

# STRATEGIES TO INCORPORATE THE VOICES OF PEOPLE WITH SIGNIFICANT DISABILITIES IN UCEDD INFORMATION GATHERING AND OPERATIONS

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**UCEDD Resource Center**  
A project of AUCD, in partnership with AIDD, to strengthen and support the network of UCEDDs

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## SUMMARY

University Centers for Excellence in Developmental Disabilities (UCEDDs) are federally funded research, education, and service centers housed in major universities across the country with at least one center in each state and territory. They work for and with people with disabilities to advance policy and practice for individuals with disabilities and their families. AUCD undertook this TA activity to compile information from experts inside and outside of the network on strategies to better attune to the viewpoints and address the needs of people with the most significant disabilities. UCEDDs involve community members in many activities, but people with more significant disabilities may have been traditionally challenging to include. This paper focuses on including people who do not use words (spoken, signed, or typed) to communicate, demonstrate with their words or behavior that they strongly dislike traditional meeting or survey environments, or who have such significant behavioral challenges that they have not traditionally been included. This report presents information on principles and best practices from citizen participation research, along with solutions and examples from around the network on inclusion of people with the most significant disabilities and resources for follow-up. The purpose of this report is to gather best practices from across the network and disability field and compile useful strategies for UCEDDs undertaking needs assessments and other community engagement activities. In researching this report, we found that much work remains to be done on best practices in inclusion for people with the most complex needs and we hope this report will both illuminate best practices from across the network and inspire others to conduct further research into this important topic.

“...Centers must address the needs of individuals with developmental disabilities, including individuals with developmental disabilities who are unserved or underserved, in institutions, and on waiting lists...”

## BACKGROUND

The DD Act requires UCEDDs to develop 5-year plans and goals that are based on data driven strategic planning and responsive to emerging needs and trends.<sup>1</sup> To learn about the needs of people with disabilities and their families in their states, UCEDDs conduct state-wide needs assessments and other surveys, often in conjunction with others such as the State Council on Developmental Disabilities. The purpose of the state-wide assessment is to gather information from a broad and geographically diverse population of individuals with disabilities and their families throughout the state. (UCEDDs also rely on Consumer Advisory Councils (CACs) to provide targeted advice on grant applications, projects, and the general direction of the UCEDD. AUCD has already published many resources related to the CACs, see [aucd.org/urc](http://aucd.org/urc).) This report will focus on inclusivity and diversity in the state-wide needs assessment and other practices that UCEDDs use to gather information from the general disability population. Ideas presented below should be applicable to both the state-wide needs assessment and to gaining meaningful input from the CAC.

The DD Act regulations and core funding applications emphasize the requirement that Centers address the needs of individuals with disabilities and their families in their respective states. The regulations specifically require that Centers “must address the needs of individuals with developmental disabilities, including individuals with developmental disabilities who are unserved or underserved, in institutions, and on waiting lists;”<sup>2</sup> Centers are expected to engage with people who have been traditionally excluded or disenfranchised. Applications for core funding also address the importance of needs assessment; Centers must provide “a portrait of State needs”<sup>3</sup> by assessing the needs of people with developmental disabilities in their states then selecting goals and designing projects for the Center based on those needs, reviewing and revising their goals based on emerging needs, and addressing how their projects are connected to those needs in the Center’s logic model.

Given the importance of needs assessments and other information-gathering to UCEDD planning and operations, it is critical that information be gained from a wide spectrum of individuals with disabilities and their families. For this report, we sought out strategies on how best to include the voices of people who many not have been typically included in UCEDD needs assessments or CACs and who, by the nature of their disabilities, face significant barriers to participation.

This report focuses on people who have the most significant disabilities. For the purposes of this report, “most significant disabilities” is defined as those disabilities which may create a barrier to participation in UCEDD needs assessments or other information-gathering activities that use traditional or conventional strategies. These could be any significant intellectual, communication, or behavioral challenges that make participation in traditional meetings, focus groups, written or oral surveys, or other information-gathering methods either very difficult or impossible using traditional methods of inclusion. These include people who do not use words (spoken, signed, or typed) to communicate, demonstrate with their words or behavior that they strongly dislike traditional meeting or survey environments, or who have such significant behavioral challenges that they have traditionally been excluded. This report provides principles

1 *Developmental Disabilities Assistance and Bill of Rights Act of 2000*, Public Law 106-402, 114 Stat. 1677. Section 154(a)(3).

