



Disability and Health Partners Meeting

Connecting to reach our full potential

May 18-20, 2010

Meeting Proceedings

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Special thanks to our 2010 Planning Committee members: Jacqui Butler, Carla Cox, Sandee Colberson, Kay DeGarmo, Danielle Edson, Karin Ford, Paul Galonsky, Janylle Gilyard, Adriane Griffen, Jocelyn Gross, George Jesien, Jennifer Li, Michael Sanderson, Jamie Lloyd Simpson, Meg Traci, and Mary Helen Witten.

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Introduction

The annual [Disability and Health Partners Meeting](#) was held on May 18-20, 2010, in Atlanta, Georgia, as part of an ongoing cooperative agreement with the [Centers for Disease Control and Prevention's, National Center on Birth Defects and Developmental Disabilities](#) (NCBDDD) and the [Association of University Centers on Disabilities](#) (AUCD). The meeting was sponsored by NCBDDD's Division of Human Development and Disability and convened State Disability and Health Grantee staff, Public Health Practice and Resource Centers, AUCD network members, and CDC staff to provide opportunities for information exchange and technical assistance on topics in the disability and health field. Topics covered included the prevention of secondary conditions in persons with disabilities, access to public health programs, emergency preparedness, surveillance, livable communities, program evaluation, health promotion, training of professionals and paraprofessionals, and evidence-based practices. Partners discussed national health and wellness policy issues, state integration and implementation of disability and health, and projects that have been developed within their programs.

The proceeding information summarizes the Partner's Meeting and highlights current projects in disability and health across the United States. This will be useful for both meeting attendees and external partners as it will provide a deeper understanding of the structure and dynamic of our partners as well as the projects supported by the AUCD-NCBDDD Cooperative Agreement. Furthermore, it is expected that this report will assist with continued partner capacity building by highlighting potential connections with external organizations working to enhance the lives of people with disabilities.

Day One: Plenary Summary

The meeting was developed around the theme *“Connecting to reach our full potential,”* with the intention of setting the course for recognizing and building upon partner collaboration as well as encouraging sustainability. The Division of Human Development and Disability, NCBDDD, CDC noted in their welcome the rapid pace of changes in the disability and health field mentioning specifically the current trend towards strengthening surveillance and documentation of health disparities in people with disabilities, implementing health interventions at the state level, and analyzing policy effectiveness in a time of funding constraints and shrinking budgets which create challenges for partner program and project sustainability.

Health Care Reform – Health Care and Accessibility

Mary Andrus, Assistant Vice President, Government Relations, for [Easter Seals](#) reported that the recent passage of the Patient Protection and Affordable Care Act (health reform) will provide potential funding opportunities for partners who apply for prevention and public health grants, which could help to maintain program sustainability.

Michael Brogioli, CEO for the [National Association of Councils on Developmental Disabilities](#) (NACDD) followed with a [presentation](#) on health reform and its impact for people with disabilities. NACDD believes that health reform will provide affordable health, dental, and vision coverage while addressing the significant health and health care disparities faced by individuals with developmental disabilities. Mr. Brogioli reported that one important area that has been addressed through health reform language is the addition of individuals with disabilities to the definitions of “medically underserved populations” and “cultural

competence.” Mr. Brogioli believes that the emphasis of greater protections through reform for people with disabilities will support the State Developmental Disabilities Councils by creating opportunities for capacity building as members (many whom are connected to the partners represented at the meeting) collaborate to educate state constituents about health reform and implementation.

Terry Fulton, Investigator for the Department of Justice’s (DOJ) [Project Civic Access](#), complemented the project work in which many partners engage by advocating for greater accessibility standards for people with disabilities during his [presentation](#) on the American’s with Disabilities Act Title II requirements and compliance. The goal of the project is to work with cities, towns, and counties across the United States to ensure that they will take steps to make their programs, services, facilities, and activities accessible to people with disabilities. In addition to examining accessibility compliance issues, Project Civic Access through the DOJ provides technical assistance through accessibility guides that detail information on common accessibility concerns such as facility and website accessibility. Technical assistance such as this is an important example of a resource that partners can utilize to build program capacity and to sustain program efforts.

Day One: Concurrent Session Summary

State of Housing and Transportation

Kelly Buckland, Executive Director for the [National Council on Independent Living](#) (NCIL) and Billy Altom, Executive Director for the [Association of Programs for Rural Independent Living](#) (APRIL) [presented](#) on housing and transportation resources. Mr. Buckland and Mr. Altom [explained](#) that both NCIL, APRIL, and Utah State University are jointly contracted through the

[Independent Living Research Utilization Program](#) to provide national training and technical assistance to directors, managers, and staff of Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs). The technical assistance is designed to strengthen the independent living movement for people with disabilities across the nation. In addition, both NCIL and APRIL have partnered with the [Easter Seals Project Action](#) to develop a national volunteer network of coaches. This network trains mobility managers on independent living concepts. Mobility managers focus on the individual and identify the best transportation options for that person's travel needs.

Healthy People 2020 – What's Next

Margaret Campbell, Senior Research Associate for Planning and Policy Support at the [National Institute on Disability and Rehabilitation Research](#) and Eleanor Smith, Executive Director for [Concrete Change, reported](#) on the revised goals of [Healthy People 2020](#). The revised goals now include understanding and capturing disability status data as a population demographic. Dr. Campbell noted that partners will have opportunities to influence and modify Healthy People 2020 objectives over time with over 575 objectives planned. Partners should also expect to collaborate to support surveillance and tracking of disability as part of the national public health agenda, and develop new projects based on emerging issues such as work force development programs, health promotion and accessibility, and emergency preparedness.

Celebration Luncheon

July 26, 2010 will commemorate the [20th Anniversary of the American's with Disabilities Act \(ADA\)](#). The ADA is a comprehensive declaration of equality for people with disabilities

across the United States. To celebrate this landmark legislation, Donna Meltzer, Chairperson for the [Consortium for Citizens with Disabilities](#), and an advocate in the 1990s to secure passage of this legislation, presented an [historical overview](#) on the Act.

Helping Hands Award

The planning committee created the Helping Hands Award in an effort to recognize exemplary programs that provide opportunities for people with disabilities to be actively engaged and productive in their community. The Award was given this year to the [Walgreens Distribution Center](#), based in Williamston, South Carolina. Ms. Angela Mackey, Career Outreach Coordinator, and Mr. Larry Kraemer, Human Resources Manager from the Distribution Center, proudly accepted the award. Ms. Mackey explained that at the Center, people with all abilities work together side by side for the same wages and benefits. In addition, the Center has implemented a navigation tool called iconology, which strategically places colorful pictures of animals and objects to help all employees navigate around the large center to different work stations. The Walgreens Distribution Center is a commendable example of a specific way in which an organization can encourage and support the hiring and recruitment of people with disabilities.

Public Health Practice and Resource Centers

A panel comprised of Public Health Practice and Resource Center representatives presented next; the [American Association on Health and Disability](#) (AAHD), the [Amputee Coalition of America's Limb Loss Information Center](#) (ACA), the [Christopher and Dana Reeve Foundation Paralysis Resource Center](#), the [National Center on Physical Activity and Disability](#), and the [Special Olympics](#) all participated. Public Health Practice and Resource Centers, which

are funded by the Disability and Health Branch of the Division of Human Development and Disability, NCBDDD, CDC, represent an important information exchange for Disability and Health Partners. Presentations by [NCPAD](#), [Special Olympics](#), [ACA](#), and [AAHD](#) are all available for viewing [online](#).

Hot Topic Discussion Summary

At the end of day one, partners met in small groups to discuss current disability and health topics of interest. Group topics included implementing evidence-based interventions, wellness through improving access, health promotion, health marketing and communication, emergency preparedness, livable communities and universal design, training professionals and paraprofessionals, and supplemental surveillance. Each group was facilitated by a Disability and Health Partner that utilized a facilitator guide (see Appendix A) created by AUCD staff. These facilitated round table discussions provided partners with the opportunity to share information, suggestions, and concerns about the issues being discussed along with the expectation that Partners could gather additional information from each other to enhance or implement programs.

Optional Physical Activity: Dance Workshop

Day one of the meeting concluded with a dance workshop, arranged by [Full Radius Dance](#), a modern dance company that incorporates dancers with all abilities, including a number of dancers who use wheelchairs. The dance company first presented a few choreographic works, celebrating technique and physicality and then engaged the audience to participate in several warm-up activities. Founded in 1990, Full Radius Dance is one of only a handful of physically-integrated dance companies in the United States.

Day Two

Day two of the meeting continued with more opportunities for partners to collaborate and share experiences by participating in a networking breakfast. Informal discussion topics included transition, funding and reporting, using the media, and the passage of health reform.

