Beyond Tokenism:

People with Complex Needs in Leadership Roles

National Study Report
Michigan Developmental Disabilities Council
June 2013 (public)

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Mark Friedman, Ph.D.
Project Director
Vice-President
Blue Fire Consulting
1509 Van Cleve Lane
Murfreesboro, TN 37129
mark@mtadvocacy.com
(615) 812-4950

Ruthie-Marie Beckwith, Ph.D.
Research Director
President
Blue Fire Consulting
1509 Van Cleve Lane
Murfreesboro, TN 37129
empfanatic@aol.com
(615) 898-0300

Ron McGough
Peer Trainer

David Taylor
Peer Trainer

Eric Thomas
Peer Trainer

Tokenism

Token

When you invited me
on this board.
You didn't say I'd
be ignored
But you have made it very clear,
That all you want is
my body here.
You point to me and
to others say
We have a self advocate
on our board.
You don't tell them
I'm just ignored.
I have a right
to be heard.
TOKEN
How I hate the word.

From The Inside Out, Poetry by Gail Bottoms.

When you treat someone like a token, it makes the person feel like you don't appreciate them for what they can offer. It makes them feel like you only see their disabilities and worry about what they can't do. People get tired of only being seen as having disabilities. They don't like talking about their disabilities all the time. They would rather show people their abilities, show what they **can** do.

From, Tokenism—It Doesn't Look Good by Liz Obermayer [Weintraub].

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Acknowledgements

Carrying out a national study of this scope and magnitude required the collaboration and support of a broad range of individuals with disabilities, professionals, family members, advocates, and others in Michigan and on the national level. Altogether, over 400 individuals gave input into the results of this effort and all are deeply appreciated for their guidance, assistance, and encouragement.

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We would also like to express sincere thanks to our friends and colleagues, Jim Dehem, Pat Carver, the national experts, the 15 national organizations that distributed the survey, and all the people who participated in the survey, focus groups and interviews. We greatly appreciate their insights, support, and help. Thanks to all of you.

Definition of Complex and/or High Support Needs

The Michigan Developmental Disabilities Council (2012) defined complex and/or high support needs as,

The needs of people with developmental disabilities that characterize the most vulnerable members of our community. They may be considered to have complex and/or high support needs because of:

A. The breadth of their needs – multiple needs that are interrelated or interconnected, requiring coordination from multiple systems; and/or
B. The depth of their need – needs requiring serious or intense life-long supports.

People with complex and/or high support needs are those who:

A. Are the least likely to get the supports they need to experience ordinary life;
B. Typically spend most of their time in segregated settings;
C. Often experience discrimination, social exclusion, or isolation in ordinary daily life unless they get specific support for realizing self-determination and participation;
D. Usually cannot exercise choice or participation in activities unless:

   a. Specific opportunities to be involved are offered to them, and
   b. Appropriate assistance to engage in them is made available.

Note: The study used the Council's definition with all respondents

Final Report and Recommendations

Overview

Over the past twenty years, self-advocacy organizations, Developmental Disabilities Councils (DDCs), University Centers for Excellence in Developmental Disabilities (UCEDDs), Protection and Advocacy (P&As), State Developmental Disabilities agencies, and others have embraced multiple strategies to increase the number of self-advocates on boards and decision-making bodies. The immergence of the self-advocacy and mental health consumer movements contributed greatly to the expectation that policy-making and other types of advisory and governance entities should include individuals with disabilities at the table. Similar to efforts by other marginalized groups, to gain influence, individuals within intellectual and developmental disabilities have had to confront tokenism and the lack of commitment to their inclusion.

The purpose of the Beyond Tokenism: People with Complex Needs in Leadership Roles national study described in this report was designed to determine A. How other groups include people with complex and/or high support needs in their leadership development, public policy advocacy, and community activities; and, B. How the Council can better include them and support them in its activities. Those findings, along with thorough in-depth dialogue with organizational leadership and self-advocates, form the basis of recommendations for best practices based on affirmed examples of successful representation. In short, we wanted to determine how far

individuals with complex and/or high support needs have moved "beyond tokenism" and into authentic leadership roles along with those factors or activities that have contributed to their ascent.

The earliest effort to identify organizations that included people with disabilities in leadership roles also engaged individuals with developmental disabilities in the design and collection of data (Powers et. al., 2002). The National Center for Self-determination and 21st Century Leadership conducted surveys of University Affiliated Programs (now referred to as UCEDDs) and Developmental Disability Councils (DDC) focusing on strategies utilized to promote participation. At that time, surveys received from 38% of the UAPs and 54% of the DDCs (an overall response rate of 46%) reported a total of 193 individuals with disabilities[1] as directly involved.

Since that time, three additional overview studies have been conducted (Blisard, 2003; Moseley, 2006; and Patterson, 2012). These three studies show a progression of greater involvement on the part of individuals with intellectual and developmental disabilities in leadership roles. However, these prior overview studies did not include a specific focus on individuals with complex and/or high needs. Within the body of empirical research, only four studies were identified that provided such an analysis (Hemsley, Balandin, & Togher, 2008; Llewellyn, 2009; Mitchell, 2009; and Radermacher, Sonn, Keys & Duckett, 2010).

The data collected and analyzed in this report were gathered from five primary activities; a comprehensive review of the literature, a workshop with representatives of

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[1] Study did not indicate whether any of these individuals had developmental disabilities

18 state developmental disabilities councils, national online survey completed by 160 organizations, five focus groups with individuals in Michigan and one with the board of directors of Self-Advocates Becoming Empowered, and interviews with 35 organizations in 32 states. Overall, more than 400 people participated in the study.

When taken together, these data provide a clear picture of what organizations are currently doing to assure that the presence of individuals with complex and/or high support needs truly results in furthering their missions and outcomes. The complexity of this undertaking was such that the support and participation of a number of organizations and individuals was necessary to achieve its desired outcomes. The cooperation of the National Associations for entities funded by the U.S. Administration on Developmental Disabilities (ADD) under the Developmental Disabilities Act (DD Councils, UCEDDs, and P & As), along with our other project partners, was essential to the development and dissemination of the national overview study.

An overview of the specific activities and methods used to develop, gather and analyze the data follow this introduction. The results of each component are reported in Parts II and III followed by conclusions and recommendations for further efforts in this area. As such, the results of the study provide a clear baseline of what has been accomplished to date and the challenges that remain.

Summary of the review of the literature

The emergence of a viable and vibrant disability rights movement forged new perspectives on the role of people with disabilities in all aspects of modern society. Similarities between this movement, the civil rights movement, and women's movements were noted in a number of early histories about the disability rights movement's evolution (Dreidger, 1989).   Initial analyses of similarities focused on the methods deployed to achieve social change as well as the institutional structures targeted for reform—including the need "to make visible the power that hides behind the rationality of administrative or organizational procedures" (Shakespeare, 1993).

In accordance to its predecessors, the disability rights movement's early objective of claiming a positive collective identity challenged two critical established preconceptions about people with disabilities at that time; their ability to control the course of their daily lives and their capacity to influence the cultural mechanisms used to define their place in society. As such, the ensuing demand for "nothing about us without us" (Charleton, 1998) mirrored the demands by people of color and women for a place at the table where such decisions were being made.   And, to the extent that doors to greater opportunities began to open, those individuals with disabilities given admittance have encountered the same degrees of tokenism as other marginalized groups.

Since 1992, a growing amount of attention has been paid to ascertaining the most effective ways to support individuals with intellectual and developmental disabilities in leadership roles. The emergence of this group within the disability rights

movement afforded them the opportunity to assert their right to influence decisions made that would effect their daily lives. The self-advocacy movement forged significant leadership who in turn began to question the societal structures that had contributed to paternalistic and authoritarian forms of marginalization. Whereas initiatives to dismantle aspects of those structures were begun by parents and professionals, these struggles gained greater legitimacy when individuals with intellectual and developmental disabilities began to take their place at the table.

As more individuals with developmental disabilities gained access to leadership roles on boards of directors, advisory committees and other decision making entities, a growing body of information has emerged that describes the progress such efforts have made. Unfortunately, very little information regarding the provision of supports to individuals with complex needs has emerged within this knowledge base.

The review of literature conducted for this research included results from an extensive search of international literature including journals, web pages, and past project training manuals and documents. Scholarly databases were searched using keywords such as: board inclusion, tokenism, women and boards, disabilities and leadership development, public policy advocacy, community activities, as well as others. The search effort yielded a total of 60 items that were categorized and analyzed from citizen participation and organizational development perspectives. These items include four prior national overview studies of overlapping categories of disability focused organizations, 15 qualitative and/or quantitative research articles, 24 publications that describe or elaborate on what specific supports may be needed and how they are

provided, 11 training manuals and handbooks, and six articles or items by authors with developmental disabilities.

Most of the significant knowledge in the field is contained in printed how to manuals and guidelines published and/or funded by Developmental Disabilities Councils and University Centers for Excellence in Developmental Disabilities. Over the past twenty years, self-advocacy organizations, Developmental Disabilities Councils, State Developmental Disabilities agencies, UCEDDs and others have embraced multiple strategies to increase the number of self-advocates on boards and decision-making bodies. The emergence of the self-advocacy and mental health consumer movements contributed greatly to the expectation that policy-making and other types of advisory and governance entities should include individuals with disabilities at the table.

As this review was conducted, themes relating to the provision of supports emerged from the literature. The theme of Individualized Supports (and Mentors) was most prevalent with attention paid to the broad range of types of supports needed as well as how best to make them available. The themes of Financial Supports and Coordination and Communication were more frequently subsumed within the theme of Individual Supports. Factors relating to the theme of Leadership Development were largely equated with changes in the individual with a disability with *individual transformation* viewed as a result of having a leadership role. Finally, factors relating to the overall outcomes were found to be in keeping with the need to attend *organizational transformational* put forth by Fredette, et al. (2007).

In order to provide for a systematic analysis, five elements essential to inclusive board practices were subsequently synthesized from the themes described as above. The five elements, described in Table 1, pay particular attention to a range of factors that influence inclusive practices and make it possible to categorize the types of supports described as important. It also affords prospective users of these tools with the ability to discern which of those identified may be the most useful and possible gaps that should be supplemented by other approaches.   Finally, the application of the elements enabled this review to ascertain whether attention was paid to a full range of functions needed for inclusion rather than an overreliance in one particular area.

Table 1: Five elements of transformational board inclusion

Elements of Board Inclusion	Descriptors
Authentic Membership	Individuals are recruited, treated, and respected as full member of the board and organization
Deliberate Communication	Individuals receive and share information in formats that can be understood and are included in the on-going dialogue of the board and organization
Full Participation	Individuals are provided with the means to be present and are engaged in carrying out the responsibilities of board members in roles and activities that reflect their the interests and preferences
Meaningful Contributions	Individuals provide input and assistance that is important to the board and organization in ways that utilize their gifts, talents, and experiences.
True Influence	Individuals enhance or alter the substance, direction, and outcomes of board and organizational purposes, policies and practices in ways that positively impact the lives of people with disabilities.

Despite the limited number of studies reviewed, a small, but distinct distribution of supports referenced emerged. Supports relating to deliberate communication were

referred to the greatest number of times followed by those relating to full participation and meaningful contributions. Less attention was given to the impact of support provision on individual or organizational transformation. However, when considering the challenges individuals with complex needs experience in this area, enhanced provision of supports in this area would appear to have great merit. Nonetheless, additional attention to supports that would facilitate greater board inclusion in other areas may have the capacity to mitigate the barriers to deliberate communication.

Within the majority of these materials specific supports felt to be useful were identified. Following a thorough analysis of these items, four primary conclusions can be drawn: 1) individuals with complex needs are successfully engaged in leadership roles when adequate attention is paid to their individual support needs, 2) research and training materials to date have focused exclusively on supports and adaptations that enhance the capacity of individuals with the intellectual and developmental disabilities to more fully participate, without concomitant consideration of the training needs of their fellow board or committee members, and 3) the identification and description of supports that have been found to be useful have not been put into the context of the elements of board and organizational development.

The findings of the review of the literature were used in the development of instruments and activities needed to complete the Beyond Tokenism National Study. The activities carried out to complete the study ultimately included cooperative and assistance from over 400 individuals.

Research Questions

The specific research questions for this study included:

1. How many people with high and complex needs, developmental disabilities and other disabilities were engaged in leadership roles?

2. What supports were considered to be the most important to provide by survey respondents?

3. What outcomes were considered to be the have the greatest impact on the individuals with complex and/or high needs who are engaged in leadership roles?

4. What outcomes were considered to have had the greatest impact on the organizations?

5. What effective practices and other recommendations did the respondents from the Best Practices Interviews share?

6. How do ADD funded programs compare to one another organizations across the country?

Method

Multiple approaches were utilized to conduct this research. The primary activities consisted of:

1. an international review of the literature,

2. interviews with Michigan stakeholders,

3. a Beyond Tokenism Workshop at the annual meeting of the National Association of Councils on Developmental Disabilities (NACDD) in 2011,

4. a national overview survey conducted via the internet,

5. five focus groups conducted with 75 individuals in Michigan,

6. a focus group with 16 members of the board of directors and nine advisors of Self Advocates Becoming Empowered, and,

7. in-depth interviews with representative(s) of 35 disability organizations in 32 states.

The international review of the literature generated research questions and provided additional information used to formulate the questions included in the online survey along with the focus groups and in-depth interview guides.

Interviews with Michigan Stakeholders

In person and telephone interviews were conducted with twenty-three key individuals from Michigan. These included 14 of the 16 Michigan Developmental Disabilities Council members and all four of its key staff persons, and the Executive Directors of the Michigan Protection and Advocacy, Inc., the Arc of Michigan, the Developmental Disabilities Institute, Wayne State University and UCPA of Detroit.

These interviews served as background information assisting with the development of the study.

Beyond Tokenism Workshop at NACDD, 2011

We conducted a Beyond Tokenism workshop with 22 members of 18 different State DD Councils at the 2011 Conference of the National Association of Councils of Developmental Disabilities. The workshop included seven Council Executive Directors. The group developed a set of barriers and success methods for overcoming the barriers. These items included tangible items such as help with logistics, mentors, plain language materials as well as the utility of pre-meetings and facilitation (see Appendix G). These items were used in developing the National Overview Survey and the Interview Guide.

The National Overview Survey

The National Overview Survey was developed to identify organizations that are including people with complex needs, the supports and strategies they have found to be effective, and the impact of their inclusion as the outcome of their inclusion. Thirty national experts were consulted during the development of the National Overview Survey (see Appendix E). Through these discussions, it was clear that there was little knowledge of which organizations were successfully including people with complex and/or high needs in leadership roles and/or other aspects of their programs and activities.

As a result of these discussions, it was decided that asking as many individuals and organizations to respond to the survey as possible would serve to; 1) identify the groups including people with complex and/or high needs; and, 2) capture the current best practices currently in use. The Council's definition of Complex and or High Support Needs was specifically included in the survey. Prior to distribution, the survey was reviewed by 25 national disability experts and field-tested by ten organizational leaders (see list provided in Appendix E). The field tests resulted in the substitution of levels of support needs in the place of specific types of disability labels. The levels of support needs consisted of: 1) difficulty reading, 2) difficulty being understood, 3) difficulty understanding the materials at the meeting, 4) using a mobility device, 5) using a personal care assistant, and 6) using a communication device.

In order to reach as many organizations as possible, most of the major national disability organizations were recruited to distribute the online survey. Fifteen national organizations agreed to distribute the survey to their membership and affiliates. All three of the national associations of DD Councils, Protection and Advocacy agencies and University Programs (UCEDD) distributed the survey as well as the Arc, US, UCPA, National Association of DD Directors Services, TASH, Ancor and many other national disability advocacy and provider organizations (see Appendix E)

Focus Groups

The purpose of the focus groups was to obtain a wider perspective of inclusive practices from people with complex and/or high support needs. This approach has since become a standard approach to obtaining input from adults with complex

communication needs (Helmsley, Baladin, & Togher, 2008). Five regional focus groups were carried out in Michigan and another with the national self-advocacy organization, Self Advocates Becoming Empowered (see full reports in Appendix C and H).

Altogether, 102 focus group participants (see table 2) provided input into the study on their experiences with participating in organizations as members and/or in leadership roles of which. Sixteen (16) of the focus group participants had complex and/or high support needs. Finally, 97 percent of the focus group participants in Michigan were members of local RICCs and as such had experience with group membership. At each focus group, the Council's definition of high and complex support needs was read and distributed to the participants.

Table 2: Focus group participants by location

Focus Group Location	Participants with Disabilities
Marquette, MI	3
Grand Rapids, MI	22
Monroe, MI	31
Flint, MI	16
Gaylord, MI	3
Self Advocates Becoming Empowered, Minnesota	27
Total	102

Best Practices In-Depth Interviews

In-depth phone interviews were conducted with 35 organizations identified as successfully including people with complex and/or high needs (see Appendix F). The purpose of the organizational interviews was to more fully identify and examine the techniques and methods found to be most successful in including people with complex needs in their governance and organizational activities. The Best Practices Interview

Guide (see Appendix B) used for the in-depth interviews was based on the results of the focus groups and National Overview Survey. Most of the interviews were conducted via phone and lasted about an hour.

The organizations to be interviewed were identified from the National Overview Survey and additional recommendations. As part of the National Overview Survey, 30 organizations were identified that included *two or more people with complex and/or high support needs* in leadership roles. Twenty-eight of these organizations were contacted and asked to participate in the Best Practices Interviews.[2] This analysis coincides with the extensive research from women's studies, cited in the literature review, from women's studies that report the inclusion of *three women as a key factor leading to successful inclusion in organizations.*

Specific questions asked during the interview focused on what factors contributed to the their success, how they differed from other groups, what supports and strategies they found to be most effective for the inclusion of individuals with complex and/or high support needs, and the impact their inclusion had on the organization.

At the end of each interview, they were asked to identify other organizations they knew to be successfully including people with complex and/or high needs. This technique, called snowballing or chain sampling, asks subjects to recommend other potential subjects based on their knowledge and experience. This technique has been found to be particularly effective at identifying hidden groups that might otherwise not

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[2] Two organizations were excluded due to significant amounts of missing data in their survey results.

be located (Patton, 1990). From this approach, an additional seven organizations were

identified for potential interviews.

Altogether, 35 interviews with organizations from 32 states were completed.

Almost all, 90%, of the interviews were conducted with the Executive Directors of the

organizations. This underscored the high interest in the results generated by the study's

activities.

Introduction to the Results

The purpose of the Beyond Tokenism National Study was to identify the best practices currently being used to support individuals with complex and/or high needs in leadership roles that the offer opportunities to influence policies and practices within the disabilities field. In the first part of the executive summary, we provide an overview of what we learned from the National Overview Survey. In the second part of the summary, we provide a synthesis of what we learned from the best practices in-depth interviews and focus groups. Findings from both parts of the summary are applied to specific recommendations for actions to be taken by the Michigan Developmental Disabilities Council as well as other organizations seeking to promote greater diversity amongst its leadership.