2 45 CFR 1388.3(d)

3 *Administration on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities Education, Research, and Service* (Washington, DC, 2012), 20-36.

for full participation drawn from public participation research, then outline tools and strategies identified by network members and other experts for the inclusion of people with the most significant disabilities in information gathering efforts.

Based on many questions received during the interview process, we wish to emphasize that this report does not assume that all people with significant disabilities have the same wants, needs, or feelings about participation, or that they all face the same challenges to participation that we outline here. Our analysis is based on the assumption that gathering a diverse sample of people is essential for UCEDD planning and that many people with significant disabilities want to participate in activities that solicit their input/opinions, but our traditional means of gathering information may have been inaccessible to them. We undertook this activity to find successful and innovative strategies to include a group of people who may have been excluded in the past.

## PRINCIPLES OF PUBLIC PARTICIPATION

Certain key principles of public participation, as defined in the public administration and citizen participation literature, can inform UCEDD efforts at including people with the most significant disabilities. When UCEDDs conduct needs assessments and other surveys to inform their work, they engage in a form of public participation. While not directly involved in decision-making (outside of the CAC), the participation of people with disabilities and their families and communities form crucial building blocks of UCEDD planning and prioritizing of resources. Many scholars and organizations devoted to public participation have developed standards and principles which are applicable to the UCEDDs' work, particularly the rights of citizens to engage in decisions that will affect them, the importance of gaining input from a diverse group of people that represents the population affected, and the benefits of public participation to the participants themselves. These principles are detailed below.

### PRINCIPLE: Nothing About Us Without Us

UCEDDs should include people with disabilities in the decisions that affect their lives. This core conviction of the disability rights movement is mirrored in public participation literature. Public participation scholar James Creighton notes that "at its most basic level, public participation is a way of ensuring those who make decisions that affect people's lives have a dialogue with that public before making those decisions."<sup>4</sup> For UCEDDs, this means that those who may be affected by UCEDD decisions have the right and responsibility to inform those decisions, including those with most significant disabilities.



<sup>4</sup> James L. Creighton, "The Rationale for Public Participation," *The Public Participation Handbook: Making Better Decisions through Citizen Involvement* (San Francisco, CA: Jossey-Bass, 2005), 17.

“For people with disabilities who may have faced discrimination, disenfranchisement, and belittlement in their communities, engaging in participation has the potential to be an even more empowering experience.”

### **PRINCIPLE: Representativeness**

UCEDDs conducting needs assessments should seek input from a diverse group that is representative of the population they serve. AmericaSpeaks, a national citizen participation non-profit, lists seven principles of public participation, one of which is to “Achieve diversity. Involve a demographically balanced group of citizens reflective of the impacted community.”<sup>5</sup> This diversity should include a diversity of abilities and incorporate people with a range of different abilities and disabilities. If UCEDDs have not heard the input of people who face greater barriers to participation than most, they have missed an important subset of the population they serve. Irvin and Stansbury bring up this specific concern in their article in the *Public Administration Review*, noting that citizen participation may be dominated by those with the time and money to participate, resulting in underrepresentation of low-income groups.<sup>6</sup> In the case of UCEDDs, the opportunities for participation may be dominated by those who are successful in the traditional participation environment, underrepresenting certain groups of people with disabilities. Including people with significant disabilities is essential to the representativeness of needs assessments.

### **PRINCIPLE: Public participation also benefits those who participate**

Finally, UCEDDs should strive to include people with the most significant disabilities because of the potential benefit to the participants themselves. Many scholars cite the empowerment and educational benefits for citizens when they participate in government. Irvin and Stansbury argue for “participation as a way of teaching otherwise powerless citizens to interact with groups in society, gaining legitimacy as political players.”<sup>7</sup> For people with disabilities, who may have faced discrimination, disenfranchisement, and belittlement in their communities, engaging in participation has the potential to be an even more empowering experience.