Surveillance Plenary

The plenary on surveillance was [presented](#) by John Bartholomew, an International Business Developer with GeoWise Ltd., who unveiled the Disability and Health Data System (DHDS), which is a new software program that the CDC will soon implement to capture [Behavioral Risk Factor Surveillance System](#) (BRFSS) data. DHDS is an interactive, accessible mapping tool that can evaluate the prevalence of chronic conditions, among other potential applications at CDC, and among the partners.

Evaluation Workshop

Following the surveillance plenary an evaluation workshop was held to encourage program direction and sustainability. The workshop was presented by Vince Campbell, CDC's Chief Disability and Health Officer, Jennifer Nichols, Senior Account Executive from Porter Novelli, and Anthony Cahill, Director from the Division of Disability and Health at the University of Mexico. Dr. Campbell discussed the ongoing process of surveillance and developing core evaluation indicators for partners to use in their states to capture data on chronic disease and secondary conditions. Jennifer Nichols from Porter Novelli [reported](#) on one CDC public health campaign implemented by several partners; the [Right to Know Campaign](#), which is designed to increase awareness of breast cancer among women with physical disabilities and encourage these women to get screened. Ms. Nichols explained that although neither a standard

evaluation nor a protocol was inherent in the design of the Campaign, an evaluation and protocol is currently being developed. The work of partners evaluating the Right to Know Campaign in their states will ultimately improve programming and reporting outcomes as well as leverage greater community resources for Partners. Dr. Cahill then reported on the Public Health Practice and Resource Centers and their use of evaluation for CDC reporting. Dr. Cahill noted that each Center conducts evaluations with similar but not exact core service volume and impact indicators. Dr. Cahill's team evaluated how feasible it would be to develop common evaluation indicators for all Centers and concluded that a single system is possible and should prove relatively easy to implement.

Success Stories

The creation of success stories is essential for partner recognition, progress, and sustainability. Chelsea Carlson Payne and Melissa Fahrenbruch from the CDC's [National Center for Chronic Disease and Prevention](#) co-presented on this subject and discussed the importance of capturing progress over time. They emphasized the importance of learning how to package success stories in order to promote visibility, educating decision makers about program outcomes, demonstrating responsible use of resources to stakeholders, providing best practices to funded partners, and attracting new partners.

Day Two: Concurrent Sessions

Obesity and Lifestyle

A significant issue for many people with disabilities is the ongoing struggle to maintain a healthy lifestyle. James Rimmer, Amy Rauworth, and Gillian Goodfriend from the [National Center on Physical Activity and Disability \(NCPAD\)](#) presented information on obesity and

lifestyle management for people with disabilities. Dr. Rimmer, Executive Director for NCPAD, reported that the prevalence of obesity is greater among people with disabilities, and in particular, among people with developmental disabilities. According to Dr. Rimmer, high rates of obesity in people with disabilities can be attributed to physiological and behavioral factors, which also contribute to and exacerbate chronic and secondary conditions. Dr. Rimmer suggested that partners promote health and fitness inclusion through all initiatives, train professionals to promote health and fitness among community members with disabilities, advocate for assuring adaptations and accessibility for people with varying types and levels of disabilities, and develop strategies to target health and fitness education towards the Medicaid population. Dr. Rimmer also reported that NCPAD is currently developing a national database of weight management programs for people with disabilities that Partners can contribute and to if they are aware of such programs in their state.

Violence Prevention

Rosemary Hughes, Senior Research Scientist from the [University of Montana Rural Institute](#) along with Joann Thierry, Behavioral Scientist from the CDC [National Center for Injury and Control](#), presented information in a workshop on the state of science around violence prevention and outreach to people with disabilities. Dr. Hughes reported that although there have been studies conducted to understand the prevalence of violence among people with disabilities; little attention has been given to sexual minorities, rural groups, and people with hard to study disabilities. However, some new violence prevention studies include members of racial and ethnic minority groups and men with disabilities. Dr. Thierry suggested that violence prevention studies need first to begin with defining the problem, identifying risk and protective

factors, develop and test interventions, and then replicate those studies. Dr. Thierry discussed that the CDC National Center for Injury and Control has included violence prevention as part of their Center-wide agenda, in an effort to drive the allocation of research dollars towards this issue.

Round Table Reception

Day two concluded with an opportunity for partners to meet in informal small groups to discuss current disability and health topics of interest. Topics included funding opportunities, transition, employment, housing, and accessibility.

Day Three

The final day of the Partner's Meeting started with additional opportunities for Partners to collaborate and share experiences with one another through a networking breakfast.

Informal discussion topics were: employment for people with disabilities, coalition building, assistive devices and technologies, as well as evaluation.

After the networking breakfast, partners participated in a morning yoga activity. Ryan McGraw, Graduate Assistant with NCPAD, led the 20 minute optional yoga exercise. Ryan reported that yoga can be beneficial for all individuals, including those with disabilities or chronic health conditions, through both the physical postures and breathwork. As such, partners with all abilities were able to participate in this morning activity.

Emergency Preparedness Plenary

Marcie Roth, Director from the [Office of Disability Integration and Coordination](#) (ODIC), Department of Homeland Security/ FEMA, presented strategies for working with local, state, and Federal agencies to ensure that people with disabilities are included and planned for in the event of a disaster or emergency. She informed the audience of ODICs work with states in the event of a disaster. Ms. Roth reported that ODIC believes when communities integrate the needs of children and adults with disabilities and others with access and functional needs into their community wide planning initiatives, they maximize resources, meet their obligations, and strengthen their ability to prepare for, protect against, respond to, recover from, and mitigate all hazards. In addition, Ms. Roth reported that ODIC's mission is preparing individuals and families and strengthening communities before, during, and after a disaster by providing guidance, tools, methods, and strategies to integrate and coordinate emergency management

efforts to meet the needs of all citizens, including children and adults with disabilities and others with access and functional needs.

International Classification of Functioning Plenary

Craig Raveslout, PhD, of the University of Montana, and [Gale Whiteneck](#), PhD, of the Craig Hospital [explained](#) the [International Classification of Functioning](#) (ICF) and the ability of ICF to measure participation for disability and health practitioners. ICF suggests that all individuals have variations in their health and abilities, experiencing limitations in ability from time to time. ICF focuses on the individual's ability to interact with their environment and reframes the concept of disability by shifting the focus from causes of disability to impact, which mainstreams the experience and recognizes disability as a universal human experience. Dr. Raveslout reported that by measuring participation using ICF in disability and public health practice, researchers can better understand quality of life for people with disabilities as well as potential effects of participation on health outcomes.

Conclusion

Gloria Krahn, Director of the Division of Human Development and Disability summarized the meeting for participants. Dr. Krahn noted that the essence of the relationship amongst Disability and Health Grantees and other partners stems from an ability, desire, and vision to connect with people doing similar work and striving towards improving the quality of life and life expectancy for people with disabilities. Dr. Krahn acknowledged that we are experiencing a time in which innovation and creativity are essential due to shrinking budgets. Specific examples of this innovation and creativity exist within the DOJ's Project Civic Access, housing and transportation management, and the progress on Visitability objectives within Healthy

People 2020.

Dr. Krahn thanked the Public Health Practice and Resource Centers for complementing the meeting theme with their panel discussion and for the work they do as catalysts for healthy living programs. She echoed the evaluation plenary theme that all efforts must be measured and evaluated to assess success. Dr. Krahn concluded by assuring participants that the discussion at the meeting over the course of three days will factor into the Division of Human Development and Disability's strategic planning process and will ultimately assist in improving the quality of life for individuals with disabilities by increasing relationships and collaborations among partners connecting to reach their full potential.

Suggested citation: Galonsky, P.; Griffen, A.; and Edson, D.; "Connecting to reach our full potential," Disability and Health Partners Meeting, May 18-20, 2010, convened by the Division of Human Development and Disability, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, and Association of University Centers on Disability.

Appendix A

Facilitator Guide

2010 Disability and Health Partners Meeting

Facilitator Guide for

Module Discussion Groups and Round Table Discussion/Reception

May 18-20, 2010

Atlanta, Georgia

At the Disability and Health Partners Meeting, facilitators will be in charge of a discussion group on either May 18th or 19th. During the discussion, the facilitator's role includes setting ground rules, keeping participants on track, and ensuring full participation from each member of the group.

The facilitator will:

- solicit thoughts and comments from each member of the group;
- encourage participants to take notes and brainstorm;
- create a "parking lot" for ideas not immediately germane to the discussion;
- not allow any one group member to monopolize the discussion;
- clarify: "So what I'm hearing is that..." and
- foster consensus through recap of discussion and, if necessary, through group votes or decisions in order to craft take home messages that have broad consensus within the group.

Taking Notes

The facilitator should ask a member of the group to be a note taker. The note taker will be the primary recorder of statements made by the group. In addition, you will want to ask the note taker to help you keep track of time.