As is the case with studies of this scope, and as the first study to focus primarily on individuals with complex and/or high support needs, the results must be interpreted with consideration given to other factors including:

Notwithstanding the contributions to the data made by individuals with complex and/or high support needs, respondents to the National Overview Survey and Best Practices Interviews were predominately professionals. Therefore, the findings here do not reflect a complete picture of what the individuals themselves have found to be the most effective practices at promoting their inclusion in leadership roles.

To some degree, the National Overview Survey questions were open to interpretation,

National Overview Surveys that were missing key data relevant to the analysis and interpretation of these findings had to be deleted, thus lowering the overall response rate.

Finally, the study's diverse activities generated significantly greater and richer data than initially anticipated and necessitated an initial prioritization of analyses in order to generate a report that would be of use to the broadest range of audiences.

Part I: Perspectives of People with Developmental Disabilities

The perspectives of individuals with disabilities were identified and collected by two methods; the review of the literature and focus groups conducted with individuals in Michigan and one with the board of directors of Self-Advocates Becoming Empowered.

Perspectives Found in the Literature

Only six items about having experienced tokenism first hand as individuals with developmental disabilities were located despite an expansive search for such work. Carlson noted the lack of such perspectives in his 2010 article, *Who's the Expert? Rethinking Authority*, "Not surprisingly, the voices of persons with IDs themselves are virtually absent from philosophical discourse about them."

> "This small but insightful collection of work illustrates the breadth and depth of consideration that individuals with developmental disabilities have given their commitment to broader representation in civil society."

Yet, when evidence of such voices is studied, it is clear that the persons themselves have been engaged in a philosophical discourse of their own. For example, in her collection of poetry, *Inside Out*, (2004), Georgia poet Gail Bottoms[3] succinctly describes her experience with tokenism in the poem, 'Token';

> You point to me and to others say, 'We have a self-advocate on our board.' You don't tell them I'm just ignored. I have a right to be heard. TOKEN. How I hate that word.

---

[3] Gail Bottoms served as President of People First of Georgia, Inc. from 1997 to 2000

In an earlier work published by the Oregon Council on Developmental Disabilities in 1999, Liz Obermayer (Weintraub)[4], a national leader in the self-advocacy movement shows great insight into how her understanding of what it meant to be a token grew over time and how the enticements of status and privilege available to members of most boards of directors influenced her initial reticence to express her dissatisfaction.

> My friend saw that I was being treated like a token but I could not see it. People cannot always see when they are being treated like a token. So I resigned because I felt like she wanted me to. I let them know I felt like they were treating me like a token. I wrote that in a letter because it felt better. I didn't really know what I was writing, but I felt like I needed to write them. Later I missed the Board, both the glory and fun parts of being on the Board. I missed learning information others wouldn't know about. (p. 2).

In her 1999 essay, "Tokenism—it doesn't look good," Obermeyer went on to identify three ways to stop tokenism; 1) involve people with disabilities on boards of directors, 2) involve more than one self-advocate, and, 3) support true participation.

More recent articles and papers by self-advocates have focused more on the barriers encountered as members of boards of directors and research teams (Shoultz, 2003 and Robinson, 2006). Tia Nelis[5] (Shoultz, 2003) describes her efforts to help make the process of research and its findings accessible to individuals with intellectual and developmental disabilities,

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[4] Liz Obermayer Weintraub is employed as a Quality Enhancement Specialist with the Council on Quality and Leadership, she is also a former chairperson of the Maryland Developmental Disabilities Council.

[5] Tia Nelis is a research associate at the Rehabilitation Research and Training Center and Aging with Developmental Disabilities located at the University of Illinois at Chicago.

If it's going to be disseminated to people with developmental disabilities, we talk about it with people with developmental disabilities first. (p. 6).

Robinson[6] (2006) provided extensive examples of how to make presentations

that everyone can understand at a RICC Leadership Retreat sponsored by the Michigan

Developmental Disabilities Council,

If we want everyone to understand, we need to present information in ways that fit their learning style and abilities. In the past people talked about special accommodations for people with learning problems. But the person isn't the problem. The presenter is the one that is challenged—to teach in ways that everyone can learn. (p. 1)

Finally, Krebs[7] (2011) stressed the importance of moving beyond tokenism as

more self-advocates claim their seats at the table,

Self-advocates should not just take up a spot so organizations can check the self-advocate box in their checklist. Once self-advocates are on boards, we need to speak out and have a voice. This means having the confidence to speak out when you are at a meeting. It also means that boards need to be open to letting self-advocates speak. Next, self-advocates need to learn to be an effective board member. They can only do this with help from the board. (p. 24)

This small but insightful collection of work illustrates the breadth and depth of

consideration that individuals with developmental disabilities have given their

commitment to broader representation in civil society. The experiences of other

individuals with developmental disabilities who took part in board and leadership

development activities were also captured in the context of research and project

reports. However, in comparison, one is left to wonder about how the richness of first-

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[6] Andre Robinson served as the Chairperson of the Michigan Developmental Disabilities Council from 2002 to 2013
[7] Bill Krebs is a Peer Trainer for the Beyond Tokenism project funded by the Pennsylvania Developmental Disabilities Council.

hand authenticity and passion must have been curtailed by the confines of professional discourse.

Focus Group Perspectives

The primary themes that emerged from the focus group discussions in Michigan centered on the barriers members felt impeded their inclusion as group members and the challenges they had to overcome in order to participate. The most significant barrier to greater participation in Michigan DDC activities expressed repeatedly by the Michigan focus group participants was the lack of transportation. For example, the van scheduled to bring more individuals to the Marquette focus group did not show up.

The focus group with the leadership of Self Advocates Becoming Empowered yielded data that reflected the members' broader experience with service in leadership roles on local, state, and national levels. Individual responses to the questions raised were then categorized using the essential elements for board inclusion. More than half of the responses, 56 percent, focused equally on factors that contributed to full participation

> What I try to do at first is listen, you know, as to what is going on, and then look at the materials that I had given to me. You know, they usually give you stuff or send you stuff. I let them know what form I needed and you know, pay attention to that. Because some of the boards and things have been hard at first, because if you don't know anyone or if you don't know what's going on, you know you have to start somewhere.
>
> I was on a state committee on education and all they wanted people to do was go in and say yes to the materials that they had sent out. So, I started asking questions and it's hard for some people to ask questions and it changed how they wanted people to do stuff.
>
> *--SABE focus group participant*

and true influence. Deliberate communication was addressed 19 percent of the responses, authentic membership by 15 percent, and meaningful contributions by 10 percent.

The results of the focus groups show the concerns of the individuals with regard to inclusion are focused primarily on full participation (being present at the table and having the supports needed to engage in the agenda) and true influence (feeling that their input and contributions impacted the outcomes of the meeting or policies of the organization).   Strategies for achieving success in these areas that were referred to most frequently by participants included adapted materials, receiving assistance from mentors (or other individuals) to process information and provide input during the meetings, and dependable transportation.

Part II: Findings from the National Overview Study

The National Overview Survey generated a very high level of interest. Almost all of the Developmental Disability Councils, a majority of UCEDDS, and Protection and Advocacy agencies completed the survey. Follow-up with groups that had not initially completed the survey was made via emails and phone calls to their Executive Director.

Study respondents demographic results

In all, a total of 160 survey responses were considered sufficiently complete for further analysis. Figure 1 provides a graphic depiction of the distribution of National Overview Survey respondents by type of organization.   The majority of responses to the National Overview Survey were from Developmental Disabilities Councils. The specific breakdown of responses by organizational type is provided in Table 3.

Figure 1: Distribution of National Overview Survey respondents by organizational type
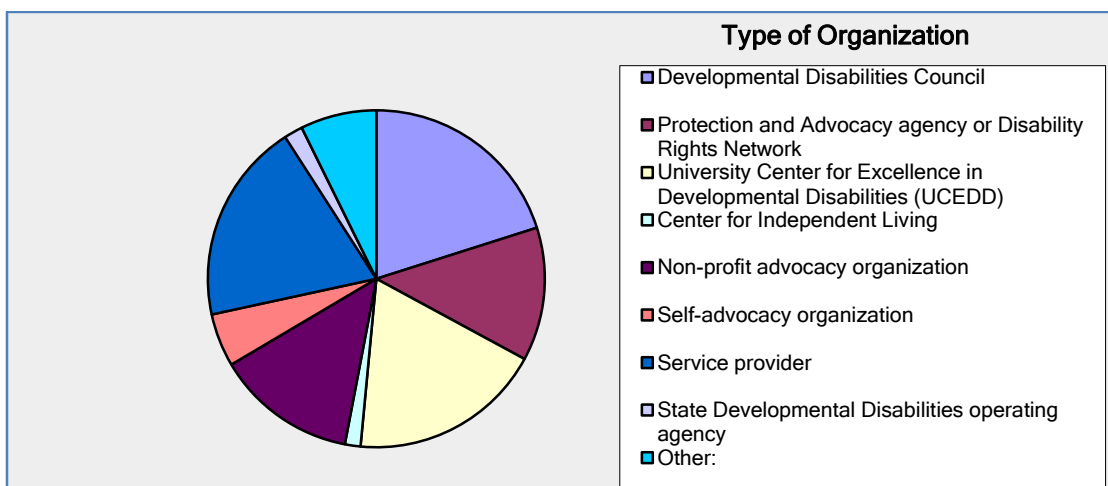
Table 3: National Overview Survey responses by organizational type

Organization	Surveys Completed	Percentage of Participation
DD Councils*	49	86% of all Councils
UCEDD's	33	49% of all UCEDDs
Protection & Advocacy	25	44% of all P & As
Total ADD groups	**107**	
State DD office	4	
Providers	25	
Advocacy	21	
Other	3	
Total non ADD	**55**	
Total all	**160**	

The DD Act mandates that DD Council comprise 33% - 36.6% people with DD

Table 4 summarizes the distribution of the results from the 160 complete responses with regard to the composition of council/board/advisory committee. As shown, 25 percent of the individuals from all of the reporting organizations were identified as having a developmental disability. Although the data needed to analyze the entire response set for the percentage of individuals with complex and/or high support needs were insufficient; the DDCs, UCEDS, and P&As reported five percent (109) of the total number of individuals serving as having complex and/or support needs.

Table 4: Number of individuals with complex and/or high support needs

Organizations	Surveys Completed	# People serving	# People with DD	Percentage with DD	# People with Complex/High Support Needs*
DD Councils	49	1,277	377	30%	68
University Programs	33	628	187	30%	31
Protection & Advocacy	25	314	54	17%	10
Total ADD groups	**107**	**2,218**	**617**	**28%**	**109**
State DD office advisory committees	4	65	21	32%	Not specified
Providers	25	291	56	19%	1
Advocacy	21	327	52	16%	6
Other	3	74	10	14%	Not specified
Total non ADD	**55**	**757**	**139**	**18%**	**7**
Total all	**160**	**2,975**	**756**	**25%**	

*The response rate to this specific question was 83% of the 160 surveys completed.

A further breakdown of demographic information for the 109 ADD funded entities is provided in Table 5.

Table 5: Additional demographic information provided by 106 DDCs, P&As, and UCEDDs

COMPARISON OF ADD FUNDED ORGANIZATIONS*			
	DDC	UCEDD	P & A
Reported Numbers	N=49	N=33	N=25
Total people serving	1,277	627	314
People with Developmental Disabilities	377	186	54
Percentage with Developmental Disabilities	30%	30%	17%
Gender (all people serving)			
Men	39%	30%	47%
Women	61%	69%	53%
Ethnicity (all people serving)	DDC	UCEDD	P & A
White/Caucasian	82%	66%	67%
Hispanic/Latino	3%	9%	6%

	DDC	UCEDD	P & A
Black/African American	7%	14%	14%
Asian/Pacific Islander	4%	7%	7%
Native American	3%	2%	5%
Other	1%	1%	1%
Age (People with DD)	DDC	UCEDD	P & A
Under 25 years old	8%	17%	8%
26-55 years old	77%	70%	77%
56 plus	15%	13%	15%
Length of Time Served (People with DD)	DDC	UCEDD	P & A
1 year	17%	24%	19%
2-3 years	35%	28%	29%
4-5 years	26%	28%	24%
More than 6 years	22%	21%	29%
% with 2 or more people with complex and/or high support needs	DDC	UCEDD	P & A
Complex/high support needs	38%	31%	8%
% with 2 or more people with this support need	DDC	UCEDD	P & A
Use a mobility device	60%	73%	17%
Use a communication device	8%	15%	4%
Personal Care Assistant	77%	58%	8%
Hearing	10%	0%	8%
Difficulty Being Understood	46%	45%	8%
Difficulty Reading	77%	61%	8%
Difficulty Seeing	23%	9%	8%
Difficulty Understanding the Discussion	75%	45%	13%
*Based on number of organizations reporting			
Note: Percentages account for missing data			

Study Results Specific to Complex and/or High Support Needs

In order to provide a clear focus on factors that contribute to the inclusion of individuals with complex and/or high support needs, responses from 28 organizations *that reported having two or more individuals with complex and/or high support needs* in leadership roles were separated for additional analyses. This criterion was

established based on the aspect of the literature review that reported significantly better outcomes when three or more women served together on a board of directors (Erkut, Kramer, & Konrad, 2008; Kristie, 2011; Torchia, Calabro, & Huse, 2011).

The Beta Analysis Tool provided online by Survey Monkey and SPSS statistical package were utilized to analyze these data. These results provide an initial glimpse into the depth and breadth of the inclusion of individuals with complex and/or high needs. The primary questions answered with regard to these 28 organizations included:

1. What types of supports are these organizations currently providing to individuals with complex and/or high needs?

2. What types of supports do these organizations report to be the most important?

3. What outcomes are considered to be the most significant as the result of their inclusion of individuals with complex and/or high needs in leadership roles?

To answer these questions, this study carried out a number of activities with a broad range of audiences, including individuals with complex and/or high support needs. For this portion of study, several subsets of the data obtained from the National Overview Study were utilized to provide for more robust analyses of the outcomes. These subsets include data from:

1. Results that were deemed complete responses from within the data set, hence a total N of 160 responses;

2. Results from the 107 responses from DDCs, UCEDDs, and P&As,

3. Results from the 28 responses from DDCs, UCEDDs, and P&As that reported having two or more individuals with complex and/or high support needs in leadership roles

were then analyzed as the subset believed to hold the most informed responses

based on their experience; and,

4. Results from the three organizations that reported having five or more individuals

with complex and/or high support needs in leadership roles were examined.

An analysis of variance based on the number of organizations reporting,

indicated a statistically significant difference in the inclusion of individuals with

complex and/or high support needs amongst the ADD funded entities (see figure 2).

Developmental Disabilities Councils lead the way with regard to inclusion followed by

UCEDDs.

Figure 2: Analysis of number of individuals with high/complex needs by type of organization

Analysis of variance of High/Complex by Type of Organization

Filters: No filters

One-way ANOVA result:

$F = 4.918$ $p = 0.00895$ **

Mean of High/Complex is significantly different by value of Type of Organization.

Type of Organization	Obs.	Minimum	Median	Maximum	Mean	Std Dev
		Distribution of variable High/Complex				
Developmental Disabiliti…	49	0.0	1	7	1.265	1.705
University Center for Exc…	36	0.0	1	4	0.8889	0.9791
Protection and Advocac…	31	0.0	0.0	4	0.3226	0.8321

Organizations that responded to the survey were asked to identify those

supports they provided to individuals with disabilities in order to provide for their

inclusion. All 27 response options included in the survey were noted as being used.

However, the total frequency count show the five supports cited most frequently were

accessible meeting space, board orientation and on-going training, financial assistance,

having two or more individuals serve, and assistance with travel arrangements (see

table 6).

When asked to identify the supports they considered to be most important of

the 27 options provided, the five supports cited most frequently were 1) accessible

meeting space, 2) adapted meeting procedures, 3) financial assistance, 5) leadership

commitment to inclusion, and 5) having two or more individuals serve (see table 7).

These findings indicate that supports that are more *intangible* such as changes in

organizational structures and practices are needed in order to assure inclusion.

Supports more noted by self-advocates and in the literature had much lower rankings,

for example: the use of mentors ranked 12th; written policies and by-laws ranked 15th;

adapted materials ranked 17th' and, having a mentor during meetings ranked 18[th.]