## **METHODS**

AUCD staff conducted interviews from June to November of 2012 with UCEDD staff and representatives from other organizations who have experience in engaging with people who communicate in non-typical ways. Staff also reached out to those who indicated that they had attempted to incorporate people with very significant disabilities into surveys, evaluations, or other activities. Contacts include:

- AUCD Council on Community Advocacy, a Council made up of individuals with disabilities and family members representing CACs from across the UCEDD network
- Allies in Self-Advocacy listerv, an email distribution list for self-advocates and supporters
- Leadership Institute alumni listerv, an email distribution list for alumni of the National Leadership Consortium on Developmental Disabilities Leadership Institute
- 30 experts in the AUCD network, including experts in self-advocacy, person-centered planning, alternate assessments in educational settings, and research methods

5 Carolyn J. Lukensmeyer and Lars Hasselbald Torres, “Public Deliberation: A Manager’s Guide to Citizen Engagement.” (Washington, DC: IBM Center for the Business of Government, 2006), 9.

6 Renee A. Irvin and John Stansbury, “Citizen Participation in Decision Making: Is It Worth the Effort?,” *Public Administration Review*. 64. No. 1 (2004): 59.

7 *Ibid.*, 57.

Interviews generally lasted from 30 minutes to one hour, depending on the detail of responses. AUCD conducted interviews with 10 people, and communicated via email with 4 others. AUCD asked respondents for specific strategies in use at respondents' organizations to include people with more significant disabilities; for resources, tools, or insights from their areas of expertise that would be applicable to involving people with more significant needs; and for their experience and opinions on the use of proxies. The following section outlines the tools and strategies that interviewees found most successful.

## STRATEGIES AND TOOLS

Throughout the interviews, respondents gave many practical tools on how UCEDDs can best include people with significant disabilities who face barriers to participation. The overarching theme of these strategies and tools is to create new opportunities to hear what people have to say. This means responding when someone uses his or her behavior to communicate, always allowing time for interviewees to respond to questions, engaging with each interviewee as an individual, and challenging interviewers to find new ways to listen. This can also mean moving past traditional means of gathering information (meetings, focus groups, interviews) and finding non-traditional means, like getting to know someone, asking questions about his or her life, or enjoying an activity together. Tools and strategies related to flexibility, informality, and accepting non-typical communication are listed below. Many strategies may not be new, but we hope this compilation of strategies will highlight practices currently in use and illuminate the gaps in knowledge where we can learn more from additional research. Specific strategies and related tools provided by interviewees and in keeping with the identified principles of citizen participation are detailed below.

Note: Some of the tools listed come from Support Development Associates, a for-profit business that specializes in person-centered planning. We reached out to experts in person-centered planning to learn their best practices in gaining information in a way that ensures that everyone involved has a meaningful, safe, and enjoyable interview process. These tools are not intended to be used without training from SDA, but provide good insight on the kind of tools UCEDDs could employ.



“...flexibility also shows the respondent that the interviewer values his or her input and is willing to shape the interview to meet his or her needs.”

**STRATEGY: Ask person-level questions that are in the “weeds,” not policy- or program-level questions that are in the “clouds”**

**Tool: The Arc Person-Centered Planning Toolkit**

A respondent with experience in self-advocacy emphasized that disability professionals too often ask questions about high-level policy, rather than simple questions about life. Interviewers should ask basic questions about the respondent’s life, and then translate those answers into policy needs or UCEDD goals. For example, an interviewer would ask about how respondent feels about his or her staff, instead of asking about high turnover rates among direct support professionals. The Arc Person-Centered Planning toolkit<sup>8</sup> provides examples of good basic questions that may be translated into areas of need for a UCEDD. For example, “I wish I had a job” or “I can’t afford to go to the doctor” can help the Center learn the key areas of need in employment and health.

**STRATEGY: Take time to get to know someone, time to let him or her respond to questions, and time to learn what their behavior means**

**Tool: Beyond Tokenism Report, Learning Log**

One of the most consistent responses was the need to allow for more time for respondents to understand questions and express themselves. This time may go beyond what traditional research may find unreasonable, and stretch into days and weeks, depending on the respondent’s communication style.

The *Beyond Tokenism* report from the Center for Development and Disability at the University of New Mexico encourages CAC facilitators to match the rhythm and pacing of the meeting to the needs of the group, making sure that everyone has time to process the information.<sup>9</sup> Similarly, when conducting interviews or focus groups, facilitators should allow as much time as an individual needs to understand and answer a question, including coming back to some questions later.

