensure their freedom.

Henry Claypool discussed his long-term support for the Olmstead decision of the U.S. Supreme Court. He was at the Centers for Medicare & Medicaid Services when the decision was handed down. Mr. Claypool wants to move towards the vision of a fully inclusive community. Mr. Claypool spoke about the benefits of the Administration’s initiatives including President Obama’s Year of Community Living, the Community First Choice Option of the Affordable Healthcare Act, new HUD funded 811 Multifamily Housing options and the Money Follows the Person (MFP) demonstration grant. HCBS regulations are open for comment right now. Mr. Claypool’s goal is to help break down the silos in service delivery.

Health and Human Services (HHS) is working with Housing and Urban Development (HUD) to get vouchers into the hands of people that need them. The cultures of HHS and HUD need to change and work together to address the lack of affordable, accessible integrated housing. Medicaid needs to be looked at with new urgency focusing on HCBS, not institutions. HHS needs advocates from the community to make change happen and to ensure that people with disabilities live in the most integrated setting. MFP now allows a fully federally funded position to bring housing and HCBS together. CMS is working with Public Housing Authorities to reduce voucher waiting lists. Advocates need to ask for housing voucher preferences for people with disabilities transitioning out of institutions. Nursing facility prevention and diversion are untapped opportunities to help people with disabilities avoid institutionalization.

Money is already being spent on people with disabilities through law enforcement, emergency rooms, hospitals etc. Shifting money to HCBS is an investment that saves unnecessary spending on these services and diverts it to more value added programs.

Change needs to come from the states. This involves collaborating with the right people including housing, HCBS providers, and elected officials.

HHS is shifting from tribal to state systems but needs input from the Native American population to assure cross-cultural application, implementation, and success. Since they are all seeking the same outcome, collaboration between the different types of disabilities within the disability community and older adults is an essential means to bring about positive systems change.

---

### **Transitions Back to the Community from Incarceration**

*Moderated by Carol Reynolds , NCD Member*

#### *Transitions to community from incarceration for people with psychiatric disabilities*

- Tim Cayton, Assistant Administrator Religious Services, Oregon Department of Corrections
- Liv Jenssen, Manager, Transition Service Unit, Dept. of Community Justice, Multnomah County

Incarceration rates have increased substantially in recent years because of the war on drugs and deinstitutionalization. 25% of people incarcerated have a psychiatric disability. As a best practice, prisons should have a mental health unit complete with transition specialists available to help get people out of correctional facilities and back into the community. Individuals about to be released should be evaluated for HCBS 6 months before leaving incarceration and should be discharged into an environment where they will not repeat their offenses. Transition plans need to be individualized, and include community engagement and a circle of support.

Many inmates are required to work 40 hours a week while incarcerated, but their salaries are so low that they have limited resources once released from prison. Employment services and Medicaid eligibility should be a key component of any transition planning.

Sex offenders face additional barriers when transitioning from incarceration into the community as well.

---

### **Law Enforcement Models and Mental Health Courts**

#### **Panel 1: Mental Health Focus**

*Moderated by Carol Reynolds, NCD Member*

- Julie Vann, Pretrial Services Officer, Mental Health Court, Washoe County, Nevada
- Jennifer Johnson, Deputy Public Defender, San Francisco Behavioral Health Court
- Beckie Child, President, Mental Health America of Oregon

A Bazelon pilot project is focusing on “unnecessary police contact” and will provide a one-year follow up report on its findings. The challenges are that the target population may not directly impact the people being unduly harmed by the law.

People with psychiatric disabilities oftentimes have trust issues with law enforcement. It is important to get law enforcement looking beyond the roles and function of policing through diverse representation in advocacy efforts. One way to do so is by establishing a Mental Health Court.

People with disabilities have the right to decide whether to participate in a Mental Health Court. They can do so in any instance, with the lone exception of murder. The creation of a criminal record adds to the discrimination faced by a person with a psychiatric disability. Mental Health Courts have criminal justice involvement and have been proven to reduce violence and recidivism. The work and needs addressed by a Mental Health Court will always exist, even without the funding. It is important for advocates to use the funding in a wiser manner by building a “consensus project” as a resource for police involvement.

Mental Health Courts help establish a relationship between service providers and law enforcement. They get services for people with disabilities to which they may not otherwise have access. Since a judge orders a Mental Health Court, which can create the gateway to services, one potential drawback is that it could be an incentive for people to commit crimes.