Notes are important because they will be used as part of the culmination of take home messages that will be reported out to all Meeting participants at the end of each day.

2010 Disability and Health Partners Meeting Facilitator Guide

Disability and Health Module Discussion Groups Agenda

May 18, Disability and Health Module Discussion Groups

Note: Each Module discussion will last for 30 minutes. Therefore, please let all group members know that after 30 minutes are up, they can move on to the next Module of their choice or can continue to stay for the entire allotted time. Be mindful of the time!

- 3:15-4:20** Module A: Implementing Evidence-Based Interventions
 Module B: Wellness through Improving Access, Health Promotion, and Health Marketing/Communication
 Module C: Emergency Preparedness
- 4:30-5:40** Module D: Communities/Universal Design
 Module E: Training Professionals and Para Professionals
 Module F: Supplemental Surveillance
-

Facilitator Introduction and Review

- A. Greeting – introductions
- B. Discussion Ground Rules
 - Make clear that all thoughts, comments, and suggestions are valid and welcomed.
 - It is important to limit side conversations and interruptions.
 - Do not allow any one group member to monopolize the discussion.
 - Identify a note taker who is willing to stay for the entire discussion and help keep time.

2010 Disability and Health Partners Meeting

Facilitator Guide

Possible Questions for Modules Sessions

Module A: Implementing Evidence-Based Interventions

1. What evidence-based interventions are happening in your state? Describe success stories and challenges. Do you have best practices that you can share? What lessons have you learned?
2. How effective are the evidence-based interventions in your state in reaching to the populations they are designed to support?
3. What are the challenges facing the sustainability of evidence-interventions in your state and the United States today? Funding? Quality research? Policy? Recruitment?
4. Most programs have a time limit. Do the evidence based interventions provide lifelong changes or only changes during the participation phase? i.e.- participation in Living Well with a Disability
5. Interventions can sometimes be generic, attempting to capture a larger audience. People with disabilities have a range of abilities and need a crafted health program specific to their ability and health. Do the evidence based interventions limit individual achievement-meaning, what's beyond the intervention? Are we limiting individual potential?

Module B: Wellness through Improving Access, Health Promotion, and Health Marketing/Communication

1. What are the main issues regarding access to wellness in your state for people with disabilities?
2. How has your project been effective in creating wellness through improving accessibility?
3. What has impeded your progress to creating better access to health promotion and wellness for people with disabilities?
4. Have you been able to effectively deliver health promotion initiatives through marketing and communication efforts?
5. What has been to challenges to health marketing and communication of wellness through improving access for people with disabilities?
6. What are the top three to five resources that you are using to improve access and health promotion in your state?
7. How does disability as a health disparity in health care reform create opportunities for us?
8. What types of experiences and challenges do you encounter in regard to evaluating your health promotion interventions?

Module C: Emergency Preparedness

1. Can you identify the main issues that emergency management planners face in regard to supporting people with disabilities during a time of emergency or disaster? Accessible shelters?
2. How has your project promoted emergency preparedness for people with disabilities in your state?
3. Registries have been presented to emergency management as a tool to plan for people with disabilities. Some have become so involved they gather more information that is required in a doctor's visit. These registries imply that transportation, assistive technology, medications and other functional needs can be met in times of disaster/evacuation merely by filling out the form. Are registries a helpful tool or perpetuating dependency?
4. In some states emergency management and public health departments are asking state governments funding to stock pile an assortment of medications to be readily available in times of disaster. Is pharmaceutical stock piling an effective use of planning dollars and effort; or is there a better way for partnering to access medications during/after a disaster?
5. Emergency planners/managers continue to believe that people with disability need a higher level of care even if they are living in communities independently.
6. Discuss shelter plans on the local level.
7. How do states include people with disabilities during different seasons of disaster (hurricanes, snow storms, etc.)?

Module D: Communities/Universal Design

1. Describe the types of universal design activities occurring in your state.
2. Lack of physical accessibility continues to be a barrier for people with disabilities to receive health care. Should physical accessibility be included in criteria for licensure for health care providers?
3. Most new construction does not “build in” foundations and framing that could be easily modified for accessibility. Home owners may build planning on retiring in their dream home, only to leave if onset of a disability occurs and modifications would be too costly. Should building codes increase guidelines that would require infrastructure or the frame of the structure be already fitted in case there is a need for accessibility modifications? – ie home building.

Module E: Training Professionals and Paraprofessionals

1. Often medical providers treat the disability and not the person. Do professionals (medical providers) view people with disabilities as healthy?
2. Can you identify where the deficits are in relationship to training professionals and para professionals who work with people with disabilities?
3. Is cultural competency an issue?
4. In rural areas telemedicine has been used to provide routine checkups. Are considerations made for people with disabilities who may use assistive technology, i.e. low to no hearing, low to any vision, cognitive disabilities? Are medical professionals well versed in communicating in alternate ways even in face to face visits?

Module F: Supplemental Surveillance

1. What are your thoughts on implementing a national surveillance system to capture ongoing data on people with disabilities?
2. What could be the challenges to implementing a national surveillance system to capture ongoing data on people with disabilities?
3. Has the BRFSS data on disability helped you in your planning and outreach efforts? If so, how? If not, why?
4. Certain BRFSS questions are only available every two years in the BRFSS, dropping the Disability questions from the core will certainly halt the state surveillance of disability. What can be done to avert that loss of information? If the questions were dropped, how researchers need to proceed to fill that surveillance gap?
5. Several surveillance tools used different model of defining disability. The American Community Survey (census) used six questions looking at participation (going out, working), emotion, and sensory problems to identify disability. The BRFSS and NHIS used broader concepts. The WHO designed the ICF. Is it possible to integrate the ICF into the BRFSS? For example through the development of an algorithm to classify disability.
6. The BRFSS is used in the substance abuse prevention world to generate states and county level estimates to alcohol use, binge drinking, drunk driving and smoking. Lately it has been reported an increase of “Drugged Driving¹” in the media. How soon can we expect to have Drug questions (Using Illicit Drug within the past 30 days and Driving after using Illicit Drug)?

2010 Disability and Health Partners Meeting Facilitator Guide

Topic Questions for Core Round Table Discussions/Reception Agenda

May 19, Round Table Discussions/Reception

Note: Each Round Table discussion will last for 30 minutes. Therefore, please let all group members know that after 30 minutes are up, they can move on to the next round table discussion of their choice or can continue to stay for the entire allotted time. Be mindful of the time!

4:30-5:10 Funding Roundtable Discussion
 Transition Roundtable Discussion

5:15-5:55 Accessibility Roundtable Discussion
 General Grantee Roundtable Discussion

Facilitator Introduction and Review

- A. Greeting – introductions
- B. Discussion Ground Rules
 - Make clear that all thoughts, comments, and suggestions are valid and welcomed.
 - It is important to limit side conversations and interruptions.
 - Do not allow any one group member to monopolize the discussion.
 - Identify a note taker who is willing to stay for the entire discussion and help keep time.

2010 Disability and Health Partners Meeting Facilitator Guide

Possible Core Topic Questions for Round Table Discussions/Reception

4:40-5:10

Funding Roundtable Discussion

1. Have funding opportunities increased or decreased for your projects over the last year?
2. If funding has increased, how has that lead to other opportunities for outreach, prevention, collaboration, etc?
3. If funding has decreased, how has your project been able to sustain its efforts with less?

Transition Roundtable Discussion

1. What are the major challenges currently for children transitioning into adulthood in your state?
2. What can be done to create equity of services for adults with disabilities once they reach the age of 21?
3. How can the Individuals with Disabilities Education Improvement Act of 2004 (IDEA) be improved upon to allow for smooth transition of young adults with disabilities into school and work?

5:20-5:50

Accessibility Roundtable Discussion

1. Many states are doing activities surrounding ADA assessment. Some are looking at physical structures, some programmatic, some policy, etc. Different states use different versions of ADA type questions/assessment checklists and forms. Depending upon the type of facility some questions may change (primary care, radiologist, recreation, fitness, etc.) Different groups use different numbers of questions and assessors when determining accessibility. How are facilities assessed in your state? What is being asked? Who does the assessing?
2. Can you identify what the main accessibility issues for your state in regard to access to health care and wellness?
3. What types of advocacy/projects have you done to move accessibility forward to improve wellness in your state?

4. What has impeded your progress to creating better access to health promotion and wellness for people with disabilities?

General Grantee Roundtable Discussion

1. Describe one project, intervention, strategy that you are particularly proud of.
2. What types of supports would you like to see more of from the CDC/AUCD?
3. If you could change one aspect of the State Grantee Initiative, what would it be? Why?
4. What types of projects, interventions, and strategies are you planning for in 2011?