For people who primarily use behavior to communicate, some person-centered planners employ a “Learning Log”<sup>10</sup> which records the details of an individual’s response in specific activities. The purpose of the log is to better understand a person’s interests and how to best support that person by closely attending to his or her responses. A technique like the Learning Log could be employed to help an individual answer a survey by recording his or her responses and behavior over time. For example, those who know and care about a person could record that she exhibits that she likes to visit her friends, but that a lack of accessible public transportation limits how often she can visit. This response would inform needs surrounding transportation.



8 The Arc. “Person-Centered Planning Toolkit” <http://www.thedesk.info/downloads/PersonCenteredPlanningToolkit.pdf> (21 August 2012).

9 Judith Stevens and Barbara Ibanez, “Beyond Tokenism: Partnering with People with Diverse Abilities on Consumer Advisory Boards,” (Center for Development and Disability at the University of New Mexico), 10.

10 Support Development Associates, “Learning Log” <http://sdaus.com/learning-log> (23 August 2012)

## **STRATEGY: Be flexible and informal with participants to match their communication style**

### ***Tool: 2 Minute Drill***

Interviewees noted the need for flexibility and informality in interviews. Many with experience in the area noted that the most valuable information comes from real conversations, where interviewers can relax and learn about a respondent's life instead of rushing through a list of questions. Interviewers may have a list of survey questions, but should be flexible to the time of the interview, order of questions, conversations deviating from the strict purpose of the interview, and both the pace and place of the interview, including returning to the interview later. This flexibility also shows the respondent that the interviewer values his or her input and is willing to shape the interview to meet his or her needs.

Support Development Associates uses a "2 Minute Drill"<sup>11</sup> as a tool to help new support staff learn about a person who might not use words to communicate. The drill involves key information about what is important to and for the individual, based on the information gathered over time in tools such as the Learning Log. Tools like this could also be used to help an interviewer learn quickly about the person they will be interviewing and help ensure that both people have a meaningful and enjoyable interview.

## **STRATEGY: Use technology to simultaneously support different communication styles**

### ***Tool: Accessible online meeting spaces that allow for chat, captioning, and screen reader accessibility***

According to some self-advocates contacted, video conferencing and tele-conferencing can help to include those who are uncomfortable in a meeting environment but are able to use, understand, or read words to communicate. AUCD office staff have successfully included participants in tele-conferences with a supported web chat and closed captioning. Participants can listen to and/or read the conversation and respond by speaking or typing. All spoken responses are included in the captioning and all typed responses are read out loud, so every participant has an opportunity to access the material multiple ways. This also creates a transcript of the call that all participants can use later.



"...self-advocates have more experience adapting to non-typical communication or behaviors and can elicit high quality responses."

11 Support Development Associates, "2 Minute Drill" <http://sdaus.com/2-minute-drill> (23 August 2012)

12 Sarah Skidmore et al., "Conducting Surveys with Proxies: Evaluating a Standardized Measure to Determine Need" (Washington, DC: Mathematica Policy Research, 2012), 4. [http://www.mathematica-mpr.com/publications/PDFs/surveys\\_with\\_proxies\\_wp.pdf](http://www.mathematica-mpr.com/publications/PDFs/surveys_with_proxies_wp.pdf)

“While it is preferable to study choice using self-reported data whenever possible, restricting consideration solely to such data disenfranchises those who are unable to self-report.”

### **STRATEGY: Train interviewers on methods to reduce barriers, employ self-advocates as interviewers**

#### ***Tool: Trainings on mitigating barriers***

Many respondents identified interviewer training as a key process in promoting inclusion. This includes training on the techniques discussed above, like allowing time and non-typical listening. In a study discussed below, Mathematica Policy Research had much more success at gaining participation when they trained interviewers on how to overcome “gatekeeper” barriers.<sup>12</sup> (While the report does not specify, these “gatekeepers” are presumably staff, caregivers, families, guardians, or others involved in respondent’s life.)

Centers should also employ self-advocates as interviewers, who are especially equipped to listen to other people with disabilities and listen for non-typical answers. Some respondents noted that self-advocates have more experience adapting to non-typical communication or behaviors and can elicit high quality responses.