The San Francisco Mental Health Court is a blueprint for other jurisdictions to replicate. No resources are required to set up a Mental Health Court, as the vast majority of the resources required are already in place. It is just a matter of coordinating them. The phases of a successful mental health court are: orientation, stabilization, independence, transition and graduation. As indicated by the average number of days in jail before a mental health court is established—5,011; during mental health court—1,086; and afterwards—230, mental health courts have repeatedly been proven to be very successful and are well received by court systems and communities. That’s a 78% decrease between the year before and the subsequent year and a 95% decrease between the year before and the year after an individuals’ participation in a mental health court.

**Panel 2: Developmental Disabilities Focus**

*Moderated by Chester Finn, NCD Member*

- Margaret Theisen, CEO, Full Access; President, Oregon Support Services Association
- Officer Gregg Magnus, School Resource Officer, Community Services Division, Beaverton Police Department

A video entitled “Against the Fence” was presented by Margaret Theisen from Full Access. It showed the story of a 30-year-old man with a Developmental Disability (DD) named Riley who was assaulted by three high school students. Riley’s testimony led to their capture and was a model for a successful collaboration between local law enforcement and a person with a disability. The assault was a “biased” crime because Riley was targeted due to his disability.

A Citizens’ Police Academy for people with DD was then discussed. It is a community engagement program that teaches preventative safety skills, how to use 911 and strategies people can use to come forward to report a crime. It is inexpensive and well received by the community. Participants learn about targeted safety areas where they can feel comfortable, the role of the police officer, using public transportation, self-protection, the legal process, fraud,

emergency preparedness, and how to be safe in their homes. Participants also learn about legal rights so they do not incriminate themselves if accused of a crime.

The necessary elements to implement a Citizens' Police Academy for people with developmental disabilities are a willing agency to coordinate the program and a slightly modified version of a general citizen academy curriculum.

**--The NCD "Living" Forum adjourned for the day.--**

**National Council on Disability**  
**Live, Learn, Earn Regional Forum Series**  
**Portland, Oregon**  
**May 5-6, 2011**  
**Thursday May 5, 2011**

**Summary of Discussion May 6, 2011**

**Welcome Back**

Sara Gelser, State Legislator for the state of Oregon gave a summary of the state budget and its impact on people with disabilities. The current situation surrounding HCBS is not about raising taxes or cutting services, but providing them in an efficient way. Sharing personal stories is the most effective advocacy strategy. She encouraged participants to hold elected officials accountable for what they do and reminded them that it is their right to do so.

---

**State Budget Discussion**

*Moderated by Gary Blumenthal, NCD Member*

*Possibilities for systems change in light of state budget challenges*

- Chuck Sheketoff, Executive Director, Oregon Center for Public Policy
- Kathryn Weit, Interim Director, Oregon Council on Developmental Disabilities
- Bob Joondeph, Executive Director, Disability Rights Oregon

No matter for what services people are advocating, it is essential to follow the revenue stream and funding sources generated from taxes. In Oregon, the Ways & Means Committee spends the money, and the Revenue committee makes it by assessing taxes. Several expenditures do not make sense. Most frequently, the highest income people pay the smallest share of taxes. Laws that have a sunset provision will end automatically if the Oregon State Legislature does not act. This is a positive strategy for advocates because it results in more investigation to determine the effectiveness of the legislation. Panelists advised looking for effective means of distribution of services. Even tax breaks for people with disabilities do not really help. One tax break for people with disabilities in Oregon saves \$177 per individual, yet cuts \$8.7 million from services. Over-spending did not cause current budget problems with HCBS; it is a revenue problem, because taxes are not being collected as they were previously.

The Ways & Means Committee should be the target for advocates' action because it is where the money is spent. When dealing with billion dollar budgets, the amount for HCBS is insignificant. While HCBS waivers are currently threatened, the system needs to eliminate institutions. The entitlement for nursing homes still exists so it is vital to preserve and maintain HCBS. The challenge posed to advocates is to maintain values while reinventing ways to provide services more efficiently. No one wants or can afford programs that are ineffective, so budget problems are an opportunity to improve services and to rebuild better and stronger programs.

The current budget situation is an opportunity for positive change. Using Oregon's history with statewide healthcare reform as an example, managed care was considered, and was an opportunity to learn and to make change.



Panelists stressed the importance of building coalitions with a variety of partners and using individual stories in advocacy strategies. Panelists encouraged participants to appear at public hearings and tell personal stories. When elected officials make decisions that impact people, they will think about those personal stories and it will impact their decisions.