Appendix B

Module Notes

Implementing Evidence-Based Interventions

What are the evidence based programs that are being implemented in the states and what is an evidence based program? Research has been done on the efficacy of the program?

- We should be careful about the use of that term
- Replication is an issue
- Replication is nearly funded
- There is a notion of exact

Does that mean evaluation too?

- It's more so the design of the program

What are evidence based programs that are being implemented in the states?

- Steps to your health-a health promotion, dietary program, targeted at individuals with ID
- Chronic Disease Self-Management Princeton Model A funding

Are there other's that are using Module A or Core Funding?

- We're using Module A to CDSMP
- VA is using living well we have 5 communities of Center for Independent Living teams, and we're looking at supporting them, as they are all very different.
- PH AD, linking the CILs to Master Trainers and a falls prevention matter of balance
- CA- Smokers hotline to get services and resources

Chronic Disease Prevention section, I'm working with the Tobacco Quit line, have you seen any issues that people with disabilities are having with the quit line?

- We're in the beginning stages and we've studied it, we will be training the staff about the challenges that people with disabilities.
- MT-Looking at using a depression screening in the quit line

Other programs?

- Cultural Competency: CDSMP is translated into other languages but only culturally competently in Spanish.
- It needs disability awareness, and the flexibility to do so
- I don't think that the research base is there, in fact people with disabilities dropped out at a higher rate

- MA-Outreach through the adult case management
- SC- we recruit from Self Advocates, Non-Profits, Schools, etc. And have reached over 6,000 people in the last 5 year
- In the living well program, we've worked with the CIL's and now we're working with homeless shelters, youth leaderships, and an Independent living
- One thing that we implemented in Living Well, we've seen that people are using it as training, We're making a Master Trainer program that will require a project that will make the master trainer show how they would use trainers
- We've also used Voc Rehab for working well. And we've and a 50% follow through.
- NY- we're working through a local health collaborative, to recruit
- MA-is using ARRA money to ILC's

What are the outcome measures?

- We're using peer support specialist, Mich.
- GA we're working with Safe Care that reaches children at risk

What measures are people using to look at these programs over the long term?

- SC -We found the people with ID hate to wear acclaromitors; if we do it again we'll need to incentivize the use of them
- NY-No data yet, but we'll add disability measures, but we don't know which
- Weight loss programs, we're measuring BMI and we're tracking over 18 months and we're additionally looking to see if it incenses community participation
- We're looking at menu guides, and we're seeing good outcomes
- We've moved from the research based intervention and we're now looking at what we can support and hopefully research
- Beyond that, it's now just what works, but for whom and at what level. LA is doing that kind of research
- During these times we're seeing it harder to implement health education, as they are more focused on staying alive
- We're moving toward health related quality of life and the secondary conditions and living will measures are too in depth to use in the field
- Our University has an IRB and when we're often having trouble with implementing a program because we're not doing research
- CDC has issues getting money out the door if it is for research
- Evidenced based interventions implementation thereof, our mission is to talk about the programs that states are using

What is evidence based intervention: Something that has research that suggests it is effective, replicable? Fidelity is required? What population is this program successful for?

- The Setting is important too, community v. institutional settings
- We're really looking at external validity

Theory based? Mechanisms of Change? What Programs are being implemented between Core and Module A funding?

- Small media campaigns, i.e. Right to Know
- PEP 2 studies, CDC and NIDAR funding for people with CP, MS, and SIC. Now partnering with Sheppard Center
- Healthy Life Styles Cir. In Organ, through the CIL's and it is cross disability
- AK- Living Well with Disabilities, through the CIL's. And Chronic Disease self-management through the people first

How are people reached?

- MT -Menu aids, is an adaptation of menu planning for group homes. Using best practices from dietitians

What's the response?

- We offer two different trainings one as an interdiction and then a more intensive
- We are also using Women Be Healthy, in Planned Parenthood.
- CILs and People First, and then hoping that they will offer it to providers
- Sheppard Center had a great outreach that they cultivated themselves.
- MT- we used a program called be healthy, we networked
- Living Well is being implanted on College Campuses. It is being implemented through our CIL
- Park and Rec in Oregon picked up healthy life styles; in Portland we use the CIL to find location
- Referrals from VR in MT, and that is resulting in refusals for Working Well,
- MT also has a NIDAR funded program that used a rural pop in SC

Has anyone approached Aging Services?

- Living Well has been picked up in ADARCs to bring them to senior centers

What outcomes are being tracked?

- This was an issue that came up last time, about funding evaluations
- We're trying to measure by behavior change programs
- In living well we see people that come in and don't set goals
- We're looking at NIH for funding to evaluate weight management in group homes

Wellness through Improving Access, Health Promotion, and Health Marketing/Communication

What are the main issues regarding access to wellness in states?

- Wellness, health clubs, financial barriers
- Oregon- have not done accessibility evaluation of fitness centers
- Attitudinal barriers in Mammography training
- Arkansas- Disability awareness training for doctors
- Doctors didn't feel disability issues were relevant, wanted treatment for secondary conditions
- Worked with Annual Public Health Conference
- Mammography accessibility was the best way to show the need for training
- Medical professionals need exposure in order to realize their need for etiquette
- Cancer coalition grant- are developing training to make materials more accessible
- Delaware- physical, financial accessibility issues
- Sign language interpreters- doctors refuse the responsibility; don't see it as necessary to communication
- Shortage of interpreters
- Wellness-it is very difficult / costly to have sign language interpreter for wellness programs for long periods
- Mammography- "they don't know what they don't know" (words on educating professionals)

Where have you see effectiveness in improving access to wellness?

- Florida- Right to Know Campaign
- Partnership with CIL
- CILs are consistently asking for health materials for women who are deaf
- Right to know event- after the event they hosted, they realized the challenge for making materials available for different languages (including ASL)
- Delaware- check out DeafMD.org- they have no sound on their site, only sign language videos for health topics. This can be inaccessible for people who do not understand ASL.
- Montana-Accessibility Ambassadors Program
- Created toolkits with materials, sent out ambassadors, only 8 out of 40 people responded on how the toolkits were used
- *Most of Module B states are only on process evaluation stage- working on receiving feedback for mammography techs
- Montana- promote the message that every mammography facility has a machine that lowers to at least 31 inches
- Make centers aware of the amenities they have and how they can serve populations
- Provide technical assistance to mammography facilities on where they can be equipment, accessible doors
- Komen Montana is their partner

- Increased their awareness, led to provision in any of Komen's grants to include disability and access
- Florida-move to ask all clients if they need any extra help or time at their appointment-want to create a standard policy
- Montana- meeting with healthcare professionals, providers to make them more aware
- Collecting stories to show qualitative data, story can be better than a pie chart in making a case
- Fitness Center Accessibility- promote options to community and fitness centers
- NCPAD helped with promotional materials, created a resource to provide information on accessibility

Barriers to Access:

- Training the professionals, getting through to them

Does anyone have advice or general protocols to getting attention?

- More cost-effective to go to National Medical Conference and present, because it is often hard to reach people
- Montana- Nursing School
- Senior nursing class in public health
- 2 students went to CILs
- CIL came and trained the entire nursing class
- Would like to make this a more widespread program
- LEND program
- 11 disciplines
- Social work invited them to come in to do "Disability 101" course
- North Carolina- provider training, Patient Centered Medical Home Model
- Basing training on reimbursement
- Montana- What does it take to get from home to wellness initiatives?

While this is related to module B it was decided that more people would benefit from a broader discussion.

What techniques / strategies are state D&H programs using?

FL shared about their *Right to Know* campaign

- Divided the state up into three regions (north, central, south)
- 1.5 people working on campaign
- Using a set of posters and tip sheets (customized) for Women with Disabilities
- PSAs in multiple stages
- Press release in sync with print and web ads
- North FL: ran during April to coincide with a cancer walk
- Central FL: Tampa, Orlando, a few smaller cities

- Connecting with partners is crucial
- Through partners, disseminate a kit of materials
- CILs are important partners (provided list of materials to CILs)
- Staying in regular contact with partners (phone calls and traveling to them to meet
- Susan G Komen, Breast Health Network (Braille)

Divided into three states--why? Media markets?

- No, divided into regions strictly based on location. Consulted at map to see where people with disabilities are located
- Counties – North (40+ counties); Central (16 counties)
- Spanish-speaking materials are especially important in central and South Florida

Working with local health departments? Has anyone used any new media / blogs?