### **STRATEGY: Provide stipends to increase both participation and social capital of participants**

#### ***Tool: Build stipends into project budgets***

Centers who successfully gain participation and feedback from people with significant disabilities also found that providing stipends and/or meals to participants increased the participants’ desire to participate and sense of importance of the interview. Stevens and Ibanez, in the Beyond Tokenism report, note that “paying money for a person’s time and travel expenses sends a clear message that you consider his or her time and expertise valuable.”<sup>13</sup> While stipends increase the participation of all people, they have even greater potential to increase commitment to the project and reinforce the positive benefits of participation for people unaccustomed to having their opinion asked or valued.

### **STRATEGY: Plan ahead to allocate resources toward inclusive participation**

#### ***Tool: Plan evaluation budgets for activities to include enhanced participation resources***

Lack of resources continues to create barriers to high quality and inclusive surveys and needs assessments. One successful Center noted that they build in funds in their evaluation budgets when they know that they will need to reach out to people with more significant disabilities. This kind of planning can mitigate, although not solve, the financial strain of attempting a highly flexible in-person survey.



13 Stevens and Ibanez, 15.

## PROXY RESPONDENTS

The use of proxy respondents remains a contentious issue in public participation, research methods, and the developmental disabilities field, but the question must be addressed when discussing involvement of people who do not use words to communicate or do not understand spoken, written, or signed language. Opinions of those interviewed ranged from the opinion that proxy responses are never acceptable to the opinion that proxy responses are a less-than-desirable-but-necessary part of gathering information from a wide diversity of viewpoints. While proxy responses are contentious, they become an important issue when researchers or others wish to gather information from people with a wide variety of disabilities. Proxies have traditionally been affiliated with research and representative samples, but proxies may also play a role in any context to gather input from people with a diversity of disabilities. Proxies have also been used inappropriately in the past, based on incorrect assumptions that people with disabilities cannot or should not speak for themselves. However, even as the field moves toward nearly 100% self-reporting, some people still rely on others to translate their communication into language. As Stancliffe, et al describe it, “While it is preferable to study choice using self-reported data whenever possible, restricting consideration solely to such data disenfranchises those who are unable to self-report.”<sup>14</sup> Disallowing proxy respondents denies participation to those who cannot respond in typical ways or who may rely on those who know and care about them to translate their communication into language. The following strategies and tools provide ideas to consider when using proxies, including tools for determining if proxies are necessary, tools for determining when a proxy respondent may or may not be appropriate, and tools for identifying a proxy respondent and testing the validity of the responses.



### STRATEGY: Determine if a proxy is necessary

**Tool:** Mathematica Policy Research Cognitive Screener, training interviewers on use of the screener

Mathematica Policy Research has examined the use of proxies in their National Beneficiary Survey (NBS), a survey of Social Security beneficiaries conducted for the Social Security Administration (SSA).<sup>15</sup> Mathematica conducted surveys via telephone, text telephone (TTY), instant messaging, Relay, in person, and with support for the beneficiary to answer independently (if needed). Proxy responses were a “last resort.” In order to determine if a proxy respondent was necessary, Mathematica interviewers conducted a “cognitive screener” that involved the interviewer explaining basic aspects of the interview process (what questions would be asked, the voluntary nature of the survey, and the confidentiality of the survey) then asked respondents to explain those aspects in their own words. Each respondent was given two chances to respond in his or her own words.

14 R.J. Stancliffe et al., “Choice of Living Arrangements,” *Journal of Intellectual Disability Research* 55, no. 8 (2010): 3.

15 Skidmore, Sara et al., 3.

“This gives the caregiver a chance to make his or her feelings known, encourages the caregiver to differentiate between his or her own feelings and that of the youth, and allows the interviewer to monitor if responses are the same in both interviews.”

Mathematica found that training interviewers on the screener dramatically improved the accuracy of determining the need for a proxy. They recorded the interviews in order to test the accuracy of the interviewers’ administration of the screener and intervened to re-train interviewers who showed a high degree of error. Even with these trainings, Mathematica also found a need for additional interviewer training on how to overcome “gatekeeper” objections to allowing the sample member to complete the survey. As noted above, these gatekeepers are presumably staff, caregivers, families, guardians, or others involved in respondent’s life. This kind of standard tool may be useful for UCEDDs conducting evaluations or other research endeavors, particularly when using a random sample.