Table 6: Total support counts by 28 groups providing support to 2 more individuals with complex and/or high needs
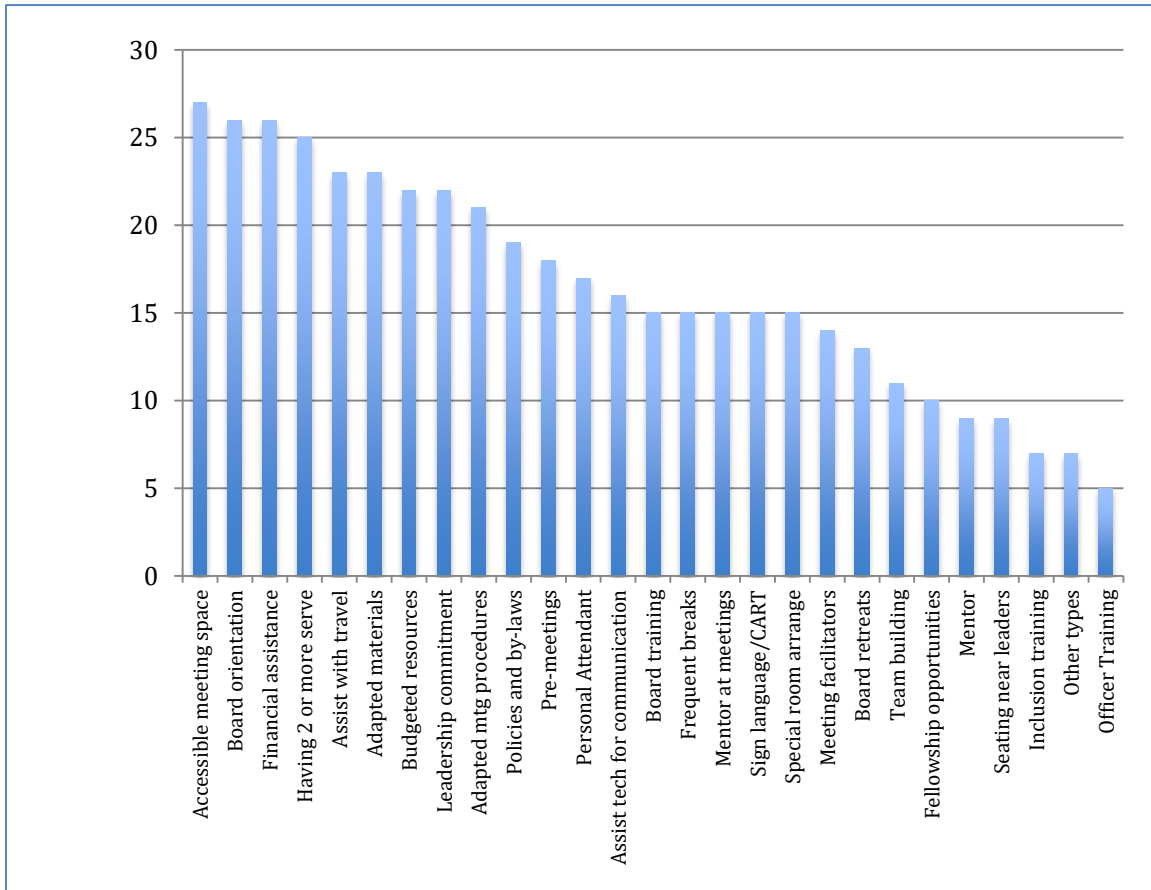
Table 7: Supports ranked in order of importance by 28 groups providing support to
2 or more individuals with complex and/or high needs
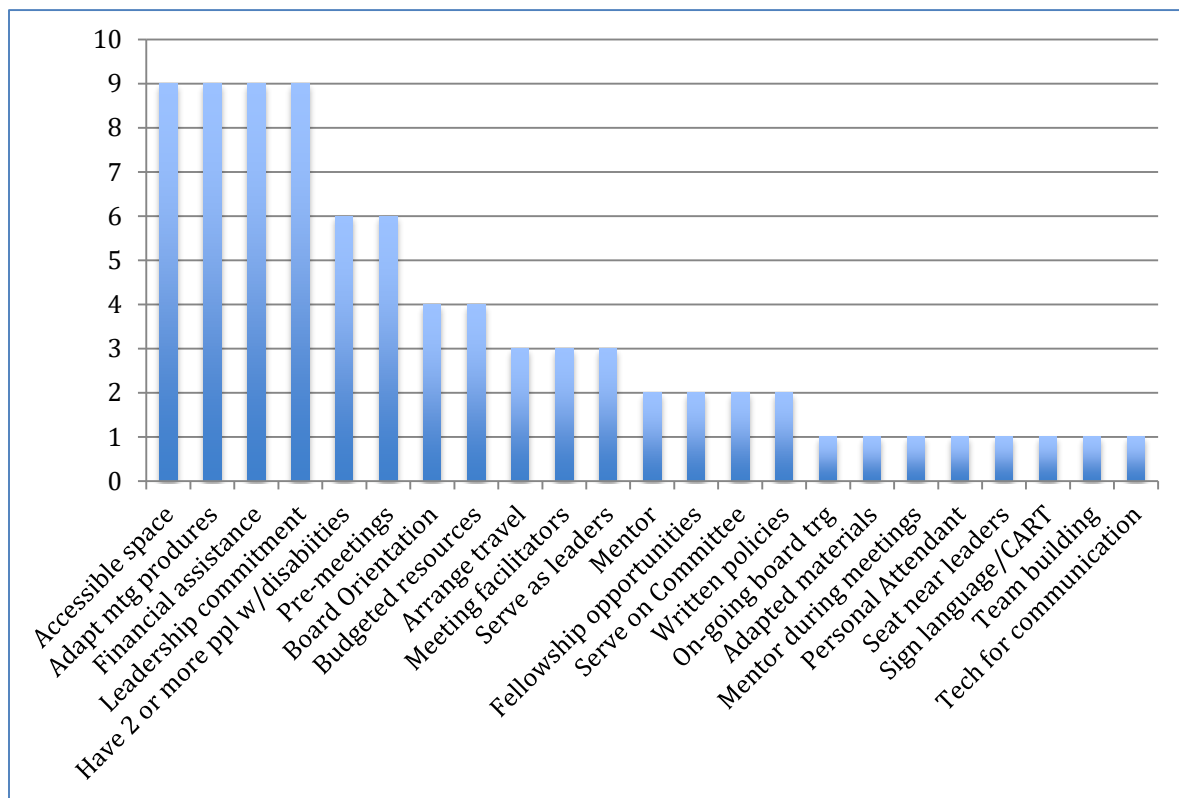
And finally, what the 28 groups identified as the most important impact of
having 2 or more individuals with complex and/or high support needs in leadership roles
is presented in table 8. The impact of having individuals with developmental disabilities
included in leadership roles show the top four to be those that reflect a focus on the
individual; leadership opportunities, expanded view of capabilities by others, stronger
relationships, and increased inclusion. Only one outcome, expanded influence with
policymakers, reflects a focus on the organization.

Table 8: Greatest impact rankings of 28 groups having 2 or more people with complex and/or high needs
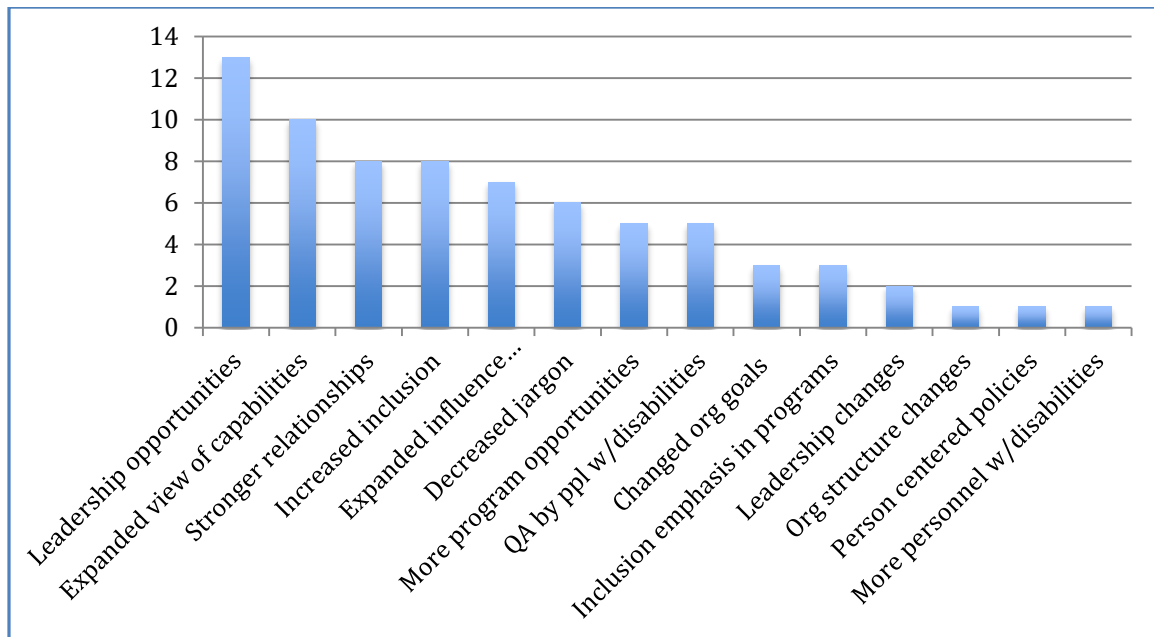
The results described thus far are those for a subset of the overall data of groups that include two or more individuals with complex and high needs in leadership roles. However, within this 28-group subset, three organizations reported having five or more individuals with complex and/or high support needs in leadership roles. Final analyses were conducted to determine whether any differences in ranking of supports importance (see table 9) or impact (see table 10) would emerge.

Table 9: Most important supports identified by three groups with 5 or more people serving in leadership roles
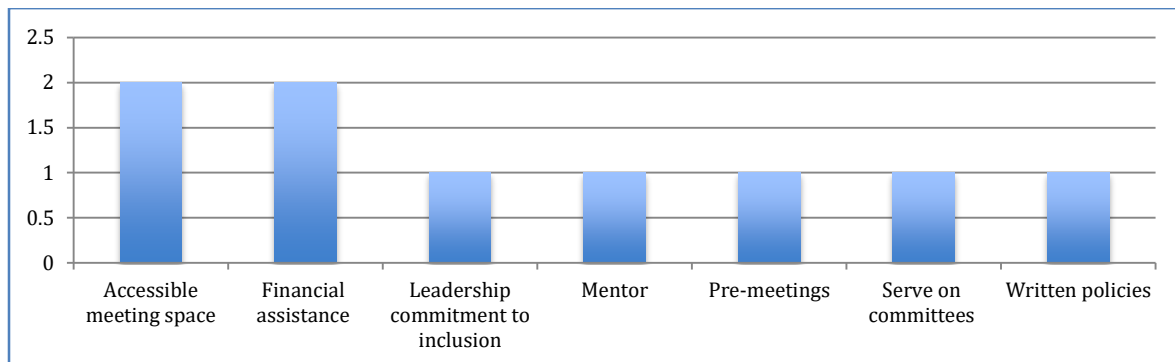
Table 10: Greatest impact by three groups with 5 or more individuals with complex and/or high support needs in leadership roles
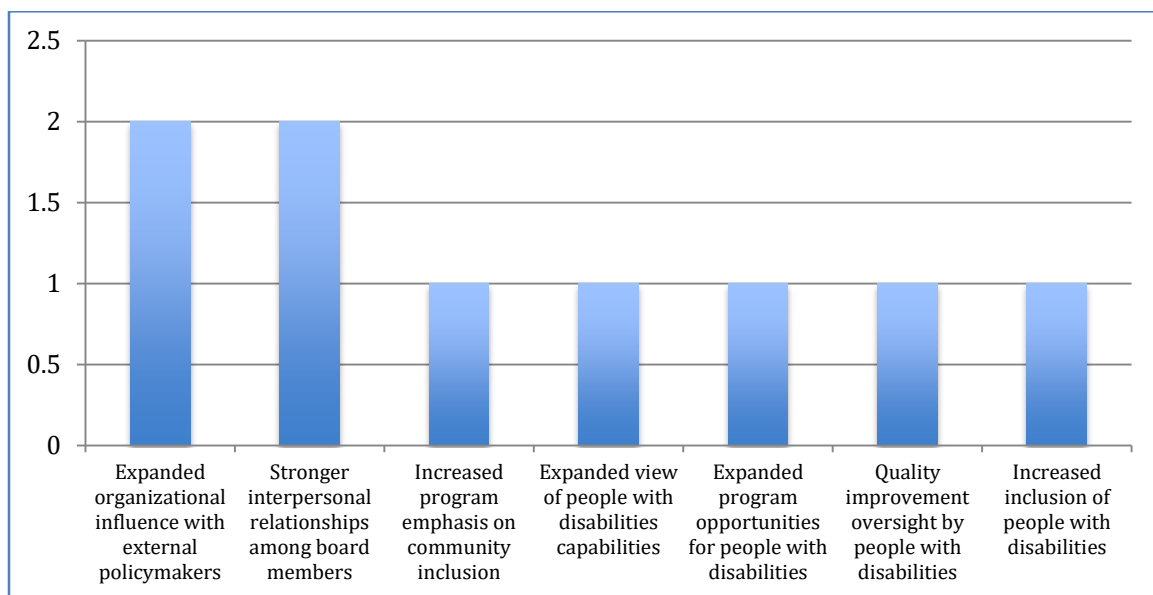
When the results of the 28-group subset of data are compared to the 3-group

the ranking of three of the top five remained the same: accessible space, financial

assistance, and leadership commitment. However, the importance of mentors and pre-

meetings were included in the top five ranking by the 3-group subset. Finally, a similar

comparison of the greatest impact results of the 28-group subset of data to the results

of the 3-group ranking again resulted in three items that were consistent with both groups: expanded influence with external policymakers, stronger interpersonal relationships and expanded views of the capabilities of people with disabilities. **Two impact items reported by the 3-group subset were different: increased program emphasis on community inclusion and expanded program opportunities for people with disabilities**. This finding would appear to indicate that as the numbers of individuals with complex and/or high needs in leadership roles increases, so does the focus on inclusion and program opportunities for people with disabilities.

This finding would appear to indicate that, as the numbers of individuals with complex and/or high needs in leadership roles increases, so does the focus on inclusion and program opportunities for people with disabilities.

Part III: Findings from the Best Practices In-Depth Interviews

In-person and telephone interviews were conducted with 35 organizations; including 21 organizations identified from the National Overview Survey and 18 from the snowball recommendations.   The interviews typically lasted an hour and followed the Best Practices Interview Guide compiled from the results of the review of the literature, the National Overview Survey, and the focus groups. The purpose of the interviews was to more fully identify and examine the techniques and methods organizations have found to be most successful in including people with complex and/or high support needs in their governance and organizational activities.

Several general themes emerged from the interviews. First, all of the successful organizations felt like they were not doing enough. They often began with, "This will be a short interview." However, when the interview ended, they commented on how useful the interview had been and how it made them think of things they were doing and how they might do better. Second, several interviewees said, "Please don't give us another checklist. We have many of those but none are tested. There is no evidence that

> If the Governor asked you to do this job for the State of Texas, the Council should do whatever it takes to get you here—
> Roger Webb, Texas DDC

> How do we get people that are all over KY to come to our board meetings?
>
> Well, we always tell them that we're going to feed them well—
> Marsha Hockensmith, KY P&A

one works better than another or at all." Third, the most frequently made comment was, "It's not rocket science," sometimes followed by, "It's just hard work."

> I have to tell you, I really think it comes down to building relationships.

Finally, while there may not be a silver bullet or secret sauce, there are many examples of best practices commonly used by the successful organizations. Because these are not prescriptive or absolute, we call these Effective Practices. We define this as those methods and processes that have been found through trial and error to be effective for successfully including people with complex needs in organizational activities.

Effective practices and transformational outcomes

As indicated earlier, common themes were identified within the review of literature as well as input from the focus groups. These themes were also found within the Best Practices interviews. What follows in this section are examples of effective practices for promoting

> "It's really important for a board member to be a board member."

transformational board inclusion identified by the directors of the Best Practices organizations. This includes summaries of how needed supports are identified and how the use of mentors has been implemented in ways that meet both the needs of the individual as well as the organization. Lastly, we have included stories that illustrate how the lives of individuals with complex and/or high support needs, and the

organizations that support them, have been affected by an unrelenting commitment to their inclusion in leadership roles.

Effective Practices for Authentic Membership

> "Its all about relationships."
>
> The Best Practices organizations were very aggressive about identifying and involving people with complex needs in their organization. A major means of recruitment was the leadership training they were providing mostly through Partners in Policy-Making or a similar training model they sponsored and/or funded. The training programs were operated either directly or through a contractor. The groups ensured that significant numbers of people with complex needs were included in the training events. This provided the organization the opportunity to get to know people with complex needs before extending them a full invitation.

Pat Seybold, Commonwealth Council on Developmental Disabilities (KY)

The council made a commitment a long time ago that when a new member comes on the council, we have a mentor/mentee relationship and as soon as that person is appointed, a more seasoned council member becomes their mentor and they are responsible in making sure the new member has everything they would need for the meeting. 2) We also spend time with whoever comes with the new member; the Councilperson will spend time discussing the role of the person who is providing the support to them. When a more seasoned council member is assigned to a new council member, the chair does the assignment. Everyone with or without a disability gets a mentor and that usually fades out over time.

Marsha Hockensmith, Kentucky Protection and Advocacy (State Agency)

Why such a high number of people with significant needs serving on the advisory board – what motivated us to include so many people? Because it has to be that way! Several years ago our advisory board was comprised mostly the mothers of adult children with intellectual or developmental disabilities. This is an advisory board of persons with disabilities – the board must be diverse including representation from disability, minority and geographic populations.

Shannon Buller, Wyoming Governor's Council on Developmental Disabilities

Most significance. It's nothing new and I have to be honest with you. Not everyone was talking or interacting, but we didn't want anyone to be the voice for anyone else. So we started mentoring so that people would have someone that they could talk to and then we extended it to where it was not only people with disabilities but also new members, so that when they came on board, it didn't matter their background or who they were – they understood the council better.

Effective Practices for Deliberate Communication

Best Practice board build a culture that promotes listening to people with complex and/or high needs. The chairperson makes sure everyone gets the to give people time to express themselves The chairperson ask for their opinions, "Do you want to make a comment?" and always explain outcomes, "What we will be doing here is voting on xzz." Finally, there is always time built in for discussion.

Materials are adapted in a variety of easy read ways; icons, graphics, color codes and organized in ways that facilitate understanding. Materials are sent in advance of the meeting and people are given the opportunity to review them in a pre-meeting to enhance their understanding and give them time to formulate their own ideas and opinions.

Sheila Romano, Illinois DD Council

One of our chairpersons had severe speech difficulties and everything had to be re-voiced. A personal assistant did this for him. He a neutral person; sometimes his wife would help. We now have another member with extreme speech difficulties; we offered a computer with voice capabilities. Now, he has a communication device and we pay someone to prep it for him. He is now on our Executive Committee. The Chairperson of another committee has a touch talker and worked at home to put in commands—for example, all in favor, all approved, so they would be preprogrammed. The Council pays a person to help him. He is very difficult to understand and he is now a Committee Chair – he didn't let that get in the way. People have gotten better at understanding him over time and we have gotten better as asking him to clarify.

Pat Seybold, Commonwealth Council on Developmental Disabilities (KY)

We have a rule that any time we have a motion, the motion is made, we stop the meeting while the mentor explains to the person what we're voting on and make sure that they fully understand what it is that you're voting on.

We use microphones. We make sure that person has access to the microphone. We have a council member that uses augmented communication and it takes a while for her to type everything in and everyone is respectful of that. The chairs that I have been working with have been very good about maintaining that control what's going on in the council meeting so that no one person dominates; every voice is heard. Finally, we try not to write any documents above a 4th or 6th grade reading level and that has made a huge difference.

Dave Richard, The Arc of North Carolina

We have another man on our board that has a significant physical disability and some cognitive disability and he has an assistant who works with him as part of his services. For him, it made more sense that his assistant would be his voice. What was awkward at first when he came on the board, members would ignore him and only go to his assistant or they would ignore the assistant and only talk to him. What we tended to see happen with the board members that they would engage him, but it was sort of a seamless process. He began speaking out more using his assistant to do so and the engagement from the board became more involved in bringing him into those conversations.

Linda West, Washington State Developmental Disabilities Council

Our Director has a knack for connecting the person's comments that may be off the mark to the current content. Our chairperson makes sure everyone gets the chance to speak. She will ask them for their opinion. "Do you want to make a comment?"

Alison Lozano, New Jersey Developmental Disabilities Council

We use 2 paddles (like table tennis ones) during the Council meetings for voting. One is green and one is red. We started doing this when I was at the Utah DD Council. One also has an exclamation on one side and question mark on the other. Everybody on the Council has to use these. This gives everybody the same opportunity to speak. They are a great equalizer. Then, the conversation will not be dominated by professionals.

Roger Webb, Texas Council for Developmental Disabilities

Another person, in the past, didn't like to have his support with him, but he was difficult to understand. So, we discussed with him that he couldn't be effective as a member unless people can really understand what he has to say and he needs not be uncomfortable if we ask either him to repeat, or ask if his attendant can help give us a summary of it. Everyone on the council needs to understand that it takes time and not be impatient.

Effective Practices for Full Participation

The organizations that were most had adapted the format of their meetings to include the following: 1) small discussion groups at meetings, 2) rooms arranged as small round tables with groups sitting together vs. hollow square hotel style, 3) short presentations at meetings followed by discussions in small groups. Frequent breaks are often helpful so that the person could work with a support person/mentor.