- FL has downloadable materials on their website, but hasn't tapped into new media yet; considering blogs in the future. The group discussed issues surrounding blogs and needing to get clearance / sign off from public affairs
- OR is on Face book, which works well for the population they're trying to reach (hands-on, older population)
- OR also sees mammography techs as another important audience in addition to consumers
- Markets training to this audience directly
- Conducts training (Disability 101)
- Provides tip sheets
- Paid for state-wide membership in Mammography Association
- FL also working with mammography techs
- Also provides customized tip sheets (similar to CDC's tip sheets)
- Strategy was to get buy-in from mammography techs so they'll spread
- Knowledge with staff (have scheduler ask specific disability Qs)

GA discussed how they've worked with the local chapters of AFP and APP to send out surveys; free of charge. So, it seems to come down to two strategies:

- Targeted (mammography techs)
- Broad (Face book)
- Barriers?
- Having to pay for access to organizations
- Keeping it current
- staff to update web / Face book content
- Public Affairs Offices (no policies on how to get info out through new media quickly)

- Actually reaching women with disabilities (FL)
- CIL in Gainesville; 16 counties, women with disabilities in 4-5 rural counties
- First challenge is to get the info to them
- Second challenge is actually getting them screening

Anyone working with healthcare plans to gain access to providers?

- FL – only access to mammography techs
- Group discussed how mailings sent to docs don't seem to be effective; training works better.
- New Mexico discussed their Developmental Screening Initiative; required to do training for recertification (suggested this as an effective way to engage providers)
- Others suggested working with "boards" like the America Board of Pediatrics
- GA discussed working with AAP's Bright Futures developmental surveillance and screening to do a lunch and learn. Go to their office to do the training (and provide lunch)
- Have considered including a parent of a child with a disability as potential presenter or someone from *Babies Can't Wait*
- Offer CEUs
- Provide CPT codes – this is helpful to docs for reimbursement (many are not aware of the developmental tests they can get reimbursed for)
- Others suggested including other state and community partners to make it a broader learning collaborative
- OR has access to insurance organizations such as Kaiser Permanent through their relationship (cooperative agreement) with Oregon Health & Science University
- Conducted train-the-trainer with KP who is now doing it through their breast health group
- Final Thoughts / Questions related to Disability and Health Module B in your State (share or ask)
- NC – federally qualified health centers to be expanded
- AUCD – look on the web for more information on health care reform
- Currently have a health care page
- Developing a health care hub (look for in about a month / six weeks; may do a broadcast e-mail)
- More in-depth info
- Long-term services and support
- Preventative interventions (potential funding?)

Emergency Preparedness

Access shelters-Problems with getting accessibility to shelters:

- People not wanting the information to be dispersed

- Representative from Red Cross works on the committee – identification of shelters that were not accessible. Prioritizing which shelters need accessibility. Emergency management department serving as limiting factor in getting the information out
- Iowa-County emergency managers – being responsible for shelter management
- Emergency managers – success driven; and may avoid unknown
- Bathroom accessibility is most important
- Fear driven limitation that emergency managers may not succeed
- People with disabilities are their own emergency managers
- AR-NO pre-identified shelters – spontaneously identified shelters based on emergency
- Red Cross spontaneously opens shelters – during storms
- People may be turned away – specifically people with DD
- CDC-State may take care of some issues with sheltering
- Project officers at terrorism and emergency preparedness want to collaborate
- Pick three communities, school built 2 years ago – shelter
- Start the process with MOUs and community stakeholders to improve accessibility to shelters
- FEMA 333 – meeting with county emergency teams
- Picked 3 teams where EM were on-board
- Collaborated with local teams
- Local shelters are more ready and prepared
- National sheltering systems – database that has all the shelters open in the county with categories for special needs shelters, categories for type and facilities at the shelter
- Designation pre-allocated for these shelters
- Optionally participator
- Shelter accessibility surveys could use this database
- Networking is high among emergency managers when one of them figures out if a system works
- Sheltering issues are hard to deal with because of lack of resources
- Some states have budget and contract where sheltering is taken care of
- 90% of emergency response in the Private sectors is from churches, volunteers
- Role of churches that are interests in forming in to a shelter. Steps to follow if churches could designate themselves as shelter. Get funds from various volunteer organizations
- Transportation issues in emergency managements
- This is not a centrally driven from state office – more local
- Digital signs – contacts to do amber alerts. DOT road signs. Can be used to program in something from the office to display any emergency
- Resources need to be allocated for more basic needs like a bathroom, accessible cot, tub bench etc
- North Carolina: CERT – Community Emergency Response Team
- Designed to be for anyone – teaches light search and rescue
- Community education
- Personal preparedness

- Logistics and planning
- Florida-Funding issues are limitations
- Mock trainings for moving people etc. need to include people with disabilities
- CERT volunteers to work in the shelter
- Communication strategies
- Normal
- Beautician
- First responders say they get no training in dealing with people with disabilities
- Needs are unique – disabilities are different
- Road maps for emergency preparedness of disabilities is lacking
- EMS training – exposure to DD affected people
- Unacceptable rating on human subjects committee – women with disabilities cannot give informed consent

Livable Communities/Universal Design

Describe the types of UD Policy in your state

- GA: One zero step entry in all new homes
- SC & AR: Complete streets compliant with ADA in both local and state levels
- NC: Walks to school program incorporated some accessibility
- SC: state DOT was sued and they had to update their ADA transition plan and they are currently focused on sidewalks
- National Level and IL: there is work being done to evaluate the participation of children with disabilities in the Walk to School/Safe Routes to School Programs, and IDOT has made participation mandatory
- MA: Working with the ageing community to address the use of subsidies for housing and using its tobacco control program to hold public hearings. MA is also awarding grants and using a CDC tool to evaluate the program
- MT: Changing its qualified plan to address UD
- Major Hospitals will be addressing Accessibility, which might create an avenue to implement health care accessibility programs

Other Universal Design/Livable Communities work:

- NC: Working to make senior centers more accessible
- MS: Acquiring foreclosed homes and modifying them before reselling them
- NCPAD: Working with ASMT to address the fitness equipment design with both the UK and US to make it accessible
- NC Dental Access: Partnered with UNC Dental School to train dentists
- MT: Uses accessibility ambassadors to do outreach
- SC: Offering free accessibility assessments through the office of rural health
- AR has a grant from the American Cancer Coalition to assess all their centers, and a grant from

- Harkin, got language into health care reform that suggested all equipment be accessible
- Parking – Orange Cones (temporary)
- Temporary Ramps
- Direct care staff can be trained as first responders
- US Citizen Corp is the organization that trains people to respond
- Special needs shelter are maintained from Red Cross
- Moving the people during emergency-mutually supportive agreements between agencies

Who pays for the costs of evacuation?

- Whoever issues the evacuation order is responsible for it.
- County board of supervisors. County government is responsible for paying for the evacuation in some states
- Clear distinction between accessible shelter and a medical needs shelter. Medical shelter is for people with medical care. Special needs shelter for those with disabilities
- Quiet areas in shelters
- Medications in relation to shelter planning
- Triage process in sheltering
- Medical shelters close to other sheltering
- Have a team of volunteer medical professionals
- Mobility, Hearing, Vision, Cognition need to be examined in deciding sheltering
- Support system – families that come with the care team
- Not to separate families
- Guidelines for classification of shelters
- ADA.gov
- Emergency management rules

Training Professionals and Paraprofessionals

Health Care Reform: How can we take advantage of Health Care Reform in training?

Example: Medical equipment and training

- Alliance for Healthcare Professionals (not Disability & Health Partner related) such as MDs, PTs, etc. met to discuss goals regarding curriculum and best methods
- Communication is key-person first language-important to know top five contraindications

Would it be a good idea to have a specific disability focus for a practice/medical profession?

Is that looking at person or disability?

- In pediatrics there is a DD focus, but hard to find an adult provider so maybe a specialty is helpful for complex adult needs
- In rural areas you may only have a choice in one doctor

- There is worry regarding incentive structure if that means patients are mostly from non-refundable reimbursable sources
- Program in VA targeted school nurses- need to find a champion for the cause
- In CA integrating into curriculum and some have separate classes

How do we get it in to core competencies?

The Alliance is developing a tip sheet for how to incorporate information into a lecture
How do you get people interested in CIFT?

- May a good time for fitness because of obesity and nutrition initiatives in health care reform

Do HCP view people as healthy?