It is important to know the system, government, and how laws are passed. Whatever the proposal is, panelists encouraged participants to look at how it will impact core values of community inclusion and be clear about how it will impact individuals. There is always a methodology behind budget cuts and advocates should try to understand why they are being made in an effort to counter them.

More than half of the money drug companies get comes from government programs. Elected officials are not bad people. They only do what they “have” to do. A budget crisis allows for discussions that may not have happened otherwise, prompting elected officials to rethink about the poor expenditure of funds on institutional care. Federal reductions will affect state services as well.

Advocates can be too narrowly focused on programs for specific types of disabilities (i.e., DD, ID, Psychiatric, Physical, Sensory, etc.) and need to keep in mind that not everyone is eligible for Medicaid. We need to look at other programs like General Relief and Temporary Assistance for Needy Families (TANF), too. Even though these are not programs specifically for people with disabilities, they oftentimes turn out to assist us in times of need.

Elected officials don’t know programs when they’re elected so it is up to advocates to help them understand programs, processes, and results. We assume everyone knows about the modern disability movement but some elected officials have very old ideas about disabilities and do not understand the direction the movement is going. Effort directed to informing officials about why antiquated policies of segregation and discrimination are not good for anyone are vital.

Advocates are citizens as well, and they should embrace this detail when meeting with elected officials. Building relationships with elected officials and getting to know reporters should be routine, as well. In both instances, it is important to learn if elected officials or reporters have any people with disabilities in their families and speak using simple terminology.

States decide how to use federal funds. Programs like Vocational Rehabilitation are just as important as Medicaid yet are not an entitlement, so millions of dollars are returned to the federal government each year because states will not pay the match requirements. This puts an additional strain on services.

---

### **Safeguarding the Rights of Parents with Disabilities**

*Moderated by Ari Ne’eman, NCD Member & Vice Chair of Engagement*

- Ella Callow, Legal Program Director, The National Center for Parents with Disabilities and their Families; Through the Looking Glass
- Megan Kirshbaum, Ph.D., Founder & Executive Director, Through the Looking Glass; Co-Director, The National Center for Parents with Disabilities and their Families

- Katy Kaplan, Assistant Director, Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities
- Kelly Buckland, Executive Director, National Council on Independent Living

The State Independent Living Council (SILC) in Idaho found that parents with disabilities were losing their children in cases of child protection, adoption, divorce, separation, and guardianship simply because they had disabilities. Children placed in foster homes simply because their parents have disabilities are in a far worse position for adequate care and community integration. Parents with disabilities are three- to four-times more likely to lose their children. Obviously, this issue calls for further engagement in this issue.

The Idaho SILC created a “Committee on Family” made up of various state agencies and people with disabilities. The committee reviewed language in legislation and sought to modernize it. They found deep attitudinal barriers, and the courts discriminated and ruled against parents with disabilities. Idaho was eventually able to change the laws but is the only state in the country to do this. This is an example of how successful SILCs can be in changing policies. If you provide the right supports to parents with disabilities, there is no reason they cannot parent. Parents should have the same rights nationwide. Presenters shared that currently, Idaho is the only state to offer such protections, though it should be a federal law.

In Idaho, the courts, the attorney general, the prosecutors, the judges, and the service providers were all involved in helping to overcome discriminatory beliefs. Then they helped to gain supports/services for parents with disabilities and conducted trainings on parenting statewide.

Disabilities are legally considered “aggravated circumstances,” in many state laws, which is on the same level as torture, murder, and abuse. Parental rights are often terminated on that basis. In some instances, taking children away from their parents exacerbates disabilities.

It is important to work with people with disabilities faced with losing their children. Children are often removed because the courts determine that the “parent is not fit to care for them.”

Some states have reviewed legislation to make sure parents with disabilities cannot be discriminated against. A California law on “mentally disabled” parents sets the standard for two doctors to conduct a parental evaluation to determine whether a parent can benefit from services. This has parallels to literacy tests and voting for African Americans.

Parenting is a civil right and there is a great prevalence of parents with disabilities in the system. It is a constitutional, family values, and human rights issue, yet the disability community seems reluctant to get involved. It should be a priority and is a critical issue.

Advocates need to understand the most common opposition positions and develop the best arguments to debunk them.

Evaluation of parenting is based on the “safety of child,” but these tests are not effective at all. They do not accurately measure or determine what sort of parent a person will be.

Discrimination against parents with disabilities runs deep. Opponents always use the “safety of the child” argument. Despite the inaccuracy of horrific accusations, discrimination is prevalent.

Getting people who lost their children involved is very challenging. Even sympathetic elected officials and policy makers do not recognize that it is an issue because it seems like it is such an antiquated way of thinking, that it is not a problem anymore.