While most organizations met quarterly for full meetings, almost all the Best Practice groups met more frequently in committees or workgroups in person or in person using regional video hookups and some via phone calls.

Heidi Lawyer, Virginia DD Council

We used to have a really long table but one year ago we changed to round tables with microphones. It helps people speak up.

Beth Swedeen, Wisconsin Board for People with Developmental Disabilities

We really simplified our packet and agenda – we have like a picture agenda now – we got that idea from Oregon and not come up with it ourselves. We have set up peer mentors for all of our new board members not just advocates, so that someone is paired with a seasoned person or a couple of seasoned people and then that's someone who they can sit by in a meeting and turn to for information if they don't understand something.

We do a lot less presentation at our meetings and large group – we've gone to smaller group work and that seems to help because if you're sitting at a table with only 4 other people, then we try to have facilitators there to elicit ideas from everyone and makes sure that everyone gets a chance to participate.

Pre-meetings are used as a means to help the complex needs prepare for the meeting. Pre-meetings are held individually or as a group with the people with complex needs. Individual meetings are usually facilitated by a paid support person or by an organizational staff member.

Group meetings are frequently led by the Executive Director and/or the Chairperson and usually held the evening before or morning of the business meetings.

Best Practice organizations were generous in allowing for accommodation expenses often needed for travel, meal, PCA, support person, overnight stays and other support accommodations. It is important to point out that most of the Best Practice organizations were under stringent State travel regulations and had to find or negotiate workarounds, waivers or approvals for these additional accommodation expenses. These expenses included additional car rentals, overnight stays for persons traveling less than 50 miles, meal costs, PCA, and contracted transportation.

We actually don't use large groups anymore, because it's very hard to talk to the person except the people on your left or right. Another thing with a larger group, it's hard to hear. We set up 6 or 7 tables with groups of 5 and then we do like a committee approach – let's talk for about 20 minutes, and then let's switch it up and everybody goes to a different table. This way people get to talk to different people and it helps them to get to know the other board members better.

We've gotten really clear feedback that people like the interactive format; they don't want to just sit and listen. How do you make this work using small groups – unusual for most council to do this? We do a lot of that through our committee work. And, also with quick updates. I

mean like during the business meeting, the committee who chose like the grant team. We have review teams for our grants – we don't have the whole council. Then, we try to have the grantees come in and do short updates of their projects so people will feel like they understand what's happening. When they do an update there's always time for the council to talk about – so, how will I bring this back to my community.

We do have something called Consumer Caucus. It's getting a little better. It's part of a committee structure, so it meets during lunch or during a time when other committees aren't meeting on Wednesday and it's a chance to pull out your agenda ahead of time if you're a self-advocate, although I have to say, that probably as many as 9 self-advocates go to it. We encourage the mentors to go with the new person. They go through the agenda ahead of time and it gives us a chance to explain as to here's what is going to happen; here's what we're going to talk about; here are some things we'd like to hear from you about and that's also the time for the new person to ask questions.

I always think we need to do more to make our materials more accessible/understandable. I also think we need to figure out the more formats that lend themselves to having *authentic participation* and by everybody – a universal design for meetings and materials.

Roger Webb, Texas Council for Developmental Disabilities

If the Governor asked you to do this job for the State of Texas, the Council should do whatever it takes to get you to meetings. We have always started at the level of how do you help facilitate a process so that each of our members are able to there; to

show up; to engage in discussion and understand the materials, so that they know what they're voting on and they feel it makes a difference.

The state expects travel reimbursements to be "reasonable and necessary"—related to the business of the organization, so on some of those issues we don't worry too much about what it costs, because the Governor decided that you're going to be my board member and that means you're supposed to come and we have to figure out a way to help you get here. At times that means we pay for accessible lift vans and drivers to pick up a person from their home and transport them to where ever we're having the meeting, usually in Austin, with or without an attendant – if they have an attendant who wants to drive, we rent the van for them – we have rented power chair or scooter so that the person, if they choose to fly, can have lift vehicles meet them at the airport.

People with cognitive disabilities—we obviously will pay for someone to fly with them if they prefer; we have made arrangements to contract with someone in their community, too, who also gets meeting materials, will arrange to meet with the individual before the meeting to review the materials so that person can hopefully better understand the content. They also have a chance to chat with us if they both have questions they don't quite understand. Again, how do you help prep people so that when they show up, they understand what we sent them and what the Council is going to be taking action on? We probably go a little bit further with people with intellectual disabilities to make sure they have that opportunity. It's always a challenge of how do you make it simple.

Some of the materials shared by other Councils that I've always been interested in are: how to make out an agenda so that it makes it clearer; what's an action item or what's the expected action for an item; what's just an information item with no action required. Some councils print their agendas with symbols or icons. We do it more with boxes at the bottom that explains the anticipated action or outcome. We've gone to what we call a tab sheet in our meeting binder so that it all stays together and the agenda references the tab number that has the item behind it. There's a cover sheet in the binder with the information about the item that might say, for example, that this item goes to 2 standing committees plus the council and it has 3 different box lines at the bottom with information about the expected action.

So there are lots of different techniques that I've seen for people to manage the discussions and to draw in each of the participants in a fun way and to make sure that people are engaged, but sometimes those things slow it down so much that the people that are caught up in the first place are really bored. There are no silver bullets on a lot of this.

As far as having a support person speaking; a number of Councils have formal written agreements between the Council and the support people or at least guidelines so they understand their role. We have shied away from doing it that way and usually, if need be, have discussions with the Council member and the Chair (or me) about issues. We still have a lot of issues that we don't have good answers for.

One of my council members has pretty significant physical limitations that result in him always using a power chair. He has limited ability to get materials in and out of

the basket on the front of his chair and needs assistance for that and it's difficult for him to turn pages. He comes with an attendant who is also his driver and helps with personal things; checks on him; helps with meals, but the member doesn't like for his attendant to be sitting by him all the time at the meeting because, then, he's not like everybody else.

In the meeting about supporting Council members, we had many suggestions on supporting people with cognitive disabilities on their board. What most of us across councils agreed, it's not anything unique to people with significant disabilities, it's what you need to do to be a DD Council member. You've got to figure out what they need to get there, what they need to understand the materials, so that they know what's being voted on.

Karen Schwartz, Vermont DD Council

We try with all the materials that we send out to people we think about the accessibility level and also how accessible they are in terms of the print. We have a couple of members with vision impairments and each one of them has a different way they want the material. Example: it's easier for us to blow something up to 20 font; someone else may want separate sheets. We try to mail everything that we're going to use a week before the meeting – we send it by email. The members that may need more time understanding we check in with them before the meeting. We do this over the phone. We have a versatile staff here.

One of our self-advocates is autistic and we have an administrative assistant that connects with him very well. At the meeting, we have a poster, what helps at

meetings – a list of basic things. We have some guidelines – we check in with people to give the time at the meeting to read the information. When new members come on board we do an orientation and we have a handbook, and then our members came up with this member guide that is a shorter version and it's very accessible and modeled from the Green Mountain Self-Advocates guidelines and has photos of every member.

Effective Practices for Meaningful Contributions

Best Practices organizations aggressively found, created and involved people in many roles. They give people roles--everyone has an assignment. They have person focus on an area interested; projects included addressing unmarked graves cemetery unmarked graves, and doing trainings around key issues, tell their stories. They carry out speaking engagements, give testimony, and attend other meetings

Beth Swedeen, Wisconsin Board for People with Developmental Disabilities

We're trying to have self-advocates be part of everything we do, so when we anything, like a presentation, we have co-presenters who are self-advocates and they might just tell something from their own experience of what works for them. We do have self-advocates reviewing all of our proposal notes for board projects. They don't just necessarily read the written applications, but are part of the discussion team. Like, we may provide the synopsis orally to them, but then in the project they can be part of the decision-making around which proposals we're going to fund.

Anna Lobosco, New York State Developmental Disabilities Planning Council

I would say at this point is that the biggest thing we do is asking our members. Recently, we had a conversation with our consumer members around the topic of engagement and, what would it take to be more engaged in our work. They told us many things in that conversation that many of them hadn't told us in the last 5 or 10 years. The work that we do, especially using public funds, requires that they have some capability to look at pretty complex funding motions and make decisions whether we should or shouldn't do it. They gave us a whole other set of marching orders that we're trying to work on. Right now we are focused heavily on providing information in ways that will help them in making good funding decisions

Our current Caucus Chairperson's push is to make sure that everybody has a chance to be involved. So before we talked about leadership, we said, maybe we need to take a step back and talk about engagement. So we came up with a 6 slide Power Point that basically said, "What is engagement and what would help you to be more engaged in our work?" Right now our members, people with developmental disabilities are all verbal and don't have too much trouble communicating. This provided time and an environment that allowed them to speak. They told us that they would like:

1. Media – Youtube, Webinars, audio recordings, conferences calls – mostly they were a little less intrigued with paper and many of them had indicated, for the first time, that they have difficulty reading or that reading is hard for them and that they prefer to get things auditorily.

2. They like pre-meeting conference calls to discuss projects and motions.

3. They want information presented in short versions and

4. They've asked for a one page, and no less than 16 point font print, overview of our funding motions.

5. They've asked that our staff contact them periodically by phone in advance of meetings.

6. They like having small group discussions (sometimes 2-3 people, sometimes up to 8 people).

Effective Practices for True Influence

Most Best Practice organizations involved people with complex and/or high support needs by helping them testify to the State Legislative Committees or other policymaking bodies. Many had more general annual legislative days that involved visiting legislative aids.

They have people review all proposal notes so they can be part of the discussion and decision-making if they can't read the materials. Almost all state reps are the directors of state Agencies. They sit next to people in the meetings it impacts them.

Emily Rogers, Washington State Developmental Disabilities Council

We do things like having people write their own messages to their legislator. We have people write a legislative agenda each year. It's really focusing on what is important to people with developmental disabilities. One of the things that we have done of late is make sure that every single person has the opportunity to speak up, whether that's through their communication

device or some sort of assistance.

We had an idea around the Respectful Language Bill and we talked to a legislator who was going to be the prime sponsor. We met with him as a group and discussed what needed to go into it. We got one of the legislator's staff to draft the bill. We came with the idea and they put it into the language that needed to go into the bill. When they needed someone to testify we had people there. We have a Rapid Response Team, a team of about 15-20 people, who have made a commitment that they're willing to receive a phone call from me at any time during those sessions, so that if there is something that comes up we're able to really figure out what's going on.

Transformational Outcomes for Individuals

Deborah Swingley, Montana Developmental Disabilities Council

We met with each Tribal Council when we had Council meetings in their areas. We were able to have a member of the Chippewa Tribe appointed to Council and at the first meeting the tribe sent seven elders and did the Honoring Ceremony for him at our meeting. They presented him with a tribe blanket and a spirit pouch.

Transformational Outcomes for the Organizations

Deborah Swingley, Montana Council on Developmental Disabilities

You are going to have to work but there is a great benefit. It has been critical to our work with legislators.

Mary Gordon, Nebraska Planning Council on Developmental Disabilities

The fact that the Council has people with high needs serving influences other State agencies to have people serve on their committees, too.

Donna Gilles, Partnership for People with Disabilities at Virginia Commonwealth University

What do you think has been the most successful influence that he has had? I think having the reminder that it's not about me and it's not about the other folks in the room, it's about people with disabilities, and nurturing that realization that **their real lives are impacted by the things** we do. I think their presence and vigilance and their knowledge and their honesty have taught people that their efforts have to mean something.

Dave Richard, The Arc of North Carolina

I think we're beginning to see a couple of things; 1) is that our partnership organizations – people that profess the same things that we do – have sort of a glass ceiling for people with disabilities in terms of a leadership role. I believe that people are thinking differently about what is possible with people with disabilities.

Effective Practices for Need Specific Supports

The essential elements for transformational board inclusion focus on the areas that will result in benefits to the individual board or council member as well as the organization where he or she hopes to have a leadership role. Barriers to achieving success in any of these areas cut across all five elements and, in the case of transportation challenges, appear to be universal. Information specific to overcoming these types of barriers are included here in the context of effective practices that address specific needs or challenges. These needs and challenges can relate to organizational practices or constraints as well as those inherent to the disabilities individuals with complex and/or high needs experience.

Effective Practices in the Use of Mentors and Other Support Persons

The Support person/Mentor is different from a Personal Care Assistant. Each role requires a different skill set. Some individuals may have both a personal care attendant and a support person/mentor.

Specific Tasks Included:
- ❖ Review agenda and meeting materials prior to the meeting Serve as a go to person to address issues as needed
- ❖ Assist with arranging transportation
- ❖ May attend pre-meetings
- ❖ May attend meeting
- ❖ May explain items at the meetings
- ❖ May assist the person at the meeting
- ❖

Almost all of the BP organizations cited problems with the support person/mentor speaking for the person or stepping over their bounds. Organizations had developed means of addressing this by: 1) having direct discussions with the support person/mentor and a contract with that spelled out their responsibilities.   Finally most of the support persons/mentors were paid.

All of the Best Practices organizations provided some type of support person or mentor to each person with complex needs. This was accomplished in a wide array of ways.

Most Best Practice organizations provided some type of support person or mentor either formally or informally. Many Best Practices organizations had provided mentors in the beginning but the support had evolved to an informal process of the support being provided by a staff person or Council, Committee member. However, no matter how informal this process, all organizations continued to make sure this support continued to be provided over time.

Effective Practices for Addressing Transportation Barriers

It is important to point out that most people with complex needs do not drive nor have their own independent transportation.

While this statement is obvious, the consequences and limitations this lack of transportation imposes on the ability of the person to effectively participate are often understated.

Transportation was the most often cited issue from the Michigan Focus Groups conducted as part of this study and described previously.

Best Practice organizations have contracted directly with outside vendors, obtained exemptions for rental cars and other travel restrictions by making it clear that they are ADA accommodations.

Although we have not identified transportation as an essential element for transformational board inclusion, it is a tremendous barrier to people's ability to access opportunities for inclusive leadership roles. Because of this, we are including those practices that made a difference for the organizations that participated in the Best Practices Interviews.

Dave Richard, The Arc of North Carolina
We reimburse well in terms of travel and other expenses that come with board members attending meetings. Our policy is that no board member should ever have to take anything out of pocket to be a part of our board.

Marsha Hockensmith. Kentucky Protection and Advocacy

How do we get people that are all over KY to come to our board meetings? Well, we always tell them that we're going to feed them well. Seriously, we inform them that we will cover all expenses for them to attend and participate as a member of our board. These expenses include; travel, lodging, attendant care, and others needed to ensure they can fully participate in board meetings. We provided car rentals—I guess, in short, we get them here by doing our best to accommodate what they need.

How do we manage to pay for car rentals? Sort of like reimbursement for mileage, lodging, attendant care and other things – we've really hadn't had any difficulty with this either. How do we manage to get around the travel restrictions? Board members adhere to the same guidelines and rules regarding mileage, lodging and meal reimbursement as set forth by the feds, the same as is required for P&A staff. We do, unless otherwise approved, stick within the 50 miles rule to cover expenses for lodging. How do we grant an exception? Actually all I've had to do at this point is just document the need for this accommodation as it relates to an individual's disability, including the need for the exception to cover overnight accommodation.

Effective Practices for Supporting People with Communication Needs

Over the last decade people with communication needs who use augmentative and/or alternative communication devices have begun to be included in leadership roles. Interviews with the Best Practice groups who have individuals with communication needs identified significant barriers remain with regard to device utilization and how they are addressed. The National Overview Survey showed people with complex and/or high needs who had communication difficulties involved in DD Network organizations in the following numbers: DD Council 15%; UCEDD 8%, and Protection and Advocacy 4%. And yet twice as many people involved in UCEDDs (15%) had communication devices compared to DD Council (8%) and P and A (4%). This most likely the result of the UCEDD's easier access to State Assistive Technology Projects.

Many Councils had people with communication difficulties serving as officers or committee chairpersons. Many were pre-programed with voice commands like, "Welcome everybody," "Do I have a motion," "All in favor," "All opposed." Several UCEDD's were able to receive support for communication devices from their State Assistive Technology Projects that were part of their organizations. Successful organizations found that while the hardest issue was waiting for the person to type in their responses, over time they came to value the person's input and were more patient about waiting. One organization had a member who used an Eye Gaze system and the members had to learn how to pose Yes/No questions that could be more easily answered.

People who were very difficult to understand but did not use communication devices posed a different set of challenges for the organizations. A staff person or personal care assistant often provided interpretation. Re-voicing, repeating or rephrasing the person's speech was frequently used successfully. Some organizations were able to help the person obtain and use a communication device over time.

Effective Practices at Supporting People with Attention Support Needs

An increasing number of individuals with complex and/or high support needs included in leadership roles require supports related to decreasing distractions or stressors that diminish their ability to maintain attention to business matters during meetings. The practice of identifying and providing supports and/or other special accommodations for individuals with these support needs is relatively new. Protection and Advocacy organizations, with their PAMI (Protection and Advocacy for Individuals with Mental Illness) Councils, have had the most experience. As such, the Best Practices organizations in this study carried out a number of strategies similar to those used by organizations that support mental health consumers in leadership roles.

Specific strategies that the Best Practices organizations found to be useful include: Having extra meeting space or an additional meeting room available should meetings be too long. One organization provides an audio feed into this room to enable continued participation. Another has found that providing members with earphones has assisted them with staying focused on the topics being discussed.

This is an area where frequent breaks and rest periods has been found to be essential. Opportunities to rest benefits members mentally and physically and can

generate the energy needed to see a meeting through to its conclusion. This is particularly important when agenda items are emotionally charged and/or have the potential to trigger emotional and/or traumatic memories (such as discussions on preventing abuse).

To keep track with providing supports in this area, Best Practices organizations use timekeepers and honor the call for breaks when requested. Meeting rooms are also arranged to limit or mitigate environmental distractions such as poor lighting, inadequate or uncomfortable seating provisions, temperature fluctuations, and noise intrusions. Finally, Council members receive orientation on how service animals used by individuals who have attention related support benefit them and how to respond to their presence during meetings.

Discussion

The Beyond Tokenism: Complex Needs Study has many lessons to teach us. The Review of the Literature established that a foundation of knowledge regarding supports for effective board inclusion exists and that more research in this area is needed to assure that future practices will be, in fact, evidence based. An analysis of the literature also provided the opportunity to evaluate whether types of supports reported to be in use are distributed across key elements of board inclusion; authentic membership, deliberate communication, full participation, meaningful contributions, and true influence. This analysis showed that although progress has been made in expanding opportunities, the transformational outcomes of these efforts have yet to be fully explored.

The perspectives of individuals with complex and/or high support needs affirmed the findings of the literature review, inasmuch as they reported that much work remains to be done before they will consider themselves to be fully included in leadership roles or other social and civic opportunities. Even so, the results of the National Overview Study do indicate that much progress has been made in expanding opportunities and engaging individuals with complex and/or high support needs in leadership roles. Developmental Disabilities Councils and UCEDDs, in particular, have begun to set the standard for inclusive board practices.