- Med students standardize patients with and without disabilities
- Med students perform worse in history and counseling when seeing PWD because they have limited time
- IL-Works with three different medical schools. Each school does disability education in a different way; 1: Mock clinic focusing on communication among patients with disabilities 2: Groups meet in large ballroom and interview patients 3: PWD panel presentation: PWD tell their story about barriers to healthcare, access, and communication-Feedback from students- This is often their first experiences with a PWD- they seem to appreciate the experience and surprised by how “regular” their lives are
- FL- Six week curriculum on disability for third year med students- panel discussion and home interviews of PWD-Pre/ post test show increase in knowledge attitudes, and comfort ability treating PWD
- OR-Targets MPH students, family practices, state public health, and hospital staff
- Difficult to vision what a curriculum would look like that would address all the issues
- IA-Important to get the students early. First year, gives them the confidence to handle the problem, by third year, more hands-on
- NJ- Grant from RWJ Foundation. To create a medical home. 65% of graduates see PWD in their practice
- Transition to adult healthcare for PW physical disabilities is a particular challenge. The challenge illustrates the importance of training para professionals, nurse practitioners, etc
- CA- project with dental providers-nurse practitioners provide oral healthcare
- For the Academy of Developmental Medicine and Dentistry –Every provider should have basic knowledge. For more extensive needs, they can refer to a specialist

- DE-Does not have a med school or school of public health- DE is addressing current providers- DE would like information on CEUs or a curriculum for current providers
- CA- Dental and nurse CEUs
- FL-Online, free for FL doctors- FL is trying to offer CEUs outside of FL but the barrier is funding

Supplemental Surveillance

- National Surveillance System to capture disabilities
- Feasibility
- Agency – census, CDC, other agencies with HHS
- Definition
- State based
- Sample size – rate outcomes in disabilities
- Age focus / life span
- How would it be administered
- Cooperativeness of populations
- Confidentiality issues
- Helpful to know what other states have done

What are components that we would be interested in learning about?

- Lots of variables- how they interact
- What the salient variables are

Challenges?

- Telephone surveys – but hearing disabilities
- Problems with the data – measurement needs to be improved

Include disability into every survey?

- People who don't identify themselves as having disabilities
- CP was the only disabilities where people would identify
- National BRFSS is considering making it not an annual question

What would you do to supplement BRFSS?

- Pay for the two questions
- Individual state money – advocacy groups
- CDC can coordinate core questions

Classification of disabilities: Definition of disabilities- Should it be a standard disabilities classification?

- BRFSS does not capture people with ID or other disabilities
- Only 70% of people self-identify disabilities
- ICF model to supplement disabilities questions to supplement the questions on BRFSS
- Debate on 2020 Healthy People to use 6 question-set
- Full cognitive testing to include questions into BRFSS – expensive
- For health departments that operate on a county basis – it might help to know prevalence by county by age group
- Ask CDC for supplemental funding for additional questions – for supplemental surveillance states
- How it is done in birth defects surveillance – hospitals
- Random child module in BRFSS
- Supplemental module for injury prevention
- BRFSS

How are we using current surveillance data?

- Policy
- Program planning
- Web-based surveys to get more information
- Information helps to contact legislators
- Inability to follow-up questions with open-ended questions about the nature of the disabilities
- Screener questions in medical settings as a part of verifying accessibility issues
- Ongoing surveillance
- County level sampling – to get minimum sample, expensive
- Illinois – use BRFSS to use state level data report
- IL has a county based behavior risk survey; 102 counties; 3 years to go round all the counties – canvass all the 102 counties. IL has 22 centers for independent living. Produced reports. Plan to extend this to other chronic diseases
- Iowa-IDPH does a yearly analysis. Helps influence state agencies. Health trends and disparities. Disabilities in relation to different health status. This year for the first time IDPH put together a disability and public health report. We were able to add a few questions on health care access. There is more information on barriers to access and to use this to influence people for funding. Worth doing.
- Easter Seals: Not directly using the data. Easter Seals does do surveys
- The mission of Easter seals is service. Do more strategic planning
- Kansas: Disability and Health issues which looks at access to health care; and refers to participation
- Access to care based on age of the affected; health insurance; age groups 18-34 years

- ICF models – will bring in more questions (6 questions)
- Care giving model-function vs. condition Issues with telephone interview – limitations. Pragmatics of getting quality data from interviews

Change BRFSS questions?

- Sensitivity and specificity of BRFSS
- CDC is doing a validation survey

Appendix C

Participant Directory



PARTICIPANT DIRECTORY

Anita Albright
Director, Health and Disability Unit
Massachusetts Department of Public Health
250 Washington St., 4th Floor
Boston, MA 2108
anita.albright@state.ma.us
617-624-5440

Martha Alexander
Health Education Specialist
CDC
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
mea3@cdc.gov
404-498-3964

Bernice Allen
Program Specialist
VA - Partnership for People with Disabilities,
UCEDD/LEND
700 E. Franklin St., P. O. Box 843020
Richmond, VA 23284-3020
ballen@vcu.edu
804-828-8593

Billy Altom
Executive Director
Association of Programs for Rural Independent
Living (APRIL)
2001 Pershing Circle, Suite 200
North Little Rock, AR 72114
bwaltom@sbcglobal.net
501-753-3400

Elena Andresen
Project Director
Florida Office on Disability and Health
UF Department of Epidemiology and

Biostatistics, PO Box 100231
Gainesville, FL 32610
kat57@phhp.ufl.edu
352-273-5359

Mary Andrus
Assistant Vice President, Government Relations
Easter Seals
1425 K Street, NW, Suite 200
Washington, DC 20005
mandrus@easterseals.com
202-347-3066

Brian Armour
HEALTH SCIENTIST
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
bka9@cdc.gov
404-498-3014

Robert Arnhold
Coordinator, Adapted Physical Activity
Program/Center on Disability and Health
Slippery Rock University, Slippery Rock, PA
15 West Gym
Slippery Rock, PA 16057
robert.arnhold@sru.edu
724-738-2847

Brent Askvig
Executive Director
ND - North Dakota Center for Persons with
Disabilities, UCEDD
500 University Ave West
Minot, ND 58707
brent.askvig@minotstateu.edu
701-858-3052

Don Betts
Deputy Director
Center for Disease Control and
Prevention/National Center on Birth Defects
1600 Clifton Rd, NE, Mailstop E-88
Atlanta, GA 30333
dib3@cdc.gov
404-498-3957

Tracy Boehm
LWD Program Coordinator
MT - University of Montana Rural Institute,
UCEDD
University of Montana Rural Institute, 52 Corbin
Missoula, MT 59812
boehm@ruralinstitute.umt.edu
406-243-5741

Julie Bolen
Epidemiologist
CDC
1600 Clifton Road, MSE88
Atlanta, Georgia
jcr2@cdc.gov
404-498-3277

Michael Brogioli
CEO
NACDD
1660 L Street NW Suite 700
Washington, DC 20036
mbrogioli@nacdd.org
202-506-5813

Kelly Buckland
Executive Director
National Council on Independent Living
1710 Rhode Island Ave. NW
Washington, DC 20036
kelly@ncil.org
202-207-0334

Jacqui Butler
PUBLIC HEALTH ANALYST
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88

Atlanta, GA 30333
zbn1@cdc.gov
404-498-0274

Anthony Cahill
Director, Division of Disability and Health
Policy
NM - Center for Development & Disability,
UCEDD/LEND
2300 Menaul Boulevard NE,
Albuquerque, NM 98107
acahill@salud.unm.edu
505-272-2990

Margaret Campbell
Senior Research Associate for Planning and
Policy Support
National Institute on Disability and
Rehabilitation Research
550 12th Street, SW, Room 4123
Washington, DC, DC 20202
Margaret.Campbell@ed.gov
202-245-7290

Vince Campbell
Supervisor Health Scientist
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
vbc6@cdc.gov
404-498-3012

Roberta Carlin
Executive Director
American Association on Health and Disability
110 N. Washington Street, Suite 328J
Rockville, MD 20854
rcarlin@aahd.us
301-963-2343

Molly Cole
Associate Director
CT - A. J. Pappanikou Center for Developmental
Disabilities, UCEDD/LEND
263 Farmington Avenue, MC 6222
Farmington, CT 06030-6222

mcole@uchc.edu
860-679-1595

Gina Cook
Senior Research Associate
UT - Center for Persons with Disabilities,
UCEDD/LEND
Utah State University, 6580 Old Main Hill
Logan, UT 84322
gina.cook@usu.edu
435-797-7080

Pam Costa
EPIDEMIOLOGIST
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
pic9@cdc.gov
404-498-3027

Beth Courtney-Long
HEALTH SCIENTIST
CDC/NCBDDD
1600 Clifton Rd, Mailstop E88
Atlanta, GA 30333
gmr9@cdc.gov
404-498-0264

Carla Cox
Disability and Health Program Coordinator
IL - Illinois Department of Public Health,
SDHG
535 W. Jefferson St., 2nd Floor,
Springfield, IL 62761
carla.cox@illinois.gov
217-557-2939

Julie Cross Riedel
Epidemiologist
CA Department of Public Health, Living
Healthy with a Disability Program
1616 Capitol Avenue, Ste. 74.660, MS 7214,
Sacramento, CA 95899
julie.crossriedel@cdph.ca.gov
(916)552-9851

