

National Study Executive Summary
Michigan Developmental Disabilities Council
October 2013

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 McGaugh
Peer Trainer

David Taylor
Peer Trainer

Eric Thomas
Peer Trainer

Executive Summary

Over the past twenty years, organizations focused on addressing the needs of individuals with complex disabilities have embraced multiple strategies to increase the number of self-advocates on boards and decision-making bodies. Similar to efforts by other marginalized groups to gain influence, individuals with intellectual and developmental disabilities have had to confront tokenism and the lack of commitment to their inclusion. As such, the purpose of the Beyond Tokenism: People with Complex Needs in Leadership Roles national study was 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.

Review of the Literature

The review of the literature yielded several themes relating to the provision of supports for effecting full board inclusion including; individualized supports (and mentors), financial supports and coordination; communication; and leadership development. Most supports 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 categorized as *organizational transformational*.

Five elements essential to inclusive board practices were subsequently synthesized from the themes described as above. These elements were used to categorize the types of supports

found to be useful as well as 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.

Research Questions

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 found to be the most important to provide?
3. What outcomes were found to be the have the greatest impact on the individuals?
4. What outcomes were found to have had the greatest impact on the organizations?
5. What effective practices and other recommendations did the Best Practices Interviews share?

Method

Multiple approaches were utilized to conduct this research. The primary activities included: 1) A review of the literature, 2) a feedback workshop at the annual meeting of the National Association of Councils on Developmental Disabilities (NACDD), 3) A national overview survey conducted via the internet, 4) focus group with the board of directors of Self Advocates Becoming Empowered, 5) interviews with 35 disability organizations in 32 states and 6) focus groups with Michigan stakeholders.

Results

The National Overview Study was conducted online, with a total of 160 survey responses considered sufficiently complete for further analysis. The 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 in order to provide a clear focus on factors that contribute to their inclusion.

The survey asked organizational respondents to identify those supports they provided to individuals with disabilities to enhance inclusion. Table 2 shows the total frequency count with five supports cited most frequently as accessible meeting space, board orientation and on-going training, financial assistance, having two or more individuals serve, and assistance with travel arrangements. These findings indicate that supports that are more *intangible* such as changes in organizational structures and practices are needed in order to assure inclusion.

Table 2: Supports ranked in order of importance by 28 groups providing support to 2 or more individuals with complex and/or high needs