The results of the National Overview Study also indicate that some of the respondents have begun to recognize the transformational benefits of moving beyond the provision of token representation to individuals with complex and/or high needs

who have been engaged in leadership roles as well as the organizations they serve. These organizations, for the most part, are those that, as a minimum, include two or more individuals with disabilities with complex and/or high support needs in leadership roles. The successes of the Best Practice organizations identified by the in-depth interviews provide substantial evidence in this regard.

The findings of the Best Practices in-depth interviews show that the Best Practice organizations have contributed a significant body of knowledge regarding effective supports for individuals with complex needs in leadership roles. These organizations clearly began with approaches forged by their predecessors and self-advocacy organizations and, through their own creativity and commitment, systematically expanded and added replicable processes and procedures for use in today's diverse and technologically advanced environments.

What became clear from the interviews was that Best Practice organizations all highly value all of their members and are willing to expend great effort to achieve their involvement. They do not cut corners or say that is too difficult or too much to do. The work is both hard and requires continuous and sustained effort. It requires great amounts of creativity along with old fashioned stick-to-it and "try another way" attitudes. Finally, financial resources and large amounts of staff time are required.

All of the Best Practices described in this report were formulated and implemented with one express purpose: to empower individuals with complex and/or high support needs to attain active and effective leadership roles. Even so, it is

heartening to note that each Best Practice organization is focused on enhancing the participation of all of its membership not just those with disabilities.

Many of the best practices are designed to reduce the 'cognitive load' created by the massive amounts of information generated through public policy formulation and advocacy functions. Thus, effective use of best practices finds that we all benefit.   This is one of the greater lessons that inclusion in general has taught us. Another important note is that many of the practices truly benefit all, just like the curb cuts were eventually found very useful by mothers with baby strollers, cross country runners, and bicyclers.

The Beyond Tokenism: People with Complex Needs in Leadership Roles national study clearly provides the evidence that there is a set of Best Practices that lead to successful inclusion of people with complex needs. It is up to us to implement them on a daily and continuous basis. The work is simple and yet hard. As several people interviewed said, "It's not rocket science, it's just hard work". To be universally successful requires a cultural shift in how we expect organizations that affect the daily lives of people with disabilities to operate. It is not enough to simply provide a seat at the table for individuals with disabilities; complex or otherwise, without providing the supports needed for them to have true influence as board members. Successful inclusion requires organizations to change their standard operating procedures. We must recognize and accept that to do otherwise is to perpetuate tokenism in its most pernicious form.

Successful inclusion is deceptively simple, in that many of the Best Practices appear, at face value, to be common—even ordinary. Because of this, they are easy to dismiss and devalue as unimportant. The common is often not appreciated. Additionally, no one particular Best Practices is, in of itself, critical for success. It is when they are taken together that they form a powerful set of practices that can change an organization's culture and lead to successful inclusion. Each of the Best Practices can evoke great depth and transformational power when fully understood.

It is likely that many of us have used some of these practices and believe ourselves to be familiar with them. Yet, the findings in this study show that individuals with complex and/or high support needs as well as other developmental disabilities continue to report that, in their experiences, these practices are not systematically made available and in some cases simply dismissed as unnecessary or burdensome. During the interviews, we were frequently told, "Oh, we know that other groups provide mentors or pre-meetings, [etc.], but we don't do that". These organizations do not realize that even though they were successfully providing supports for some elements of board inclusion, they could be limiting the effectiveness of the people they sought to include by not making available the full range of what might be necessary for them as individuals.

User friendly, easy-to-read materials are perceived to be one of the largest unsolved challenges. This is paradoxical since many how-to manuals exist which are little used. For example, it is commonly acknowledged that a best practice is enlarged type, simple fonts and symbols. This is relatively easily accomplished with modern

computer software and Google images. Yet, the results from the National Overview

Study indicate that fewer than one half of the success organizations were

implementing this. We believe that the results of this study calls the question--What

will it take for the Best Practices to become standard practices that are used

everywhere?

We hope you will join us in this very rewarding and challenging endeavor.

Recommendations

The following recommendations are based on the Goals in the RFP which were:

How can the Council and the Council's grantees increase the number of people it includes, improve how well it supports them in full participation, and advocate for full inclusion in the activities of others?

1. <u>Mentors and Support Persons – Develop a process for obtaining, training, supporting and providing mentors/support persons to all new members with complex needs</u>. Rationale: The purpose of the mentors/support people is to provide additional support to people with complex needs participating in Council activities. Best Practice organizations all provide mentors/support persons formally or informally Council will need to explore and experiment with the different means of providing mentors/support person from the options described in the Full Report, determine what model will best fit the Council and develop an implementation process. The process should include a policy or statement on the purpose and role of mentors and support persons, training and support. Several examples used by Best Practice organizations are included in the Appendix.

2. <u>Modify Council Meetings to be Interactive</u> – Modify Council meetings to utilize small group room set ups, discussions and possibly facilitators from the group.

Rationale: Best Practice groups found interactive meetings significantly increased the engagement of all Council members. This included the use of round table setups, group discussions and possibly facilitators to increase the involvement of everyone and particularly people with complex support needs. This was particularly true of the organizations including the most people with complex needs. Many groups utilized facilitators with each group to further participation. As described in the report, interactive meetings were one of the most effective methods for obtaining participation from all members but particularly people with complex needs. Use small discussion groups as a regular part of Council meetings. Changing the meeting format can be a difficult process as people accommodate themselves to a different format.

3. Pre-meetings – Conduct pre-meetings with people with complex needs prior to the full Council meetings.

Pre-meetings can be held individually with the person prior to the meeting or Group Meeting held the evening before the full Council meeting. Council will need to examine the pros and cons of the different methods of providing this and determine the methods that will have the best fit with Council.

Rationale: Best Practice organizations found individual and group pre-meetings contributed to their ability to more fully participate. Pre-meetings help with comprehension of documents and decrease cognitive overload.

4. Workgroups/Committees: Recruit additional people with complex needs to serve on workgroups/committees.

Work with existing grantee programs to identify and invite people with complex needs to serve.

Rationale: The study survey and interviews showed that best practice organizations used workgroups and committees as a means to involve and recruit people with complex needs to later serve on the Council, committees and boards. The Workgroups/Committees serve as a low risk means to help people with complex needs gain leadership skills and test their interest in further involvement. This process will provide Council with an opportunity to gain experience with mentors and support people and to meet and get to know potential Council members with complex support needs.

5. Recruit new people with complex needs to serve on Council

While appointing someone to the Council is a longer-term project, Council could be working with the following: 1) appointments process to enable the appointment of additional people with complex needs, 2) recruit new people from within its existing network of grantees including the training programs, RICCs and leadership development projects, and 3) providing leadership opportunities for new potential Council members.

Rationale: The Best Practice organizations were very aggressive about identifying and involving people with complex needs in their organization. A major means of recruitment was the leadership training they were providing, mostly through Partners in Policy-Making or a similar training model they sponsored and/or funded. Recruitment to Council is a longer-term process requiring the Governor's appointment.

6. <u>Support and require grant projects to include people with complex needs as planners, participants and implementers.</u>

Best Practice organizations included requirements in RFP's, work products and grant negotiations to ensure the participation of people with complex needs. They also worked closely with grantees during implementation to ensure participation in project planning, implementation, advisory groups and training events. Inclusion goals were built into project work plans, reviews and RFP documents. Colorado and Minnesota DD Councils were particularly successful.

7. <u>Training Events – Work with and require the inclusion of people with complex support needs as planners and participants in all DD Council funded training events</u>

Rationale: Council funds an extensive training network through its grantees.
This provides a tremendous opportunity to involve people with complex needs in Council activities. Most Best Practice organizations use training events as a major recruitment method towards greater involvement, generally through a Partners-in-Policy training model. These events provided the organization the opportunity to get to know people with complex needs before extending them a full invitation to join. The

organizations assured a high level of participation by working closely with the contractors through project workgroups or on-gong oversight. Several Councils made this a requirement in their Request for Proposal documents and awarding of contracts process.

Michigan does not have such a training program but has a new training initiative currently in curriculum development. This provides a tremendous opportunity to ensure that the curriculum will use easy read materials and meet the needs of people with different complex needs. The training program also offers an opportunity to ensure that a significant percentage of people with complex needs will be participants and potentially co-presenters. This would demonstrate excellent role models for participants and other organizations. Successful examples include the Colorado and Minnesota DD Councils.

8. Enlist the support of the DD Network partners (Developmental Disabilities Institute (UCEDD) and MI Protection and Advocacy) to work collaboratively on the inclusion goal. Rationale: Organizations that were successful in any one state frequently had one or more of their DD Network partner organizations (DD Council, UCEDD or the P and A), equally successful. States that were particularly effective were: Kentucky, Colorado, New Mexico, Georgia, Kansas, Maine, North Carolina and Illinois.

Michigan has a long history of the DD Network partner organizations working together to achieve goals. This is particularly important in this area as many other states have found this to be especially effective.

9. Engage the Developmental Disabilities community in involving people with complex needs

Rationale: The Developmental Disabilities system is a relatively small community. As the Council is more successful at involving more people with complex needs in a variety of activities, it will serve as a model to other DD organizations and influence their behavior. Involving these organizations at this early stage of implementation can result in more impact. A major change strategy is to involve the people you wish to change in the change process.

10. Acknowledge and anticipate that additional financial and staff resources are needed to provide the supports and accommodations to successfully include people with complex needs.

Rationale: It is clear that in this time of sequestration, budget cutbacks and future financial constraints there will be few additional funds to pay for accommodation expenses. This makes it even more important to acknowledge and plan how the goal of inclusion can be successfully accomplished in a time of financial constraints.

11. Provide Generous Reimbursement of Council Expenses and Obtain Travel Waivers if Necessary

Transportation was the most often cited issue from the Michigan Focus Groups conducted as part of this study and described previously. Almost all people with complex support needs do not drive and require transportation from a third party. Travel problems directly limited the participation of people with complex needs in three of the five focus groups. Most of the Best Practice organizations were under stringent State travel regulations and had found workarounds, waivers or approvals for these additional accommodation expenses. These expenses included additional car rentals, overnight stays for persons traveling less than 50 miles, meal costs, PCA, and contracted transportation.

Best Practice organizations all had generous expense reimbursement policies. Most had obtained special ADA approvals or waivers of state travel regulations to allow additional coverage. Several Council members mentioned this as a problem related to their participation in Council meetings and activities. Solving this issue will be particularly important as more people with complex needs are recruited to serve on Council, committees and workgroups.

12. Employ people with disabilities as staff on Council and in Council projects.

The National Overview Survey identified a direct correlation between the number of staff with disabilities and additional people with complex needs being included. Examples of employment are:

- Washington State DD Council employs a person with intellectual disabilities full time to provide training and technical support to their self-advocacy groups. They created a Public Policy organization with a person with developmental disabilities as its director.
- Wisconsin DD Council helped their self-advocacy organization hire a person with complex needs as their director.

Hiring a person with complex needs as a paid Council staff person is understandably a long-term project, however, Council can encourage and support grant projects to include people with disabilities as project staff. Several states give extra points for the inclusion of people with disabilities in the grant selection scoring process.

13. Training – Create a Clearinghouse to provide knowledge and information of the 'Best Practices for Including People with High and Complex Support Needs.'
Rationale: There is a great amount of knowledge available in this area. Many manuals and how to guides exist, however the knowledge is not widely known nor utilized.

14. Identify roles and opportunities for the addition of people with complex needs into Council and grant activities, particularly for leadership development.

Rationale: Most of the Best Practice organizations were both creative and aggressive in identifying roles to enhance participation and engagement. Council should explore directly and through the RICCs and grant projects how people with complex needs can be assisted to serve on policy-making and governmental bodies, testify at legislative hearings, participate as co-presenters and leaders in training events.

15. Include people with complex needs to serve as local leaders

Local Leaders has been a successful and unique strategy and model implemented in Michigan. Local Leaders serve as very important role models to both the disability and the public. Local Leaders provide an untapped opportunity to include people with complex needs in value enhancing roles that make a significant difference.

16. Identify and pursue methods to continuously develop and sustain the effort to include people with complex needs.

Rationale: The Best Practice organizations had an unquenchable thirst for improvement and doing better. This goal will require extensive effort over a long period of time. There are many Best Practices to replicate but there are no silver bullets. Best Practice organizations have created methods they use to continuously pursue this goal. These methods include debriefings, formal and informal assessments after every Council meeting to ask what else can we do to enhance participation? Other methods included open discussions at Council and staff meetings and appointing a designated staff person and Council member to pursue and sustain this goal.

17. Technology: Experiment with innovative technology such as:

- Talking web pages (ReadSpeaker – adopted by the Florida DD Council)

- iPads (text to speech)

- Webinars

- Headsets at meetings to reduce distractions

- Regional video conference meeting systems that two DD Councils are using to bring together people locally for statewide meetings (Delaware and Montana DD Councils).

18. Create a Community of Practice to share knowledge and information to sustain the effort – Create an online and in-person community of practice for support and sustainability.

Rationale: Inclusion for people with complex support needs will be a long-term task. The effort will have to be sustained over time. The successful DD Councils all described the importance of receiving help from their peers, sharing ideas, and in-person discussions as critical to their success.

19. Pursue and create Community Building projects as spear headed by Georgia DD Council – There is great interest in the Council for including people with complex needs in community activities. The Study explored this area with the Best Practice organizations. There is currently a movement amongst eight to ten Developmental

Disability Councils to embrace Community Building through Asset Based Community Development. This model, pioneered by Professor John McKnight, is different from past Council efforts in that is seeks a collaborative effort with communities. Rather than asking the community to do something for the Council, it asks what can the Council do for the community and in so doing include people with disabilities. This effort has been most adopted by the Georgia Council and includes people with significant complex needs as participants. Interestingly, the Georgia Council has made two learning tours to Michigan to see local programs at the Arcadia Institute and the Boggs Center.

20. Dissemination – Spread the word in order to garner support and partners

Hold a Forum for key stakeholders and make presentations at Michigan conferences on Best Practices for Including People with Complex Needs.

21. Create technical expertise in the creation of Easy Read materials in the Michigan DD System

Rationale - Difficulty with materials due to literacy issues was the number one item cited by the Executive Directors who were interviewed, as a major barrier to involving more people with complex support needs. There is a movement to create user-friendly materials called Easy Read that has an extensive knowledge base and expertise that is not widely known nor utilized in the US.

22. <u>Native Americans</u>

During the Survey and Best Practice Interviews several DD Councils described innovative work they were doing with Native American tribes that may be of interest to the Council. They are: Arizona, Alaska, Montana, and Wyoming DD Councils.

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APPENDICES

Appendices to Final Report

Appendix A: Review of Literature

Appendix B: Instrumentation

Appendix C: Self-Advocates Becoming Empowered Focus Group Report

Appendix E: Organizational Partners and Experts Committee Members

Appendix F: Best Practices Interview Respondents

Appendix G: Results of Beyond Tokenism Workshop at 2011 NADDC
            Annual Meeting

Appendix H: Michigan Focus Groups Report

Appendix A: Review of Literature

Previously submitted.

Appendix B: Instrumentation

Beyond Tokenism National Overview Survey via Survey Monkey

Part 1: Organizational Overview

Note: We have extended the cutoff date to March 31st in order to obtain additional participants.

This survey is being conducted on behalf of the Michigan Developmental Disabilities Council. The purpose is to identify the best practices that disability organizations are using to fully include people with developmental disabilities with high support needs in their leadership development, public policy and community activities.

The results of the survey will create a snapshot of the best practices currently being used across the country.

The survey is being widely distributed by more than twelve national disability organizations including DD Councils, Protection and Advocacy agencies, University Centers for Excellence in Developmental Disabilities, State Developmental Disabilities departments and many others (a complete list is provided below).

Your participation is vital in helping to create this important knowledge base of best practices that organizations can use to fully include people with developmental disabilities.

The survey consists of 20 questions and will take approximately 20 minutes to complete.

We will send everyone completing the survey an Executive Summary of the Best Practices Report. We will also invite you to a special Webinar on Beyond Tokenism.

If you have any questions about the survey, please contact Mark Friedman, Ph.D., Director, National Beyond Tokenism Board Diversity and Inclusion Study. Email: mark@mtadvocacy.com Cell phone: 615-812-4950.

Thanks for your help.

If you prefer to complete the survey by phone, please call 615-812-4950 or on paper by downloading the form at https://bluefire-beyondtokenismtraining.pbworks.com/w/file/58702705/Survey%20paper%20version.pdf

The Survey Partners include the following organizations:
1. National Association of Councils on Developmental Disabilities (NACDD).
2. National Disability Rights Network (NDRN) - Protection and Advocacy agencies.
3. National Association of State Developmental Disabilities Directors Services (NADDDS).
4. Self-Advocates Becoming Empowered (SABE).
5. American Association on Intellectual and Developmental Disabilities (AAIDD).
6. The Arc of US
7. TASH
8. ANCOR
9. American Speech and Hearing Association, Special Interest Group on AAC.
10. Association of Assistive Technology Act Programs (ATAP).
11. Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).
12. Autism National Committee (Autcom).

Please answer the following questions:

1. Type of Organization

○ Developmental Disabilities Council

○ Protection and Advocacy agency or Disability Rights Network

○ University Center for Excellence in Developmental Disabilities (UCEDD)

○ Center for Independent Living

○ Non-profit advocacy organization

○ Self-advocacy organization

○ Service provider

○ State Developmental Disabilities operating agency

○ Other:

Describe your organization if not a DD Council, P and A or UCEDD

[   ]

*2. Contact Information

Organizational Name	
Primary Contact	
Position	
State	
Telephone	
E-Mail	

Part 2: Demographic Information

Now we have a few questions about the demographics of the Council, Board or Advisory Committee. For the purposes of this survey, we are asking you to answer the questions for the following entity:

DD Council - The full Council only
P and A: The Governing Board only
UCEDD: Advisory Committee only
State DD operating agency: Advisory board or committee (if multiple advisory groups, choose one to report on).
For all others - The Governing Board

*3. Number of people serving on the Council, Board or Advisory Committee

Total number of people serving	
Number of people with a developmental disability	

4. Characteristics of the people serving (please enter the number of people in each category).

Person with any disability	
Family Members	
Disability Professionals	
Other members	

5. Demographics: (please enter the number of people for each category)

Men	
Women	
White/Caucasian	
Hispanic/Latino	
Black/African American	
Asian/Pacific Islander	
Native American	
Other	

Part 3: Supports for Inclusion

Organizations that are including people with developmental disabilities in their organizational activities have found the following supports useful. Please check the supports your organization currently provides to promote inclusion and add others.