### **STRATEGY: Determine what questions a proxy may answer**

#### ***Tool: National Core Indicators example***

The question of whether it is acceptable to use proxies for some respondents produced a wide variety of answers. While none of the interviewees found proxy respondents to be the most desirable way to gain information, most found it necessary if surveyors hoped to get answers from all respondents. In these situations, proxy respondents might be appropriate to gain information about an individual’s life, but not their satisfaction or opinions.

The National Core Indicators (NCI) project is an effort implemented by state developmental disabilities (DD) agencies — coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) — to measure and track the performance of state DD services. The project gathers information on individual outcomes; health, welfare, and rights; system performance; staff stability; and family indicators for people with developmental disabilities in 29 states. Each participating state randomly samples at least 400 individuals with developmental disabilities receiving services. Within this sample, the NCI allows for proxy respondents in some parts of the survey, but not others.<sup>16</sup>

The NCI survey is broken into two sections. Section I includes questions about satisfaction and opinions, including work and daytime activities, home life, friends and family, satisfaction with services and supports, and self-determination; Section II includes questions about community inclusion, choices, rights, and access. Proxies may be used in Section II, but not in Section I. Allowed proxies are a family member, friend, or support worker. Responses to Section I are excluded if:

- The individual responded to less than half of the questions in Section I
- The interviewer recorded that the person did not understand the questions being asked
- The interviewer recorded that the person gave inconsistent responses

The NCI project does not use proxies to gather information on respondent satisfaction. This example suggests that the NCI project has found it appropriate to use proxy responses to gain information about an individuals’ life, but not his or her satisfaction or opinions.

<sup>16</sup> HSRI and NASDDDS “National Core Indicators Consumer Outcomes” March 2011. [http://www.nationalcoreindicators.org/upload/core-indicators/NCI\\_CS\\_09-10\\_FINAL\\_Report\\_2.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/NCI_CS_09-10_FINAL_Report_2.pdf)

## **STRATEGY: Determine who may serve as a proxy responder and employ strategies to elicit accurate responses**

**Tool:** Relationship Map, proxy respondent example, statistical methods in quantitative research

The question of who may serve as a proxy produced a wide variety of responses. Family members of people with significant disabilities more often responded that family members are the best proxies, while professionals who are not family members most often responded that service coordinators or others who know the individual well are the best proxies. Self-advocates more often responded that proxies are never appropriate.

If a Center determines that proxy responses will be necessary, a tool from the person-centered planning process may be helpful in choosing a proxy responder. When determining who (in addition to the individual) should be involved in a person-centered planning process, Support Development Associates use a Relationship Map<sup>17</sup> to find people who know and care about the individual. Participants are not chosen based on their formal connection to the individual (parent, sibling, staff, service coordinator, etc.) but based on their informal relationship with the person. The planners ask questions like, “What do you like and admire about \_\_\_\_\_?” or “When is the last time you had fun with \_\_\_\_\_?” These questions are designed to tease out those who love and care about the person, who are most likely to be able to set aside their own thoughts and answer as they truly believe the individual would answer. Proxy respondents should be those who are best equipped to translate an individual’s behavior or demeanor into typical communication that can be recorded by an interviewer.

One network Center sometimes uses proxy respondents for youth enrolled in a therapeutic foster care program. As a result of the nature of foster care, their current caregivers are often the only relationship that many of these youth have. The Center surveys the youth on their satisfaction with their care, but some of the youth, because of significant intellectual or communication disabilities, cannot answer questions when asked, either because they do not understand spoken, signed, or written language, or because they cannot reply in a traditional spoken, signed, or written manner.

The Center employs a number of strategies to mitigate the potential conflict of interest in asking caregivers to rate their own care, including the following.

1. The Center conducts a separate initial interview with the caregiver alone to ask for their input on the program, before conducting the interview where the caregiver serves as the proxy. This gives the caregiver a chance to make his or her feelings known, encourages the caregiver to differentiate between his or her own feelings and that of the youth, and allows the interviewer to monitor if responses are the same in both interviews.
2. Interviewers repeatedly remind proxies that they are responding as if they were the youth with a disability and asks the proxy respondent to give examples for why they think the youth would respond a certain way. This encourages the proxy to think critically about their responses and allows the interviewer to know if the responses are based on the youth’s behavior or demeanor. This also creates the opportunity for the proxy respondent to translate or interpret the youth’s behavior into typical communication, rather than to speak for the youth.