This is an evolving issue now because the end of forced sterilization and deinstitutionalization gives the opportunity for people with disabilities to become parents. Changing parenting policies state by state will take far too long, so a national solution is needed now.

A Bazelon paper on the limitations of the Americans with Disabilities Act (ADA) found that child attorneys and social workers do not know about, acknowledge, or use the ADA. The ADA cannot be used exclusively as reason to keep kids with their parents with disabilities, but since it applies to the adoption process, it can be used if accommodations are denied.

Attorneys are reluctant to take cases involving parents with disabilities because they are very difficult to win. That is why legislation that addresses this issue very important and needs to be pursued.

---

### **In and Of the Community**

*Moderated by Marilyn Howe, NCD Member*

*Once in the community, how does one cultivate a sense of community (acceptance, social capital, etc.)?*

- Mike Green, ABCD In Action
- Sharon Lewis, Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services
- Lynnae Ruttledge, Commissioner, Rehabilitation Services Administration, U.S. Department of Education

To truly be in the community, people with disabilities should be involved in non-disability issues. Talk to business about people with disabilities as a customer, not as a charity. Join THEM; do not always expect them to join US. No matter where you live, step outside of our disability-related world. The way to engage people is through meaningful conversations. Potential for partnerships exist within businesses, community organizations, etc. "Real Communities Georgia" is a model program. The State DD Council is sponsoring communities of practice. We have much to teach our communities about inclusion, and they have much to teach us about involvement.

Ensure that we have community builders. A real community life is not just about services. It is about relationships, friends, and neighborhoods. It is about building relationships from businesses you frequent. Informal relationships turn into informal respite services. Relationships turn into jobs and other opportunities. This change has to come from the bottom up. It is not a policy issue but rather a matter of individual social capital. The disability community needs to move outside of the service delivery system by leveraging supports. This is not going to come through the human service delivery system.

A section of the new healthcare law requires jurisdictions to allocate resources responsively, including strategies for independence and community integration. We need to engage people with disabilities as service providers, not just consumers of services. Getting this done comes from the individual and local levels. We want people to have rich lives, not just deinstitutionalized lives.

Fundamentally, we need to address people's attitudes about disabilities. Our discussions focus on what we cannot do, rather than what we can do. We tend to characterize people by their limitations, not strengths. People with disabilities have assets that need to be accentuated by showing strengths that contribute to the community. Look at models of employment and how people with disabilities are an asset. Work on access to programs, not creating new ones specifically for people with disabilities. The most uncommon partners are people who really have not thought about us nor know about us. Think about what we bring to the table. People with disabilities are an untapped market and we would do well to collaborate with the aging population and movement, as well.

Advocates should seek to change disability culture to leverage supports to be members of the community in the most meaningful possible way by showing young people with disabilities what their strengths are from early on in their lives and careers.

---

### **NCD Town Hall / Listening Session (*OPEN TO THE PUBLIC*)**

NCD Vice Chair Linda Weathers welcomed the over 30 people attending the Town Hall meeting and gave them a summary of NCD's three identified focus areas: Living, Learning, and Earning. Ms. Weathers explained that NCD wants to give people an opportunity to share priorities to represent first-hand issues in an annual progress report updating the President and Congress.

NCD has the authority to call hearings. This has never been done before, but will occur in Washington, DC on May 12, 2011. Comments heard today will be used to design questions NCD can incorporate into its Congressional Forum the following week. NCD wants to replicate the hearings in the states and wants to hear the names of programs people would like to see replicated and funding they want to continue. NCD is looking for individual stories particularly in the area of budget cuts, availability of housing, community supports and transition experiences.

Comments from the town hall are as follows:

- Support for brokerage service providers. Case managers focus on keeping people with disabilities in the community.
- There needs to be additional funding for Medicaid services. In addition, transition, community socialization, integration, and involvement need to be stressed.
- Budget cuts directly affect the ability of people with disabilities to stay in their own homes. We need to work towards making the system more efficient rather than cutting services.