6. Please check each of the supports your organization provides.

☐ Accessible meeting space

☐ Adapted meeting procedures

☐ Assistance with travel arrangements

☐ Budgeted resources specifically for support

☐ Board orientation

☐ Board ongoing training

☐ Board retreats

☐ Financial assistance (travel, stipends, childcare, hotel, Personal Attendant)

☐ Frequent breaks or rest periods

☐ Having two or more people with a disability serving

☐ Inclusion training for board members and management

☐ Leadership commitment to inclusion

☐ Mentor

☐ Mentor at meetings

☐ Meeting materials in alternative formats (Braille, Large Print, Color Coding, Etc.)

☐ Meeting facilitators

☐ Officer Training

☐ Opportunities for board fellowship

☐ Personal Attendant

☐ Pre-meetings (to review agenda & prepare for the meeting)

☐ Seating near board officers or leadership

☐ Sign language interpreters/CART (closed captioning on screen)

☐ Specialized room arrangements

☐ Team building exercises or activities

☐ Utilization of assistive technology for communication

☐ Written policies or by-laws that promote inclusive board practices

Other types of support provided (please describe)

7. Please select the three supports that you think are the most important (click on each box to see the drop down items).

	Items
Most Important	�⊏
Second Most Important	⊏dropdown⊏
Third Most Important	⊏dropdown⊏

Part 4: Support Needs

The next section asks questions about the support needs of the people with developmental disabilities serving on the Council, Board or Advisory Committee of your organization.

8. Number of people with a developmental disability with the following support needs who:

Use a mobility device [ ]

Use a communication device [ ]

Use a personal attendant [ ]

Have difficulty hearing what is said [ ]

Have difficulty being understood by others [ ]

Have difficulty reading the meeting materials [ ]

Have difficulty seeing the meeting materials/ presentations [ ]

Have difficulty understanding the discussion at a meeting [ ]

9. Number of people with developmental disabilities in each age group (approximate)

Under 25 years old [ ]

26-55 years old [ ]

56 plus [ ]

10. Number of people with a developmental disability who have served for the following number of years (approximate).

1 year [ ]

2-3 years [ ]

4-5 years [ ]

More than 6 years [ ]

11. Have any people with developmental disabilities served as Officers currently or in the past? (Select all that apply)

[ ] President / Chairperson

[ ] Vice President / Vice Chairperson

[ ] Treasurer

[ ] Secretary

[ ] Other

[ ] None

Part 5: Inclusion Outcomes

Many disability organizations involve people with developmental disabilities in a broad range of the organization's activities. Now we are asking questions about the ways that you accomplish this.

12. Please check all the ways you involve people with developmental disabilities in your organizational activities:

- [ ] Serve on Subcommittees
- [ ] Serve as Volunteers
- [ ] Participants in training events (i.e. Partners in Policy Making)
- [ ] Participate in advocacy work
- [ ] Peer mentors
- [ ] Peer trainers
- [ ] Serve as trainers
- [ ] Serve as public speakers
- [ ] Serve as paid staff full time
- [ ] Serve as paid staff part-time

Other ways you involve people with developmental disabilities:

13. How has including individuals with developmental disabilities impacted your organization?

	Items
Biggest Impact	⌄
Second Biggest Impact	⌄
Third Biggest Impact	⌄

Other impacts

14. Please describe your biggest success in including people with developmental disabilities in your organizational activities.

15. Please describe your biggest challenge in including people with developmental disabilities in your organizational activities.

Part 6: People with High and Complex Support Needs

The Michigan Developmental Disabilities Council is working to more successfully involve people with high and complex support needs in its organizational activities. To further this goal, the Council has developed a definition which we are asking your help in answering the following question.

16. Using the definition below, how many people with developmental disabilities serving on the Council, Board or Planning Committee have the following support needs:

No support needs

Low support needs

Moderate support needs

High/complex support needs

Definition of Complex and High Support Needs
The Michigan DD Council defines complex and/or high support needs as needs of people with developmental disabilities that characterize the most vulnerable members of our community. They may be considered to have complex and/or high support needs because of:
A. The breadth of their needs – multiple needs that are interrelated or interconnected, requiring coordination from multiple systems; and/or
B. The depth of their need – needs requiring serious or intense life-long supports.

People with complex and/or high support needs are those who:
A. Are the least likely to get the supports they need to experience ordinary life;
B. Typically spend most of their time in segregated settings;
C. Often experience discrimination, social exclusion, or isolation in ordinary daily life unless they get specific support for realizing self-determination and participation;
D. Usually cannot exercise choice or participation in activities unless:
1. Specific opportunities to be involved are offered to them, and
2. Appropriate assistance to engage in them is made available.

Part 7: Nominate Other Organizations

Please nominate any other organizations that you believe promote the inclusion of people with developmental disabilities in their activities. We will conduct follow up interviews with the organizations that have been identified.

17. Success Organization #1

Organizational Name

Person to Contact

Email or telephone

Reason for nomination

18. Success Organization #2

Organizational Name

Person to Contact

Email or telephone

Reason for nomination

19. Success Organization #3

Organizational Name

Person to Contact

Email or telephone

Reason for nomination

Part 8: Other Resoures

20. Please list any resources (organizational policies, by-laws, procedures, training materials) you would like to share for promoting board inclusion. We will add these items to the Beyond Tokenism Resource List and send you a copy and webpage link.

21. Anything else you would like us to know?

22. Thanks for your help. We will send you a summary of the results when done.

Thank you for your time and assistance in completing the Beyond Tokenism National Diversity and Inclusion Survey.

If you are completing the survey on paper, please fax to 615-904-008 or
Mail: 1509 Van Cleve Lane, Suite 501, Murfreesboro, TN 37129

Please direct any questions, concerns or issues about the survey to:
Mark Friedman, Director, Beyond Tokenism National Diversity and Inclusion Study
Email: mark@mtadvoacy.com Cell phone: 615-812-4950

We would like to express our appreciation to the following survey partners who are assisting in distribution:

1. National Association of Councils on Developmental Disabilities (NACDD).
2. National Disability Rights Network (NDRN) - Protection and Advocacy agencies.
3. National Association of State Developmental Disabilities Directors Services (NADDDS).
4. Self-Advocates Becoming Empowered (SABE).
5. American Association on Intellectual and Developmental Disabilities (AAIDD)
6. The Arc of US.
7. TASH
8. ANCOR, National association of developmental disabilities service providers.
9. American Speech and Hearing Association, Special Interest Group on AAC.
10. Association of Assistive Technology Act Programs (ATAP).
11. Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
12. Autism National Committee (Autcom)

Michigan Focus Group Discussion Guide

1. Introductions

1. Round robin: Name and involvement in RICC?
2. ___Men ___Woman
3. Age ___<21 ___22-25 ___26-35 ___36-50 ___50 plus
4. Where are you from? ___East ___Middle ___West
5. How many people live with family? ___In a group home? ___By self?
6. Guardians: ___
7. How many roommates? ___1 ___2 ___3 ___4 ___5 ___more
8. How many people have a community job? ___
9. How long in RICC? ___1 yr. ___2-4 yrs. ___more than 4 yrs.
10. What groups are you involved in? ___1 ___2 ___3 ___4 ___5
11. Been an officer? _____
12. Access to a phone: ___yes ___no ___time limited
13. Cell phone: ___
14. Decisions for you? ___Self ___Family ___Staff
15. Controls your money? __self ___Family ___Staff

2. Demographics

1. ___Mobility device
2. ___Communication device
3. ___Personal Attendant
4. ___Difficulty hearing what is said in meetings?
5. ___Difficulty being understood in meetings?
6. ___Difficulty reading meeting materials
7. ___Difficulty seeing the meeting materials?
8. ___Difficulty understanding discussion at meetings?

3. Report and your responses – Some groups provide these types of support:

1. Mentors? – Have you had? Would you like? Would it help you?
2. Paid Assistant?
3. Talking stick?
4. Travel paid?
5. Paid for missing work?
6. Transportation?

7. Training in leadership? Orientation? Serving on committees? Leading meetings?
8. Prepare for a meeting? Pre-meetings?
9. Review meeting materials? Help with? (in advance?)
10. Jargon, Plan language?
11. Large type?
12. Accessible space?
13. More than one self-advocate?
14. Help with notes?
15. Take extra time in meetings?
16. Getting to know other people? Board/committee members

Other
1. What type of support helps you to speak up and participate?
2. What supports do people provide that are helpful?
3. What helps you to be more involved in? What else do you need?
4. What prevents you from being more involved?
5. Why do you want to be more involved?
6. How can the Council improve how much and in well it includes people with high and complex support needs in its activities like planning and decision-making.
7. Wrap up

Interview Guide with Best Practices Organizations

Name: _____

Title: _____

Organization: _____

State_____

Type: _____

Phone: _____

SURVEY

___Rank: _____

___Total #

___People with DD

___Percentage

SUPPORT NEEDS

__High/Complex   __Mod   __Low   __None   ___High+Mod

Support Needs Types

___Sum Needs___

___Communication device (how do you support the person?)

___Difficulty being understood

___Difficulty reading materials

___Difficulty understanding the discussion

___New people (1 year)

Most Important

      1. _____

      2. _____

      3. _____

Impact

      1. _____

      2. _____

      3. _____

Biggest Success: _____

___SM#

___Survey print out:

___Calendar:

INTERVIEW QUESTIONS

__Tape Recorder ON
__Thank you for doing this interview and the online survey
__Survey background
__Answers are all Anonymous
__Will send you a Report at end

Interview Questions

1. __Background: Tell me a little about yourself & how long you've been with _____ ?
2. __How often does the _____meet and for how long?
3. __What is the most significant thing you did to fully include people with high and complex support needs?
4. __How did you do that? __How did you make it work?
5. __Recruitment: How did you recruit people w/ HC/S needs? __Age __Ethnic
6. __How did you get the person appointed? Chairperson?
7. __Orientation: When a new member w/ dd is appointed what happens?
8. __What are the biggest challenges you have had fully including people w/ HC/S needs? Attendance? Travel?
9. __How did you overcome these challenges?
10. __Supports: What support do you provide for __communication device, __reading, __understanding discussion, __being understood? (See survey)
11. __How do you involve people w/ HC/S needs in leadership development?
12. __How do you involve people w/ HC/S needs in public policy advocacy?
13. __How do you involve people w/ HC/S needs in community activities?
14. __Success: What person w/ dd has been your biggest success
15. __Motivation: What motivated you to include ___ people w/ HC/S needs?
16. __Different: What would you do different if went back to the start and could do over again?
17. __More of: What do you want to do more of?
18. __Impact: What has been the impact on people w/ dd and on others?
      1. survey answers 1, 2, 3
19. __Advice - What advice would you give a peer ED trying to do this better?
20. __Materials, documents for training or support
21. __Snowballing – Who else should I be talking to? What orgs are doing this successfully?
22. __Anything else that I should have asked you?
23. __Photos
24. __Will send you copy of Final Report
25. __Revolutionary Leaders
26. __Other: _____
27. __Tape Recorder Off

Appendix C: Self-Advocates Becoming Empowered Focus Group Report

Beyond Tokenism National Study
Report on Focus Group
Self Advocates Becoming Empowered
St. Paul, Minnesota
May 31, 2012

Introduction

The purpose of the Beyond Tokenism National Study is to identify the best practices currently being used throughout the United States and elsewhere to effectively include people with developmental disabilities with high and complex support needs in participating in policy-making, advocacy, and community activities of disability policy-making bodies. The Study is funded by the Michigan Developmental Disabilities Council and is intended to enhance the capacity of the Council to more fully include people with high and complex support needs in all of its activities.

Over the past decade, policy-makers have begun to include people with developmental disabilities on boards, policy-making bodies and all of their organizational activities (Caldwell, 2009). At the same time, researchers have begun to involve people with developmental disabilities directly in research through action research projects where the people with disabilities are active agents in the research rather than simply subjects to be acted upon (Beresford, 2003; Heller, 1996, 1995). More recently researchers have begun to ask people with developmental disabilities their opinions directly through individual surveys and focus groups (Llewellyn, 2009). Surveys have been found to have serious methodological problems with respondents from marginalized groups often answering what they think the researcher wants to hear, referred to as acquiescence, or answering most questions with the last option provided, (Finley 2002, 2001). Focus groups have been found to overcome these limitations and to be an especially effective method to include individuals and groups that have been previously excluded such as ethnic minorities, young people, old people and particularly people with disabilities (Kass, 2001).

In order to obtain a wider perspective of people with high and complex support needs being included in DD Council activities, a focus group was held with the Board of Directors of Self-Advocates Becoming Empowered (SABE), the national self-advocacy association. The focus group was held May 31, 2012, in St. Paul, Minnesota following a regular board meeting. Thirteen board members participated from ten states including Texas, Georgia, New York, New Mexico, Arkansas, Vermont, California, Minnesota, Oklahoma and Utah. Two thirds of the participants were considered to have high and complex support needs and the balance had moderate support needs

Six of the 13 participants had participated in a Focus Group previously. All of the participants had extensive experience and involvement with Developmental Disabilities

Councils, Protection and Advocacy organizations and University Centers for Excellence in Developmental Disabilities as well as other disability groups. The majority of the participants had served on multiple councils, boards, committees and task forces with the average being 3.6. The focus group lasted two hours and included eighteen questions.

Process of the Focus Group

The Focus Group was facilitated by the Beyond Tokenism Study Project Director who has extensive experience conducting research with people with developmental disabilities including focus groups, surveys and directed interviews. The facilitator began the Focus Group by explaining the purpose of the group. A consent form was read aloud to all the participants explaining the voluntary participation and confidentiality of the information. Everyone agreed to participate and signed the consent form (see attached form).

Content of the Focus Group

Question 1: Why do you serve on Boards or committees?

"I think that they don't understand a lot of times why people with disabilities need to be on boards – they don't think we can do it. We want to show people what we can do."

"I like to be on boards or committees to help make changes, let your voice be heard and helping in making decisions in laws or policies."

"I'd like to do this so that our voices can be heard and that they actually hear from someone that lives with a disability instead of just reading about it. Some people don't even interact or even talk to people with disabilities and they are making decisions on things."

"I think the reason why it is important to serve on these boards, because when decisions are made about lives, we should be at the table whenever decisions are made about us, we should be at the table. And, also, it's just to watch where everything is going."

Question 2: How do you get in these groups, how do you have some say on things?

"Participate or volunteering in some of the committees – be active."

"If you are chair of a committee, they will listen to what you have to say. Other people that are working with you can make things happen in whatever Council you're on."

Question 3: How many people have been officers of the boards and how did you get to be an officer?

"You put your name on list and have them vote for you."

"You've got to prove yourself." If they put you in as Chair, you've got to really prove that you can handle and do it."

"The other thing is to have a campaign letter – that's what I did when I ran for Vice President. I did a campaign letter."

"Sometimes it's just who you know!"

"I believe people need to have confidence in themselves to ask for when they need help. For example: I was one of the first ones to be on the Arc, US Board; also, The Arc of Nebraska. Every time we'd have a meeting, we would go over the board pack so that I was informed. I think that's a big part of it."

"It's who you know – how do you get known by other people? A lot of times, if you can, you have to go to some of the national conferences where a lot of the professionals are at, and then get you name out there and you can talk about the training you've had, the presentations given, and get to know them that way."

Question 4: What are some of the things the organizations have done to support your full participation?

"One of the things that they can do to help you is when you don't understand something; you need to have the responsibility that you have to say that you don't understand it. The responsibility they are to take their time to explain things to you."

"They could introduce you to people or they could invite you to other meetings or other places that they go to and introduce you to new people."

"My work did it for me – they provided me with an assistant to help me with computer stuff or whatever – scheduling things, and helped me when I go somewhere. They help me to be able to prepare and have the tools I need when I travel across the state to meet with families and things like that."

"I have proper support – like when I come here, our Council helped pay for me to be here and to help me understand more. They pay the person to come down and help me take notes and if I'd get lost or if I don't understand, they explain to me – this is what they're meaning or this is what they're doing. I'll ask is this proper or is this not proper, and they can tell me that this is proper and this is why."

"I also think that the chairperson of that organization can set an example for others to follow by how they include or interact with people with disabilities on that board or committee. Set an example on how to interact with people with disabilities."

"With me, I didn't have any type of support to help me understand stuff. I was, for the first time, on a committee and they were discussing stuff and I didn't know a couple of things, and I asked for help and they didn't listen to me. A couple days later, I went to someone at the Arc and I talked to him and said that this wasn't right, because there are two advocates on here and they have supporters – when I went in, I had no one. He said, well, you know when I'm there you will have a supporter too."

Question 5: How important is it to get to know each other?

"I think that can make or break you. If someone says that you don't have the confidence in yourself to begin with, then how people include you is going to give you confidence."

"It helps just getting to know each other."

"There could be an orientation on how to help or support someone. They can introduce you to other people or they could invite you to things after the meetings – dinner or something – go out and socialize with everybody else."

"Most people get out of their comfort zone. The hardest thing for me was to get out of my comfort zone. I went and shook hands and that's not me. It brought up the fact that if I can do that, there are other things I can do."

Question 6: What things help you to get out of your comfort zone? What are some things to help you to be better able to speak up?

"What I try to do at first is listen, you know, as to what is going on, and then look at the materials that I have given to me. You know they usually give you stuff or send you stuff. I let them know what form I needed and you know, pay attention to that. Because some of the boards and things have been hard at first, because if you don't know anyone or if you don't know what's going on, you know, you have to start somewhere. I was on a state committee on education and all they wanted people to do was go in and say yes to the materials that they had sent out. So, I started asking questions and it's hard for some people to ask questions and it changed how they wanted people to do stuff."

Question 7: A lot of people have talked about being afraid to participate. How many people were afraid when they went to their first meeting? [Everyone raises their hand]. What happens when you are afraid and how do you overcome it?

"You just don't say anything. You think that if you say something, someone is going to take it wrong and then you have that thought in your head and it just stops you from saying anything."

"I am shy."

Question 8: What else can organizations do to more fully include your participation?

"Another thing is that people don't listen to us. They should try to understand what we're saying because there are people out there that did not understand about people having disabilities. The reasons why I'm saying this is because when I was growing up, there was nothing around for my Mom and I, you know, to get help. There was nothing. So, now, there is stuff out there, but, still, to this day, they still do not listen to what we have to say. Another reason I'm saying this is that there is a DD Council in my state that doesn't understand and they don't want to listen to what we have to say. Even the people who are at the Capitol; they don't want to listen to us."

"You know I'm just thinking about the first question you asked your comfort level and how people get into their comfort level. So, I'm tying it into that question and summarize a little bit about what you are asking. Like first, you asked about your comfort level. Your comfort level does depend on how you feel in meetings. So, if someone is not comfortable in their group that can cause fear. Your fear kinda gets in the way of your speaking up. I forgot to answer the first questions about your comfort level. For me, I would say that if you know someone that is a part of that group, have your accommodations ahead of time, have that person help you. I think the more you can do that, that can help to overcome some of the fear you have. Because, sometimes what happens is that when you're not comfortable, it causes fear, and I think your comfort level depends on whether or not you feel if your accommodations are going to get met."