Alissa Cyrus
HEALTH SCIENTIST
CDC
1600 Clifton RD NE, Mailstop E88
Atlanta, GA 30333
fdx7@cdc.gov
404-498-2606

Dan Dao
Epidemiologist
KS - Kansas Department of Health & the
Environment, SDHG
1000 SW Jackson STE 230,
Topeka, KS 66606
ddao@kdheks.gov
785-291-3741

Kay DeGarmo
Program Associate II
IA - Center for Disabilities and Development,
UCEDD/LEND
100 Hawkins Dr, 263 CDD
Iowa City, IA 52242
kay-degarmo@uiowa.edu
319-358-6499

Peter DeGuire
Arthritis Epidemiologist
MI - Michigan Department of Community
Health, SDHG
201 Townsend Street, PO Box 30195
Lansing, MI 48909
deguirep@michigan.gov
517-335-8703

Charles Drum
Assistant Director for Public Health,
Community Outreach, and Policy
Oregon Institute on Disability and Development-
UCEDD/LEND
707 SW Gainest Street
Portland, OR 97239

Danielle Edson
Project Specialist
Association of University Centers on Disabilities
1010 Wayne Avenue, Suite 920
Silver Springs, MD 20910
dedson@aucd.org
301-588-8252

Eva Egensteiner
Health Communications Specialist
FL - University of Florida, SDHG
101 S. Newell Drive, UF, PO Box 100195
Gainesville, FL 32610
eegenst@php.ufl.edu
352-273-5102

Melissa Fahrenbruch
Professional Development Team Lead
CDC/DASH
2900 Woodcock Blvd.,
Atlanta, GA 30341
eya6@cdc.gov
770-488-6167

Sheila Fitzgibbon
Senior Director, Paralysis Resource Center
Christopher & Dana Reeve Foundation
636 Morris Turnpike Suite 3A,
Short Hills, NJ 7078
sfitzgibbon@ChristopherReeve.org
973-467-8270

Sharon Fleischfresser
Title CYSHCN Medical Director
Wisconsin Division of Public Health
W. Wislon PO Box 2659,
Madison, WI 53701-2659
sharonfleischfresser@wisconsin.gov
608-266-3674

Karin Ford
Disability Consultant
Iowa Department of Public Health
321 E. 12th Street,
Des Moines, IA 50319

kford@idph.state.ia.us
515-242-6336

Michael Fox
Research Science Officer
Centers for Disease Control and
Prevention/National Center on Birth Defects
1600 Clifton Rd, Mailstop E88
Atlanta, GA 30333
imv9@cdc.gov
404-498-3806

Paul Galonsky
Disability Policy Leadership Fellow
MD - The Association of University Centers on
Disabilities
1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
pgalonsky@aucd.org
301-588-8252

Jamylle Gilyard
HEALTH SCIENTIST
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
jax8@cdc.gov
404-498-3479

Gillian Goodfriend
Project Coordinator
NCPAD
1640 W. Roosevelt Rd. Suite 705,
Chicago, IL 60608
ggoodfri@uic.edu
312-996-0907

Catherine Graham
Rehabilitation Engineer
SC Interagency Office of Disability and Health
3209 Colonial Drive,
Columbia, SC 29203
catherine.graham@uscmed.sc.edu
803-434-3189

Adriane Griffen
Project Director, CDC Cooperative Agreement
MD - The Association of University Centers on
Disabilities
1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
agriffen@aucd.org
301-588-8252

Nancy Guenther
Program Manager
California Department of Public Health
1860 Hawkhaven Way,
Sacramento, CA 95835
nancy.guenther@cdph.ca.gov
916-552-9840

Allyson Hall
Associate Professor
FL - University of Florida, SDHG
101 S. Newell Drive, UF, PO Box 100195
Gainesville, FL 32610
hallag@phhp.ufl.edu
352-271-5129

Lori Haskett
Director, KS Disability and Health Program
KS - Kansas Department of Health & the
Environment, SDHG
1000 SW Jackson, Ste 230,
Topeka, KS 66612-1274
lhaskett@kdheks.gov
785-296-8163

Susan Havercamp
Associate Professor
University of Florida SDHG
1581 Dodd Drive, 285c McCambell Hall
Columbus, OH 43210
susan.havercamp@osumc.edu
614-247-6629

Blythe Hiss
Information Specialist
NCPAD
1640 W. Roosevelt Rd. # 711,

Chicago, IL 60608
sbonne2@uic.edu
312-996-5965

Martha Hodgesmith
Associate Director
KS - Schiefelbusch Institute for Life Span
Studies, UCEDD/LEND
Univ of Kansas, 1000 Sunnyside Ave, Room
4089
Lawrence, KS 66045
marthah@ku.edu
785-864-4095

Judith Holt
URLEND Co-Director
UT - Center for Persons with Disabilities,
UCEDD/LEND
6880 Old Main Hill,
Logan, UT 84322-6880
judith.holt@usu.edu
435-797-7157

Jessica Howell
Assistant Director
GA - GSU UCEDD
34 Peachtree Street, Suite 1700
Atlanta, GA 30303
jhowell@gsu.edu
404-413-1287

Cathy (Cat) Howland
Project Coordinator
KS - Schiefelbusch Institute for Life Span
Studies, UCEDD/LEND
Univ of Kansas, 1000 Sunnyside Ave
Room 4089
Lawrence, KS 66045
catr@ku.edu
785-864-4096

Joy Hujick
Public Health Analyst
CDC
1600 Clifton Road, Mail Stop E88

Atlanta, Georgia 30333
ezz0@cdc.gov

Patricia Isenberg
COO
Amputee Coalition of America
900 E Hill Avenue, Suite 205
Knoxville, TN 37915
pisenberg@amputee-coalition.org
865-524-8772

George Jesien
Executive Director
MD - The Association of University Centers on
Disabilities
1010 Wayne Avenue,
Silver Spring, MD 20910
gjesien@aucd.org
301-588-8252

Vijaya Kancherla
AUCD-CDC Fellow
Centers for Disease Control and Prevention
(CDC)/NCBDDD/DD, 1600 Clifton Road, NE,
MS E 88
Atlanta, GA 30333
ixi1@cdc.gov
(404) 498 4293

Galatas Kate
Associate Director
CDC NCBDDD Health Communication Science
1825 Century Center,
Atlanta, GA 30345
kkg2@cdc.gov
404-498-3484

Lisa Kilpatrick
Public Health Analyst
RTI International
2951 Flowers Road South, Suite 119,
Atlanta, GA 30341
lakilpatrick@hotmail.com
770-407-4908

Gloria Krahn
Division Director
CDC/National Center on Birth Defects
Developmental Disabilities
1600 Clifton Rd, Mailstop E88
Atlanta, GA 30333
gfk2@cdc.gov
404-498-6160

Barbara LeRoy
Director
MI - Developmental Disabilities Institute,
UCEDD
4809 Woodward Ave., Ste. 268,
Detroit, MI 48202
b_le_roy@wayne.edu
313-577-0334

Candice Lee
Disabilities Program Coordinator
MI - Michigan Department of Community
Health, SDHG
109 W. Michigan Avenue, PO Box 30195
Lansing, MI 48913
leec@michigan.gov
517-335-3188

Scott Lindgren
Professor
IA - Center for Disabilities and Development,
UCEDD/LEND
100 Hawkins Dr, 341-A CDD
Iowa City, IA 52242
scott-lindgren@uiowa.edu
319-353-6142

Karen Luken
Project Director
NC - North Carolina Office on Disability &
Health, SDHG
CB 8185, UNC-CH,
Chapel Hill, NC 27599-8185
kluken@email.unc.edu
919-966-0881

Chris Mackey
Healthy Communities Coordinator
NC - North Carolina Office on Disability &
Health, SDHG
CB 8185 UNC-CH,
Chapel Hill, NC 27599-8185
mackey@mail.fpg.unc.edu
919-966-0865

Fauzia Malik
Educational Outreach Manager
NM - Center for Development & Disability,
UCEDD/LEND
625 Silver Ave SW, Suite 324
Albuquerque, NM 87102
fimalik@salud.unm.edu
505-925-7610

Laura Martin
Director of Operations
MD - The Association of University Centers on
Disabilities
1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
lmartin@aucd.org
301-588-8252

Suzanne McDermott
Principal Investigator
University of South Carolina Interagency Office
for Disability and Health
Family and Preventive Medicine, 3209 Colonial
Drive
Columbia, SC 29203
suzanne.mcdermott@uscmed.sc.edu
803-434-2445

Ryan McGraw
Graduate Assistant
NCPAD
1640 W. Roosevelt Rd, Room 711,
Chicago, IL 60608
rmcgra5@uic.edu
800-900-8086

Darcie Mersereau
VP, Health Programs
Special Olympics
1133 19th St, NW 12th Floor,
Washington, DC 20036
dmersereau@specialolympics.org
202-715-3600