“The field must continue to search for successful strategies and conduct research on the best ways to include those who may have traditionally been excluded.”

17 Support Development Associates, “Relationship Map” <http://sdaus.com/relationship-map> (23August 2012)

3. All caregivers receive training in Attachment Regulation Competency, which is a therapy aimed at children and families who have been exposed to trauma and teaches caregivers to regulate their own affect and attune themselves to what someone may not be expressing verbally.

This Center had the most extensive plans and strategies to handle the conflict of interest presented by proxy respondents, yet still found their process “deeply flawed.” None of the researchers or surveyors interviewed was entirely comfortable with the proxy process, but those who use it saw it as a necessary, if imperfect, step in gaining information.

In a statistical method to accommodate the use of proxy data, studies conducted with National Core Indicator data undertook statistical methods to help control for potentially confounding factors. Using proxy data for choice and opinion questions introduces potential for confounding variables, particularly given the significant differences between respondents who did and did not use proxies — self-reporters were more likely to have mild or moderate ID, more likely to lease or own their own home or apartment, and more likely to be young and female. Stancliffe et al<sup>18</sup> and Lakin et al<sup>19</sup> chose to analyze all data together but control for confounding factors by including self or proxy responses as an independent variable in their regression analyses. This technique allows researchers to both track systematic differences in proxy versus self-reporters and control for those differences when analyzing other aspects of the data.



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18 Stancliffe et al., 5-6.

19 K. Charlie Lakin et al., “Choice-Making Among Medicaid HCBS and ICF/MR Recipients in Six States,” *American Journal on Mental Retardation* 113, no. 5 (2008): 333.

## CONCLUSION

This report has provided tools and strategies on how to better attune to the viewpoints of people with most significant disabilities. The focus of the report was on inclusion of people who have traditionally faced high barriers to participation, particularly given intellectual, communication, or behavioral challenges. Interviews with AUCD network members and other noted experts in the field, including self-advocates, uncovered strategies for inclusion that focus on flexibility and finding new opportunities to listen. This report also provided information on the use of proxy respondents.

Increased inclusion in public participation has the potential to produce benefits not only for UCEDDs, who gain a better understanding of the needs of their constituents, but also for the participants themselves, who can gain empowerment and social capital in a world that has traditionally undervalued their participation. However, this area continues to challenge professionals, families, and self-advocates and no one has yet developed a comprehensive tool or strategy. Few respondents were entirely comfortable with their own strategies and most were reluctant to describe their efforts as successful. The field must continue to search for successful strategies and conduct research on the best ways to include those who may have traditionally been excluded.

As Stevens and Ibanez remind us in the *Beyond Tokenism* report, while working to increase inclusion we must realize that we are never “there” in including and valuing the input of people with disabilities.<sup>20</sup> This report has compiled ideas and strategies from across the network, but is intended to be a part of a continuing conversation and effort to increase inclusive practices and challenge ourselves to mean “all means all.”



20 Stevens and Ibanes, 17.

## ACKNOWLEDGEMENTS

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## ADDITIONAL RESOURCES

In conducting research for this report, AUCD had interviews with people still in the process of conducting their research. These two resources should come available in the coming months.

Mark Freidman of the Beyond Tokenism Project is conducting a survey of the methods that disability organizations use to fully include people with developmental disabilities with high support needs in leadership development, public policy, and community activities. The results of this survey are intended to create a snapshot of best practices across the country. Dr. Freidman was still collecting data until November 21, 2012.

Cristina Gangemi and Dr. Jon Swinton of the University of Aberdeen have created a consultancy whose aim is to provide training, resources, and education on innovative supports and inclusion of people with all kinds of cognitive disabilities. This consultancy is based on qualitative research testing methods of inclusion with focus groups of people with a diversity of disabilities. Their findings will be available in March of 2013. Information can be found at: <http://www.abdn.ac.uk/kairos-forum/>.

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