"I think also that you can help you when you are on a committee, like asking you later on if there is anything that you need help with, any other supports that you need, do you understand what's going on. You know, that kind of stuff helps people get comfortable with a group. You know, making sure that people are okay- asking if they want to add something when things are out there and people are asking questions."

"I also think that if you're going to have a person with a disability to be on your board or committee is that you need to talk to them about what the accommodations are and the supports they need. For example: some people may not know how to read and making the material so that people can understand it and a lot of us don't understand the words. Another thing that I think is helpful is that they color code the material, like green is money, blue is the minutes – I'm not sure if I'm telling it right, but just for an example."

"Another way is to explain the "big words" and put it into our "readers".

"You know they need to treat us like we're human beings. It's like they want to touch us, but they don't dare because you're going to break or you have a disability, is there anything I can do. They treat you like a baby. They should treat us like they would want to be treated."

"What I was thinking of is have someone in there for people who cannot take notes right, to help take notes for other people."

"We can ask if we can have someone take notes and if they ask why, say because you know I cannot take notes right."

Question 9: How does it help you to have someone taking notes for you?

"I also think like when we're in a meeting, it goes too fast for people. So things that you're responsible for need to be written down. Also, it helps to remind you of things."
For someone like me, that would be helping me to understand – that would be my minutes for me to know and to refresh.
"I think that it also helps to have more than one person taking notes on a board or committee because it makes you feel at ease if you have someone else to talk to and it's also intimidating when you have all these professionals and you are the only one with a disability and trying to speak out for what you believe in and try and help them to understand."

Question 10: Why is it important to have more than one self-advocate in the group?

"I think that it's important because you want them to know that people are different and that you have different views. People are not all the same, just like people on this board are not all the same. All opinions count. That's important to let them know, because sometimes they will point out and say, you're different from other people, and you're to the point that the very first time you say something, it's different from what they want you to say and when you disagree with them – oh yeah, you're different alright. Then, you're starting trouble."

"One thing that would be important is to put board content on CD's."

"It not only helps me, it would help other board members so that they can get the information."

Question 11: Some people talk about having the material two weeks in advance –is that so important?

"The reasons that it's important, you'll actually be able to participate in the meeting and if we don't understand it, then how are we going to be able to participate in the meeting. So we need to have time to allow people to go over the material with us so that we can understand it and so that we can form opinions of how we feel about things."

"I think that it's so important to be prepared ahead of time so that everyone, not only does it show that you're able to be prepared for a meeting but so are others."

"Sometimes when they give you those board packets, they're so big, and not everything that's in there, you have to read. So what we did was put in a beginning page on the top of it that said you have to make a decision about this – you have to vote on this – and there's another page on top of the other thing that you don't have to vote on and says, this is just for your information to read later. So that you can pay attention to the important stuff that you have to be concerned about during the meeting, and the other stuff you can worry about later. That way, people can do that, and the color coding was done so that everyone could be on the page, along with pictures, so that people will know that this is the minutes – there's a picture of the recorder – and all of this is on that front page so they will now the difference."

"I think that having an agenda prepared sometimes before a meeting is good because there may be topics that you have to pay attention to and then there are topics that you don't have to pay attention to, and I think in my experience when I have agendas ahead of time, we go over the agendas, I know at what point on the topics that I need to pay attention to so that if I have something to say about it."

Question 12: Who helps you be prepared for a meeting?

"It has to be someone that you can trust."

"I think it's important to pick your own support person, because that's a person you feel comfortable with; you know that person so that they know how to support you; they know how to help you to understand the materials that you're going over and I think that helps a person to be able to go to a meeting feeling more prepared."

"It's like the people who you know. Like me, I have two people with the state Arc that will go over the agenda with me just to make sure that I understand what's going on and for me being prepared in case I'm asked a question."

"On the Council – what we did was to get all the self-advocates together and take about 10-15 minutes to discuss the agenda and what's going to be discussed during the meeting. This way, if we had any questions we could ask – ok, I'm confused about this or I'm confused about that – or I don't understand about this, and that really helps because you're going in to a meeting more learned because you know what's going on. That 10 minutes of support really does help."

"It's part of my job as self-advocate to provide support."

Question 13: How many self-advocates should serve on a board?

"Depends on the size of the group."

"I also think it depends if it's like the DD Council or another organization other than a self-advocacy organization, because then the whole board should be."
"Legally, I think it has to be 50%."

"50% of people with disabilities or a family member."

"It should be half and half. Everyone seems to agree that it should be more than one."

"I would say in a large organization, at least 10, because when it comes to comes to voting and some of those kind of things, you have people that are strongly wanting something, most of the time if you only have 1 or 2, you are automatically out-voted, unless you can convince some other people to see it in the way that you're talking."

"Also, I think, if there is more than one person with a disability, they have to be from different parts of that state."
"A lot of it has to do with diversity and there will probably never be that diversity."

"Most of the time you get people from the rural areas and there are so many in cities, and outside of that, it's hard to get to your meetings."

Question 14: Let me come back to what we discussed a little earlier – influence and there was a lot of reaction on this – a lot of you feel that's why you're on these committees. How do you make a difference?

"Making your voice be heard."

"Speaking up.

"The passion of the issue."

"Sometimes you just say what you're feeling – sometimes you have to think if it affects you it affects other people."

" How it affects you makes a difference because we're the only ones that can say that."

"Asking you to be part of something other than being on a board."

" We don't sugarcoat the information, we just tell it like it is."

"Don't be afraid to speak up for what you believe in."

Question 15: What can the organization or the Council do to better help you?

"Make you look good – you don't want to just look good, you want to be heard by a lot of these people"

" Have someone from the Council be in our shoes and see how we feel."

"I think they want you on there because if you turn them down, they get highly upset. I was asked to be on our DD Council and I said, I don't want to be on it, I'd rather stay in the position that I'm on, because I would be able to tell you what's good and what's not good, what I like or don't like. If I'm on a Council, I can't do that, it changes the dynamics, I'd become one of you and not be able to tell you what to do."

"I think that whatever your position on a board is, you can help influence others – an officer can also help influence others."

Question 16: How much influence do you feel you have being on these committees?

"It depends."

"If I'm on it I'm going to have my influence whether they like it or not."

"The National Council that I'm on now there are people with disabilities but come from different backgrounds and we all work toward the betterment of people with disabilities and our input counts and then we get to shape things for the President

and the Congress. Actually the good thing is, we can tell them if they're wrong about something. They're asking for our advice."

"In my experience, the amount of recommendations that you get by being on a committee and people telling you whether or not they like your opinions. How you serve on one board can lead you to becoming a member on another board."
"Standing up for what you believe in – you may be rewarded, but it's a dirty job."
"You have to listen to people with disabilities – provide support for them – help them build their confidence so that they believe in themselves – so they will speak up for themselves."

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Appendix E: Organizational Partners and Experts Committee Members

Michigan Study on People with Complex Needs in Leadership Roles

15 Survey Partners

1. National Association of Councils on Developmental Disabilities (NACDD).
2. National Disability Rights Network (NDRN)
3. National Association of State Developmental Disabilities Directors Services
4. Self-Advocates Becoming Empowered (SABE).
5. American Association on Intellectual and Developmental Disabilities (AAIDD).
6. The Arc of US
7. TASH
8. ANCOR
9. American Speech and Hearing Assoc. Special Interest Group on AAC.
10. Association of Assistive Technology Act Programs
11. Rehabilitation Engineering & Assistive Technology Society of North America
12. Autism National Committee (Autcom)
13. Association of University Centers on Disabilities (AUCD).
14. National Consortium on Leadership.
15. UCPA, US

16 National Experts

Self-Advocacy Experts

1. **Jenn Seybert** (New York) uses Facilitated Communication and Augmentative and Alternative Communication (AAC) devices for her communication. She founded one of the first Autism self-advocacy organizations in Pennsylvania. She serves as a presenter on Autism. She serves on the Executive Board for the Autism National Committee (AUTCOM) as Vice President. She has provided self-advocacy Autism training in England. She has published numerous articles on Autism in journals, magazines, newsletters, and several books. She is featured in two videos, Paula Kluth's "We Thought You'd Never Ask" and "Kayla's Voice: Empowering People with Autism" by Steve Hartman. She is currently pursuing a Master's degree in Disability Studies at Syracuse University.

2. **Eloise Woods** (Alabama) - former consumer member of Alabama Developmental Disabilities Council. Currently serves on Alabama State Mental Retardation Community Services Planning Board, First state President of People First of Alabama. Formerly board member of Home of Your Own of Alabama.

3. **Nancy Ward** (Oklahoma) - founder and first Chairperson of Self-Advocates Becoming Empowered, former Board member of TASH and the Arc of US. Employed by the Arc of US on the Medicaid Desktop Reference project. Ms. Ward is considered to be "the mother" of the self-advocacy movement in the US.

4. **Liz Weintraub** (Maryland) - Recently appointed to the President's Committee on People with Intellectual Disabilities. Serves on the board of directors of the Alliance for Full Participation, Jewish Foundation for Group Homes, Maryland Assoc of Community Providers, Shared Supports of Maryland, and Human Services Research Institute Board of Directors. Employed as Self-Advocacy Project Specialist, Association of University Centers on Disabilities (AUCD) and Self-Advocacy associate, the Council on Quality and Leadership (CQL).

5. **Barbara Coppens** (New Jersey) - Employed as Disability Rights Advocate at Disability Rights Network of New Jersey. Serves on the Board of Directors of The Arc of US; Arc of NJ; Advisory Board of Matheny Medical and Educational Center; Developmental Disabilities Coalition of NJ; Consumer Advisory Committee of Boggs Center, NJ (UCEDD). Former resident of State Developmental Center.

6. **Bill Byrne** (New Jersey) - Winner of Colleen Fraser, Self-Advocate of the Year Award 2010. Serves on the Board of Directors of Self-Advocates Becoming Empowered (SABE) and The Arc of New Jersey. Member of the Morristown Rent Leveling Committee, President of New Jersey United Self-Advocates (NJUSA), Founder and past President of Unity Club Self-Advocacy group and Chairperson of the New Jersey Statewide Self-Advocacy Network. Trainer to first year medical students at UMDNJ's Robert Wood Johnson Medical School. Employee of Bell Bartain High School.

7. **Debbie Robinson** (Pennsylvania) - Appointed by President Clinton to the National Council on Disabilities. Executive Director of Speaking For Ourselves, a statewide self-advocacy organization in Pennsylvania. Life story highlighted in O'Connor, S., Fisher, E. & Robinson, D. (2000) Intersecting cultures: Women of color with intellectual disabilities. In R. Traustadottir & K. Johnson (Eds.). Women with Intellectual Disabilities: Finding a place in the world. London: Jessica Kingsley Publishers.

8. **Tia Nelis** (Illinois) - Self-Advocacy Specialist at Rehabilitation Research and Training Center, Institute on Disability and Human Development, University of Illinois at Chicago. She founded and served as President of People First of Illinois She has been honored with the Burton Blatt Award by Tash and the Elizabeth Boggs award from AAMR.

9. **Betty Williams** (Indiana) - Coordinator of Consumer Education and Training, The Arc of Indiana; former President of People First of Indiana; President of Self-Advocates Becoming Empowered. Formerly on the Mayor's Council for People with Disabilities, the national board of directors of the American Association of People with Disabilities

(AAPD), and The Arc of US board of directors.

10. **Alina Szamatowicz** - is the winner of the Brighter Futures Award; the youngest person to ever receive this award. Presenter at Arcadia University, the Florida Inclusion Matters Conference and TASH. She has complex communication needs and communicates through gestures and expressions and uses a wheelchair.

<u>Family and Professional Experts</u>

1. **Donna (Szamatowicz) Bouclier** - communication interpreter for her daughter, Alina. Ms. Bouclier has assisted Alina to present at national, state and local conferences on complex communication needs. She is a family trainer and has provided training internationally in the Ukraine and the Caribbean for UNICEF.

2. **M.J. Bartelmay** - Board member of The Arc of US, Past President of The Arc of Pennsylvania. Father of a person with a developmental disability. Member of the Arc of US committee to increase the participation of self-advocates serving on state and local Arc boards of directors.

3. **Amy Goldman** (Pennsylvania) - National expert on Augmentation Communication; Director of Pennsylvania's Initiative on Assistive Technology, Associate Director of the Institute on Disabilities, Temple University, Director of the Mid-Atlantic Consortium on Accessible Information Technology in Education. Licensed speech-language pathologist specializing in the area of augmentative and alternative communication (AAC). Member of the Steering Committee of the American Speech-Language Hearing Association (ASHA) Special Interest Division on AAC.

4. **Marcia Tewell** (Colorado), Executive Director, Colorado Developmental Disabilities Council - Expert on the use of facilitated leadership to involve people with developmental disabilities serving on boards and policy-making bodies (See Facilitated Leadership Ground Rules in Attachments-Documents).

5. **Steven Stock** (Colorado) - Expert on assistive technology for people with cognitive disabilities. Designer and developer of assistive technology software and hardware. Vice President, AbleLink. Developed specialized accessible online survey tool for people with cognitive disabilities. President of local Arc chapter in Colorado.

6. **Joe Caldwald** (Illinois) - author of seminal journal article on board inclusion. Caldwell, J., & Hauss, S. (2009). "Participation of Individuals with Developmental Disabilities and Families on Advisory Boards and Committees," published in the Journal of Disability Policy Studies. Adjunct Assistant Professor, University of Illinois at Chicago. Creator of online Oral History

Appendix F: Best Practices Interview Respondents

	State	Organization Name	Interviewee	Title
ORGANIZATIONAL INTERVIEWS CONDUCTED				
DEVELOPMENTAL DISABILITIES COUNCILS				
1	AL	Alaska Governor's Council on Disabilities and Special Education	Teresa Holt	Executive Director
2	AZ	Arizona Developmental Disabilities Planning Council	Larry Clausen	Executive Director
3	CO	Colorado Developmental Disabilities Council	Maria Tewell	Executive Director
4	DE	Delaware Council on Developmental Disabilities	Patricia Maichie	Executive Director
5	GA	Georgia Council on Developmental Disabilities	Eric Jacobson	Executive Director
6	IL	Illinois Council on Developmental Disabilities	Sheila Romano	Executive Director
7	KY	Commonwealth Council on Developmental Disabilities	Patricia Seybold	Executive Director
8	LA	Louisiana Developmental Disabilities Council	Sandee Wichell	Executive Director
9	MA	Massachusetts Developmental Disabilities Council	Don Shannon Lee Sandy Houghton	Executive Director Trainer Self-Advocate
10	MD	Maryland Developmental Disabilities Council	Brian Cox	Executive Director
11	MN	Minnesota Governor's Council on Developmental Disabilities	Coleen Wieck	Executive Director
12	MT	Montana Council on Developmental Disabilities	Deborah Swingley	Executive Director
13	NC	North Carolina Developmental Disabilities Council	Holly Riddle	Executive Director
14	NE	Nebraska Planning Council on Developmental Disabilities	Mary Gordon	Executive Director
15	NJ	New Jersey Developmental Disabilities Council	Alison Lozano	Executive Director
16	NY	New York State Developmental Disabilities Planning Council	Anna Lobsco	Deputy Director
17	OH	Ohio Developmental Disabilities Council	Carolyn Knight	Executive Director
18	TN	Tennessee Council on Developmental Disabilities	Wanda Willis	Executive Director
19	TX	Texas Council on Developmental Disabilities	Rodger Webb	Executive Director
20	UT	Utah Developmental Disabilities Council	Claire Mantonay	Executive Director
21	VA	Virginia Board for People with Disabilities	Heidi Lawyer	Executive Director

22	VT	Vermont Developmental Disabilities Council	Karen Schwartz	Executive Director
23	WA	Washington State Developmental Disabilities Council	Ed Holen Linda West Emily Rogers Brian Dahl	Executive Director Program Specialist Self-Advocate Program Specialist
24	WI	Wisconsin Developmental Disabilities Council	Beth Swedeen	Executive Director
25	WV	West Virginia Developmental Disabilities Council	Linda Higgs (Steve Weisman)	Program Specialist
26	WY	Wyoming Governor's Council on Developmental Disabilities	Shannon Buller	Executive Director
UNITERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES				
27	CO	JFK Partners	Tracy Price Johnson	Discipline Director
28	IA	University of Iowa Center for Disabilities and Development	Ann Riley	Program Manager
29	MT	Rural Institute on Disabilities	Ellen Cordon Kim Brown	Program Managers
30	NM	Center for Development and Disability	Barbara Ibanez	Project Manager
31	VA	Partnership for People with Disabilities at Virginia Commonwealth University	Donna Gilles	Executive Director
32	VT	Center on Disability and Community Inclusion	Deborah Lisi-Baker	Associate Director
PROTECTION AND ADVOCACY ORGANIZATIONS				
33	KY	Kentucky Protection & Advocacy	Marsha Hockensmith	Executive Director
34	MI	Michigan Protection and Advocacy	Elmer Cerano	Executive Director
35	PA	Disability Rights Network, PA	Mark Murphy	Executive Director
36	VT	Disability Rights, VT	Ed Paquin	Executive Director
OTHER				
37	NC	Arc, North Carolina	Dave Richard	Executive Director

What has been your Council's experience?
(exercise at NACDD conference November 2011)

[1] Biggest Barriers?
1. Knowing about different boards you can sit on.

2. If don't have a computer, then share Information by call or snail mail.

Most Successful?
1. Break down information for people who don't understand.

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[2] Biggest Barriers?
1. People are noisy
2. Simple & to point
3. People help to much

5.

Most Successful?
1. People are nice/polite
2. Billie help with light
3. New
4. I talked the lots
     Mentor-friend

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[3] Biggest Barriers?
1. We do very complicated work/meeting formats

2. Attendance & homework

3. Acronyms

4. Paper overload

5. Completing commitments
   - picture clues
   - bound packet
   - larger print
   - color coding

Most Successful?
1. Small group discussion
2. Assigned staff "assistants" (not personal care, participation assistants)
3. Advance caucus preparation & opportunities to ask questions
4. Fewer acronyms & meeting specific acronym listing
5. Less paper

6. Feedback survey

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[3] Biggest Barriers?	Most Successful?
1. Time to do work, get things done. always in a hurry	1. Face to face meetings
2. Too much written information not enough photos	2. Microphones
3. Not plain language interpreters	3. Transcribing meeting
4. Classes – self advocates vs. families	4. Friendly people
5. Arriving in town too late the night before	5. Color coding
6. Staff not asking questions/listening to people	6. All can call before meeting/pre-meeting

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[4] Biggest Barriers?	Most Successful?
1. Sometimes meeting room too small – hard to navigate.	1. Lots of microphones
2. Too much written material, not logical order	2. Interpreters for Deaf/Hard of hearing
3. Distractions/background noise	3. Orientation
	4. Robert's Rules Training, Encourage opinions and Ideas of all
4. Too much to do, too little time	5. Live transcription of council meetings

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[5] Biggest Barriers?	Most Successful?
1. Not interested dept. reps	1. Adv Committee training a position users & presenting
2. Keep up with meeting - topics not together - language used	2. Adv prepared/knowledgeable o topic areas before meeting
	3. Pre-council prep meeting run by J JA

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[6] Biggest Barriers?	Most Successful?
1. Lack of understanding role (all board members)	1. Good facilitation
2. Lack of respect	2. Plain language materials
3. Too much and too little time	3. Equal respect for all members
4. No commitment to assuring meaningful participation	4. Coalition building

5. Lack of knowledge and skills to improve
   Participation by all board members

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[7] Biggest Barriers?	Most Successful?