Marcia Miller
HEALTH EDUCATION SPECIALIST
CDC/NCBDDD
1600 Clifton Rd, Mailstop E88
Atlanta, GA 30333
mfv9@cdc.gov
404-498-6408

Sharon Moore
Public Health Analyst
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
sjh6@cdc.gov
404-498-3017

Brenda Munson
Project Assistant
ND - North Dakota Center for Persons with
Disabilities, UCEDD
500 University Ave West,
Minot, ND 58707
brenda.munson@minotstateu.edu
701-858-4477

Janelle Nanavati
Director, Research & Evaluation
Special Olympics International
1133 19th Street, NW,
Washington, DC 20036
jnanavati@specialolympics.org
202-824-0368

Vanessa Nehus
Principal Investigator
AR - Partners for Inclusive Communities,
UCEDD/LEND
2001 Pershing Circle, Suite 300,
North Little Rock, AR 72114
nehusvanessar@uams.edu
501-682-9900

Theresa Paeglow
Program Manager
NY - New York State Department of Health,
SDHG
Riverview Center, Suite 350,
Albany, NY 12020
tnp01@health.state.ny.us
518-408-5683

Chelsea Payne
Health Communication Team Lead
Centers for Disease Control and
Prevention/Division of Adolescent and School
Health
4770 Buford Highway, NE, MS K29
Atlanta, GA 30341
cpayne2@cdc.gov
770-488-4737

Beth Plahn
Board Member, Past-President
HHT Foundation
Box 313, 48557 Westover Place
Garretson, SD 57030
bplahn@alliancecom.net
605-351-3595

Ellen Pliska
MCH Senior Analyst
Association of State and Territorial Health
Officials
2231 Crystal Drive, Suite 450,
Arlington, VA 22202
epliska@astho.org
571-527-3187

Ismaila Ramon
AUCD-CDC Fellow
Centers for Disease Control and Prevention
(CDC)/NCBDDD/DHDD, 1600 Clifton Road,
NE, MS E 88
Atlanta, GA 30333
ITL2@cdc.gov
404-498-2762

Amy Rauworth
Associate Director
NCPAD
1640 W. Roosevelt Rd. Suite 705,
Chicago, IL 60608
rauworth@uic.edu
312-355-1584

Craig Raveslout
Director, Rural Health Research
MT - University of Montana Rural Institute,
UCEDD
52 Corbin Hall, The University of Montana
Missoula, MT 59812
craig.raveslout@umontana.edu
40-243-2992

Amanda Reichard
Research Director
KS - Schiefelbusch Institute for Life Span
Studies, UCEDD/LEND
Univ of Kansas, 1000 Sunnyside Ave., Room
4089
Lawrence, KS 66045
reichard@ku.edu
785-864-4095

Val Renault
Information Coordinator
KS - Schiefelbusch Institute for Life Span
Studies, UCEDD/LEND
Univ of Kansas, 1000 Sunnyside Ave., Room
4089
Lawrence, KS 66045
vrenault@ku.edu
785-864-4095

Cheryl Rhodes
AUCD-CDC Fellow
Centers for Disease Control and Prevention
(CDC)/NCBDDDD/DD, 1600 Clifton Road, NE,
MS E 88
Atlanta, GA 30333
jgy6@cdc.gov
404-498-6507

Jim Rimmer
Director
NCPAD
University of Illinois at Chicago, 1640 West
Roosevelt Rd.
Chicago, IL 60608-6904
jrimmer@uic.edu
312-752-0900

Sharon Romelczyk
Graduate Research Assistant
DE - Center for Disabilities Studies, UCEDD
461 Wyoming Road,
Newark, DE 19716
sromes@udel.edu
302-831-7499

Michael Sanderson
Interim Program Director
NC - North Carolina Office on Disability &
Health, SDHG
1928 Mail Service Center,
Raleigh, NC 27699-1928
michael.sanderson@dhhs.nc.gov
919-707-5620

Jamie Simpson
Disability Program Coordinator
KS - Kansas Department of Health & the
Environment, SDHG
1000 SW Jackson St., Suite 230
Topeka, KS 66612
JSimpson@kdheks.gov
785-296-7990

Lisa Sinclair
HEALTH POLICY ANALYST
CDC/NCBDDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
lvs4@cdc.gov
404-498-3019

Vanessa Smith
Program Coordinator
AR - Partners for Inclusive Communities,
UCEDD/LEND
2001 Pershing Circle, Suite 300,
North Little Rock, AR 72114
smithvanessal@uams.edu
501-526-5962

Eileen Sparling
Project Coordinator
DE - Center for Disabilities Studies, UCEDD
461 Wyoming Road,
Newark, DE 19716
sparling@udel.edu
302-831-8802

Deborah Spitalnik
Executive Director and Professor of Pediatrics
NJ - The Elizabeth M. Boggs Center on
Developmental Disabilities, UCEDD
335 George Street, PO Box 2688,
New Brunswick, NJ 08903-2688
deborah.spitalnik@umdnju.edu
732-235-9326

Bethany Stevens
Faculty Member
GA - GSU UCEDD
34 Peachtree Street, Suite 1700
Atlanta, GA 30303
bethany.stevens@gsu.edu
404-413-1281

Esther Sumartojo
Associate Director for Science
CDC/Natl Cntr Birth Defects & Developmental
Disabilities
1600 Clifton Road,
Atlanta, GA 30333
ESumartojo@cdc.gov
404-498-3072

Ken Surdin
Public Health Specialist
CDC
1825 Century Blvd NE, Room 2044
Atlanta, GA 30345
ksurdin@cdc.gov
404-498-3082

Mark Swanson
Lead Health Scientist
CDC
1600 Clifton RD NE, Mailstop E88
Atlanta, GA 30333
cfu9@cdc.gov
404-498-3076

Ronda Talley
HEALTH SCIENTIST
CDC/NCBDDD
1600 Clifton Rd, Mailstop E88
Atlanta, GA 30333
rkt6@cdc.gov
404-498-3562

Claudia Tamayo
Project Manager
Florida Office on Disability and Health
101 S Newell Drive, HPNP 3101, Po Box
100231
Gainesville, FL 32611
kat57@phhp.ufl.edu
352-273-5286

Sonya Tang
Research Assistant
FL - University of Florida, SDHG
101 S. Newell Drive, UF, PO Box 100195

Gainesville, FL 32610
sonya25@ufl.edu
352-273-5102

Annie Todd
Health Educator Consultant
Florida Office on Disability and Health
4052 Bald Cypress Way, HSFC Bin A-18,
Tallahassee, FL 32399
kat57@phhp.ufl.edu
352-273-5286

Meg Traci
Project Director
Montana Disability and Health Program
52 Corbin Hall,
Missoula, MT 59812
matraci@ruralinstitute.umt.edu
406-243-4956

Monica Uhl
Virginia HPPD Project Director
Virginia Health Promotion for People with
Disabilities (HPPD) Project
Virginia Commonwealth University, 700 E.
Franklin Street, PO Box 843020
Richmond, VA 23284-3020
muhl@vcu.edu
804-828-8587

Royal Walker
Executive Director
MS - Institute for Disability Studies, UCEDD
3825 Ridgewood Road, Suite 727
Jackson, MS 39211
rwalker@ihl.state.ms.us
601-432-6261

Linda Walsh
Pres/CEO
Virtual Training Systems
430 S. Dixie Hwy #211,
Coral Gables, FL 33146
lwalsh@vtsystems.org
786-325-3480

Angela Weaver
Project Coordinator
Oregon Institute on Disability and Development-
UCEDD/LEND
707 Gaines Street SW
Portland, OR 97239
voltolin@ohsu.edu
503-494-3331

Kiyoshi Yamaki
Research Assistant Professor
IL - Institute on Disability & Human
Development, UCEDD/LEND
1640 W. Roosevelt Rd.,
Chicago, IL 60608
kiyoshiy@uic.edu
312-413-7860

Glen White
Director
KS - Schiefelbusch Institute for Life Span
Studies, UCEDD/LEND
Univ of Kansas, 1000 Sunnyside Ave, Room
4089
Lawrence, KS 66045
glen@ku.edu
785-864-4095

Gale Whiteneck
Director, Research Department
Craig Hospital
3425 S Clarkson St,
Englewood, CO 80113
gale@craighospital.org
303-789-8204

Rob Wild
Research Associate
GA - GSU UCEDD
34 Peachtree Street, Suite 1700
Atlanta, GA 30303
rwild@gsu.edu
404-413-1281

Mary Helen Witten
PUBLIC HEALTH ANALYST
CDC/NCBDDD
1600 Clifton Rd NE, Mailstop E88
Atlanta, GA 30333
muw4@cdc.gov
404-498-3023