- Person-centered planning helps people reach their own goals and is 100% community based.
- More case management services are necessary. It costs an average of \$1,200 a year per person for self-brokerage, but \$50,000 a year per person to receive services in an institution.
- People without Medicaid use services and are at risk of having their services cut.
- Brokerage companies are an essential component of HCBS.
- There is a need for affordable, accessible integrated housing. One commenter lives independently in a condominium where she cooks her own meals and does her own laundry. She believes that everyone should live independently.
- There needs to be more inclusive childcare programs. It is challenging to find childcare, especially for kids with disabilities. Childcare providers for children with disabilities need resources to help them without having to contact parents all of the time.
- Continuing funding for tribal vocational programs is needed, especially in rural communities where there is a lack of transportation, assistive technology, and deaf counseling. Accessible, affordable integrated housing is non-existent.
- Need support services in the community so people aren't isolated. Shouldn't be segregated in ghettos. Supports are vital to help people with disabilities become viable tax payers.
- Develop housing specific for individual disabilities that provide 24 hour care and a building with a doctor's office in the lobby.
- Improve access to healthcare and dental care.
- Have services specialized by different disability types.
- NCD should look at systemic issues with public schools, as they are disproportionately cutting services for kids with disabilities, which end up segregating students with disabilities.
- Prejudice of people with disabilities. Totally unacceptable attitude that people have. More systemic change needs to come from the top.
- People with mental illness face unique barriers. Demand increasing but services declining because of budget reductions. People need more opportunities like this to provide input. There is a need for more funding and advocacy for programs serving people with mental illness.

- There is an overlap of services for older adults and people with disabilities.
- NCD should support services for multicultural outreach.
- Homelessness disproportionately impacts people with developmental disabilities. Shelter plus care housing vouchers are a vital means to rectify this.
- Brokerage services teach vital independent living skills. Budget cuts will hurt this program, community living, especially for people who aren't Medicaid eligible.
- Spending too much on reactive services which are costlier than preventative services. Local funding cuts.
- Early intervention results in less reliance on services later on in life which saves money in the long run.
- Support collaboration with the Corporation for National Community Service. By serving with AmeriCorps, people with disabilities will gain employment skills, living skills, and social skills.
- Additional services specifically for people with Multiple Sclerosis (MS) are needed. People are oftentimes forced to stop working when diagnosed with MS which can lead to homelessness.
- People with disabilities need to pay rent late without incurring any late fees. If people with disabilities are evicted, then there are higher security deposits in the future.
- People whose sole source of income is SSI/D are not able to live gainful lives in the community.
- There is a great need for affordable, accessible, integrated housing.
- Resources for HCBS need to be distributed differently. They shouldn't be siloed through the various types of disabilities, but rather the type of service provided.
- There is a need for direct federal funding of Centers for Independent Living (CILs). Some states do not have a positive working relationship with their CILs, which leads to disproportionate funding.
- Specific requirements guaranteeing physical access to cluster mailboxes in neighborhoods and multifamily housing units needs to be established nationwide.
- There is a need for additional expenditures that support HCBS. There is also a need for services available to people with disabilities transitioning out of high school and into adult services. School districts need to be held accountable for IDEA compliance with an emphasis on integration.

- Raise the bar for expectations of HCBS for children growing up with disabilities, families, educators and communities.
- There needs to be an additional push for deinstitutionalization. Community integration saves money and employment and respite services provide opportunities for people to participate fully in the community.
- Self-advocates are seeking services appropriate to varying types of disabilities. Services currently offered to people with developmental disabilities are not adequate. Poor quality of services results in poor quality of lives of people with disabilities. Additional training for service providers is needed, as well.
- Funding for self-advocacy and empowerment programs.
- NCD needs to address Social Security marriage penalties and the low, \$2,000 savings threshold for SSI de-eligibility.
- Adults with disabilities need additional services, especially for aging parents who cannot care for their adult children with disabilities. HCBS are inadequate. There needs to be community based residential programs with access to employment and nearby communities.

---

### **Wrap Up, Next Steps**

*Moderated by Ari Ne'eman, NCD Member & Vice Chair of Engagement*

Vice Chair Ari Ne'eman thanked people for participating and announced that NCD is launching a new website the week of May 9, 2011. He encouraged people to subscribe to the NCD E-Newsletter and to find NCD on Facebook. Further comments can be submitted by e-mail to [ncd@ncd.gov](mailto:ncd@ncd.gov).

Mr. Ne'eman thanked the attendees, staff, contractors, and NCD Council Members for participating. He summarized the forum's recurring themes:

- Value of inclusion
- Community living
- Solidarity across the disability rights movement

Mr. Ne'eman stressed that there must be a unified disability community. To that end, community input is vital for NCD to set its priorities. He indicated that the participants' feedback will be used in preparation for a NCD Congressional Forum on May 12, 2011 at 3:00 p.m. in hearing room 2322 of the Rayburn House Office Building in Washington, DC.

**--The National Council on Disability's May 2011 Regional "Living" Forum adjourned.--**