1. Not being familiar w/meeting etiquette
2. Not being informed on topics
3. Time..Patience..Pace..Listening

4. Feeling included professionally and socially
5. How to be "politically" effective

Most Successful?

1. Consumer Caucus (Pre-Board Mtg)
2. Mentorship
3. Organized Social Dinner
   (open to all/optional)
4. Training

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[8] Biggest Barriers?

1. Understanding grants and how I can be
   involved and how to participate
2. How policy issues are connected in my own
   life

Most Successful?

1. When others on the Board have good
   active listening skill
2. Information from others presented in
   Plain language – not rushed

Beyond Tokenism National Study
Report on Michigan Focus Groups
October - November 2012

Introduction

Five focus groups were held with Michigan citizens with developmental disabilities during October and November 2012 as part of the Beyond Tokenism National Study. An additional Focus Group was held with the Board of Directors of Self-Advocates Becoming Empowered (SABE) and is reported separately. The purpose of the focus groups was to obtain information on the barriers and supports that enhance and inhibit the ability of people with disabilities with high and complex support needs to fully participate on boards, policy-making bodies and in community activities.

Over the last ten years, there has been an increasing usage of surveys and focus groups as a means to obtain the opinion and input of people with disabilities (Llewellyn, 2009; Caldwell, 2009; Helmsley et al, 2008). Surveys have been found to have serious methodological problems with respondents from marginalized groups often answering what they think the researcher wants to hear, referred to as acquiescence, or answering most questions with the last option provided, recency (Finley 2002, 2001). Focus groups have been found to overcome these limitations and to be an especially effective method to include individuals and groups that have been previously excluded such as ethnic minorities, young people, old people and particularly people with disabilities (Kass, 2001).

The Beyond Tokenism National study conducted five focus groups with 78 people with developmental disabilities in the five DD Council regions of Michigan. The recently hired RICC Coordinators arranged the focus groups in each of the five regions.

The five focus groups were held as follows:

	Location	Date	# Participants with Developmental Disabilities
1	Monroe	11/9/12	31
2	Grand Rapids	11/7/12	22
3	Flint	11/28/12	16
4	Gaylord	11/29/12	6
5	Marquette	10/23/12	3
	Total		**78**

Process of the Focus Group

Two individual with developmental disabilities were hired at Peer Trainers and participated as co-leaders of the focus groups. The Peer Trainers attended two days of training to teach them how to co-lead focus group. A mock focus group was help November 5, 2012 with a local service provider to provide hands on experience in leading a focus group.

The Focus Group was co-led by the Peer Trainers and facilitated by the Beyond Tokenism Study Project Director who has extensive experience conducting focus groups and research with people with developmental disabilities. The facilitator began each Focus Group by

explaining the purpose of the group. A consent form was read aloud to all the participants explaining the voluntary participation and confidentiality of the information. Everyone agreed to participate and signed the consent form. A short presentation was made about the preliminary results of the National Beyond Tokenism Survey. The majority of the Focus Group was spent obtaining the feelings, experiences and examples of participating in organizational and community activities. All of the participants in the Focus Group received a Certificate at the end of the meeting.

Background of the Participants
  Forty-three percent (43%) of the participants were men and sixty-two (62%) were women. None of the participants were under 21 years; 23% of participants were young adults (aged 22-25); 23% of participants were aged 26-35, 34% were aged 36-50 and 19% were over 50 years old. The significant number of young adults was from a newly formed RICC (Monroe) that had individuals from the local school transition program.
  Thirty-two percent (32%) of the participants had guardians overseeing their personal and financial affairs. Community jobs were held by 23%. Jobs included many microenterprises as well as community employment.
  Twenty-three percent (23%) of the participants have been involved in the RICC's for less than 1 year, two to four years (15%) and more than four years (25%).
  100% of the participants had access to a phone with 79% having a cell phone. No one had their phone time limited other than a limit on the number of cell phone minutes available.
  Twenty-six percent of participants (26%) used a wheelchair or crutches. Four percent (4%) used a communication device. Nice percent (9%) had a personal attendant. Regarding ability to access the meeting, 11% had difficulty hearing what was said in meetings. Seventeen percent (17%) had difficulty being understood. Forty-five (45%) percent had difficulty reading the meeting materials. Twenty-six percent (26%) had difficulty seeing the materials and 30% had difficulty understanding the discussion at the meetings. Twenty-six percent (26%) of the participants were described as having high and complex support needs. None of the participants had no support needs.

Content of the Focus Group
  Transportation was cited repeatedly by almost every participant as the number one barrier to greater participation in Council and community activities. RICC members raised this issue repeatedly regarding attending local and regional meetings. Several Council members themselves who have difficulty finding transportation to Council meetings raised this issue. The issue of transportation was raised repeatedly in every focus group by every category of participant.
  Focus Group participants had the following to say:
- The biggest thing for me, like I said, is that I want to help people more, but the problem is getting here – transportation
- I need somebody to drive me to and from the meeting and possibly help me get into the building.
- One time we went to Lansing to see about getting a bus. We had a bunch of handicapped people that went to the chairperson in Escanaba and they got the transportation people to contact Lansing and that's how we got it started. They came up to talk to us about the program. I used to show them the route, because they didn't know the route.

- I can never ever go to the legislation place down state because of my physical disability, I can't get out of the wheelchair, so that eliminates travelling down state.

What help do you need to participate more fully?
- I need someone to help me read and help with writing. I have a hard time understanding what people are talking about. I don't have writing skills so I have to use a scriber – a person who writes for you.
- It's also important, depending on the kind of meeting, which usually happens in most meetings, having a copy of the agenda, so you can refer to what is going on and any kind of handout materials.
- Materials that you can bring back with you and have somebody go over it with you. Just to give an example: often, you know, we participate in council meetings – their teleconferences, as an example – and they will send us the agenda and the handouts ahead to time. And, if you have time, you can print those off, and at larger meetings, usually; they'll have copies, which are a big help because a lot of times people may not have access to a computer to print off their own materials.
- Some of us that have a major shortage of attention span. After about 45 minutes, you start seeing people glazing over or falling asleep and just having a rough time. The 2 hour teleconferences and the DD Council, last about 1-2 hrs. and after about 45 minutes you can kind of tell that people are starting to lose their interest in what's going on, because all of a sudden they'll start talking about something that we talked about 45 minutes ago and you're an hour and half in the meeting and it's like, ok we lost somebody. So, having meetings that run too long, sometimes for some of us, we just start zoning out into the atmosphere.
- I have my assistant to help other people as well as helping me.
- I always go online and research stuff before I participate in the meeting. So, it definitely helps me to have something to research. Because, I'm always like, why do I want to go to this? It helps to have prior knowledge of what's going on.
- One thing that I do is that I'll watch other people at the meeting and if somebody that has been really quiet and they act like they have something to say I may ask them, do you have something to add. I think if we do that for each other it helps.
- If I know a lot about the subject and if I have knowledge of the subject, that's helpful too.

What type of leadership training has helped you?
- I've been to peer mentor council conferences – we actually have one coming up December 6 & 7 and I will be attending that.
- We have a legislative thing going on for all the RICCs all around the state.
- We talk to our legislators and we have workshops the day before. We get to meet the legislators.

What helps you to speak to a legislator?
- We have a meeting to discuss what issues are going to be discussed.
- When we have a Regional RICC meeting and during those meetings we get a chance to watch people role play or participate in role play. I think that helps a lot because when you're in the actual situation you can recall what you did in the role play.

- I agree. I was there last month for a role play. Glen was Mr. Senator No Good. My friend was there and she was in the role play with me. There was another role play with Terry Hunt talking on the phone.
- I wasn't in it, just watching but my friend was in it though.
- I even did a sketch down there in Lansing. A skit. I talked to the senators and we did a little play, and this guy beside me was a senator. We call that a role play. Yeah, I played that and we did a good job on that. I even helped with the role play that was all about helping people try to work even though they have Medicaid and stuff, so they don't lose it.

What helps you at the meeting?
- When we are at RICC meetings we have to prepare an agenda and we have to write down things that we do. I call someone up and meet so we can go over the agenda – like my chairperson.
- Sometimes you have to do research and think about things before the meeting.
- I try to make a list of things that I need to bring.
- I just find out when I get there and figure it out then.
- I make sure that I have everything out so that I can put it in my backpack or something.
- I write a list down or I try to.
- It was funny on Monday at the RICC meeting I forgot to bring the talking points that we were supposed to go over and there were 3 people at this table that pulled them out of their folders because they had notebooks and folders with them. I got my talking points. I think maybe their notebooks help them.
- The notebooks are really important.
- They can help me by explaining things slowly. They explain it nice and slow to me
- It's good to have a notebook, but I'm not able to carry one, so if you can't carry one, it doesn't help you.
- If you can't carry a notebook, then it helps to carry a bag or something or have someone help you.
- She has a program that makes the print larger for her.
- I think large print helps a lot of people that can't really see – it makes it easier for them.
- Some of the RICC meetings we have to have extra time for some people to be heard.
- When someone uses a talking stick Terry Hunt actually used one at one of the RICC meetings – he had an umbrella and he designated one person to walk around and the person who had the umbrella was allowed to speak. It took time for the person to walk around it, but it gave you time to think about what the person had said. Everybody wasn't talking at once and it was really nice. The person passing around the stick, you just can't start talking without that person coming over and that takes time. So you have time to think about your thoughts before you say things. It's almost the same as passing a microphone around. You can actually use a microphone that's not turned on or a marker. It helps to make sure that everybody gets to say what they want to say.
- I wish boards would use a talking stick to help from them getting out of hand because of people talking over each other. A real board is supposed to wait for the chairperson to acknowledge the member to speak.

- She likes when they use a talking stick because she has a hard time explaining things and this gives her time to say what she wants to say.
- I think you should have a timer so that each person has a certain amount of time to say what they want to say.
- I receive my council packet, I sit down with it with the Chair and I read it cover to cover – all the reports – and when I went to Lansing, I knew what was going on.
- I don't comprehend very well and being the secretary of RICC, I've finally figured out that I'm supposed to use the agenda when I take notes. Otherwise, I just write down every word that everybody says and then when we go to the minutes, none of my words mean anything. I'm still working on that – basically, comprehension.
- I'm usually distracted if there are other noises in the room. I don't ask for help – I never ask for help.
- Everybody is pretty well organized, so when I lose it, I can get back into it and what I've missed,
- After the meeting we go through our notes and we write up our minutes. We try to do that the following day if not the same day of the meeting. She reminds me of what we talked about last month and we go over those minutes so I can get a follow-through as to what we're talking about and what we're trying to do.
- I get the agenda and I write my notes next to the Agenda. Example: Ok this is George and this is what George said. I'm doing it that way now, where before I would write down, George said, blah, blah, blah!
- I get help with it [the agenda] because I don't know everything yet.
- At my first meeting I had someone help me with the time keeping.
- I go over and talk to new people at the meetings. I introduce myself and tell them what the program is. For each new person we have packets that describes different things that we're involved in. One of the main things that we always do is to explain what's in the packet.
- I get my paper and my packet all together, so when I sit down to the meeting, I was ready to begin.
- When it comes to writing I really depend on that a lot because I'm not very good at writing. Even on my job that I have to write things, it's a struggle sometimes, because I can't spell very good and if you can't spell you can't look things up in a dictionary – for years people would say just get a dictionary – and I struggled with that until one day someone said to me, how can you look something up in a dictionary if you don't know how to spell it? So, I have an App on here that has a microphone and I can talk into it and it will print it out. So, when I get stuck on a word, this really saves me a lot of time. I can hit the microphone and say what I want to say and it will write out in text. I talked to my employer about getting me the Dragon Speech and if I really push that I think that they would. So, I really count on them to help take the notes and stuff. It's called Talk and Text and you can get it on your phone. All the Smart Phones have it. When I call someone up like I'm going to text them, and then I'll say the word that I'm trying to figure out how to spell and then it will come out and then I erase and say, oh, that's how you spell that.
- A friend of mine helps me to get my courage to speak up. We looked over our notes and practicing on how to say the minutes and the agenda. She comes once a week to help me

write letters. She helps me with the phone calling and helping to write for a grant that we're trying to get. She's working on that with us right now.
- Sometimes it takes a little while for people to speak up. When I first started I wasn't as talkative as I am now. It seems like that people are there for a little when and then they get more talkative and get more active as they keep going.

What other barriers do you face?
- Part of the problem is accessibility because if the place isn't accessible I can't participate. It has to be wheelchair accessible so that I can get into the building, making sure the bathrooms are accessible.

What types of things are you doing in the RICCs to be part of the community?
- We're doing a project – Shred the Hate - involving getting rid of the "R" word – retarded. That's one of the biggest campaigns that we've been doing. I have this bracelet – I've had it so long, that of course you can't see the words on it – It used to say – shred the hate on it. So, a whole bunch of people at our RICC group have been going to different schools talking about it – and we have pledge forms to have people pledge that they're not going to do it anymore and stuff. We've been to 4 schools and one church.
- We've even been getting involved with the Animal Shelter lately and helping with that a little bit too.
- We went to the schools and telling the little kids to quit using the "R" word and that was hurtful – possibly being a bully. We've also been talking a lot about trying to stop bullying. We've also gone to churches. In fact, I'm going to be speaking at one of them over by a school because they're making fun of us again.
- We have been trying to get a light put on a street here and that's one of the focuses we've been trying to get done.

What could the DD Council do better to help you?
- This year we lost our fiduciary and our RICC got disbanded and this was because the DD Council required so much of our RICC to do as far as paperwork, accounting and stuff like that and that's why we lost it. In my opinion I would like to see the RICC going back to the simplified way of being RICC.
- I have to agree with that because our RICC has lost a lot because of the requirements – we lost our physical agent – we found another one but it's taken a lot of time.

How do computers help you?
- He uses Dragon Speech version on his computer.
- I use it [laptop] to take notes or get on it to talk to friends and ask them questions about things.
- I use Facebook to talk to my friends.
- Facebook helps me by telling me when the meetings are, what time they are, and what they're going to ask. It's always good to get on your email too and find out about meetings that are coming up.
- Email helps you send information back and forth, ideas, and it's just great for everything.
- It's like the teleconference we did for peer mentoring we used email for information.

- It [teleconference] helps us a lot by giving us a lot of information. They ask you what your update is on your Round Robin or something like that. They tell you when your conferences are. They ask you what you've been doing for your peer mentoring.
- I been on a few teleconferences and they are very informative in letting you know what's going on in the area, but with a teleconference you only have a number of minutes to discuss your problem.
- I just don't attend. Sometimes you can hook it up to Google but then people say they have a hard time hearing it.
- You get to listen to what's going on because they have a lot of people.
- We do this at the Drop-In Center.
- I use email and I'm quite interested policies. I receive Action Alerts through email.
- My computer is set up that when I turn it on, it will talk to me because of the program that is built into it.
- We do data entry on a computer. We use Power Point and word documents.
- I watch a video to see how to use it.
- I have a touch screen that helps.
- We use an iPod to help us
- I can talk to it – like look up information on something – and it will bring up the information. You can use it as a GPS system if you need to look for an address.
- I need an iPad or a talking computer.
- Kelsey is talking about using Power Point – that's where you put it up on a big screen – like words and things and says she needs it short and sweet to be able to understand. Someone else states that they're making a Power Point and putting pictures in it of what they do.
- Sometimes in groups, people make things in colored paper and then they can say, look at the yellow page or the red page. April says that colored paper helps her.
- What helps me is that my teacher had me do a voice test – you put a CD in the computer – and I sat there and listened to it because I have to hear certain type of things to understand what they mean.
- There's also a program called "Dragon, Naturally Speaking" for people having trouble writing –
- I have a hard time writing and could use that.
- Sometimes I write but it's not that legible. Sometimes when I'm on the computer I type and if I spell words wrong, on the computer I can use spell check.
- We use Facebook to contact different people – we use it as a class – we use different pictures when different events come up.
- I do 2 types of chat – video chat and regular chat.
- My computer already has the webcam on it.
- I use Skype. People can see you and you can see them. You don't have to type, you just talk to people. You can either type or do video.
- I post videos of what's going on, for example: for our church group, I use video chat to show my friends and family what I was planning for that day – like planning my lessons and stuff.

- I talk to former teachers, whether from high school. I just type in their name and see their profile and then I ask if they want to be my friend and if they want to Skype and if they say yes I talk to them.

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Focus Group Discussion Guide

1. Introductions
1. Round robin: Name and involvement in RICC?
2. ___Men ___Woman
3. Age ___<21 ___22-25 ___26-35 ___36-50 ___50 plus
4. Where are you from? ___East ___Middle ___West
5. How many people live with family? ___In a group home? ___By self?
6. Guardians: ___
7. How many roommates? ___1 ___2 ___3 ___4 ___5 ___more
8. How many people have a community job? ___
9. How long in RICC? ___1 yr. ___2-4 yrs. ___more than 4 yrs.
10. What groups are you involved in? ___1 ___2 ___3 ___4 ___5
11. Been an officer? _____
12. Access to a phone: ___yes ___no ___time limited
13. Cell phone: ___
14. Decisions for you? ___Self ___Family ___Staff
15. Controls your money? __self ___Family ___Staff

2. Demographics
1. ___Mobility device
2. ___Communication device
3. ___Personal Attendant
4. ___Difficulty hearing what is said in meetings?
5. ___Difficulty being understood in meetings?
6. ___Difficulty reading meeting materials
7. ___Difficulty seeing the meeting materials?
8. ___Difficulty understanding discussion at meetings?

3. Report and your responses – Some groups provide these types of support:
1. Mentors? – Have you had? Would you like? Would it help you?
2. Paid Assistant?
3. Talking stick?
4. Travel paid?
5. Paid for missing work?
6. Transportation?
7. Training in leadership? Orientation? Serving on committees? Leading meetings?
8. Prepare for a meeting? Pre-meetings?
9. Review meeting materials? Help with? (in advance?)
10. Jargon, Plan language?
11. Large type?

12. Accessible space?
13. More than one self-advocate?
14. Help with notes?
15. Take extra time in meetings?
16. Getting to know other people? Board/committee members

Other
1. What type of support helps you to speak up and participate?
2. What supports do people provide that are helpful?
3. What helps you to be more involved in? What else do you need?
4. What prevents you from being more involved?
5. Why do you want to be more involved?
6. How can the Council improve how much and in well it includes people with high and complex support needs in its activities like planning and decision-making.
7. Wrap up