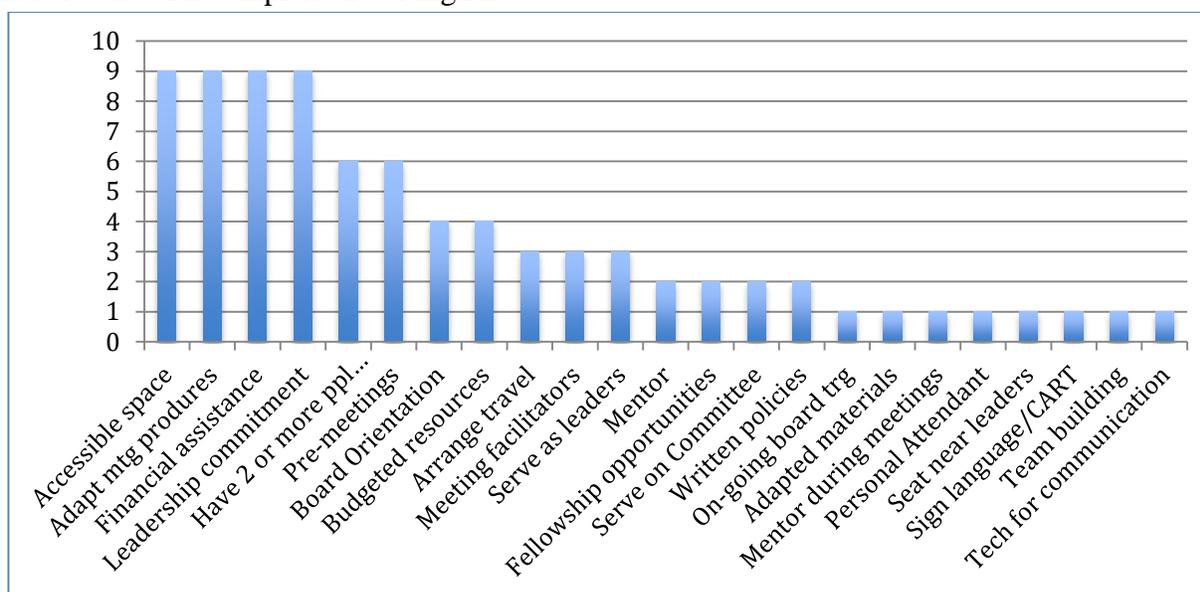
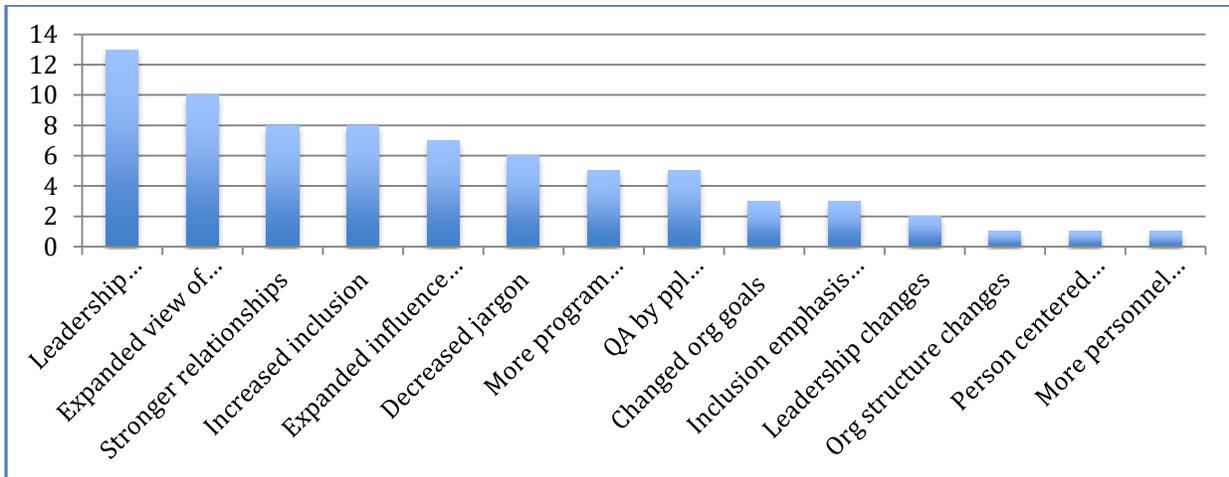


Table 3 shows the greatest impact for the organizations having two or more individuals being included in leadership reflect a focus on the individual. These are: 1) leadership opportunities, 2) expanded view of capabilities by others, 3) stronger relationships, 4) increased inclusion, and 5) expanded influence with policymakers. The issue of expanded influence with policymakers bears greater examination as affecting policy is one of the major goals of almost all of these organizations.

Table 3: Greatest impact rankings of 28 groups having 2 or more people individuals



Three organizations within this 28-group subset were identified as 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 4) or impact (see table 5) would emerge.

Table 4: Most important supports identified by three groups with 5 or more people

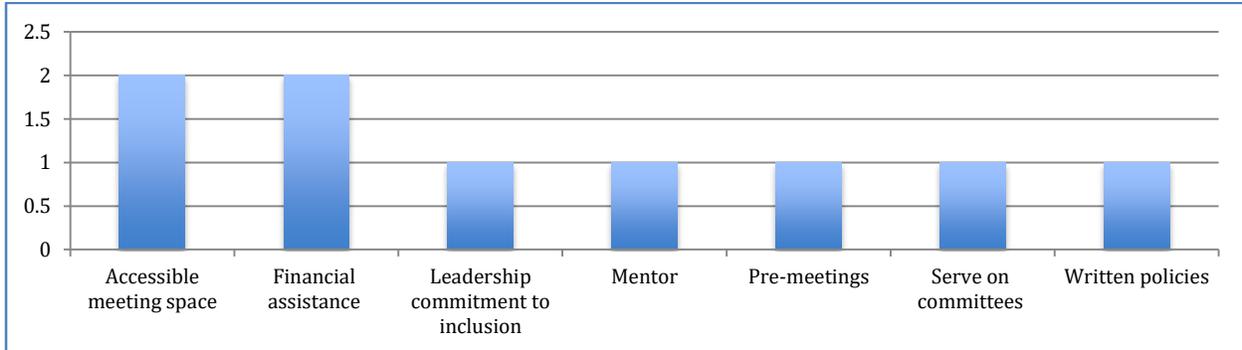
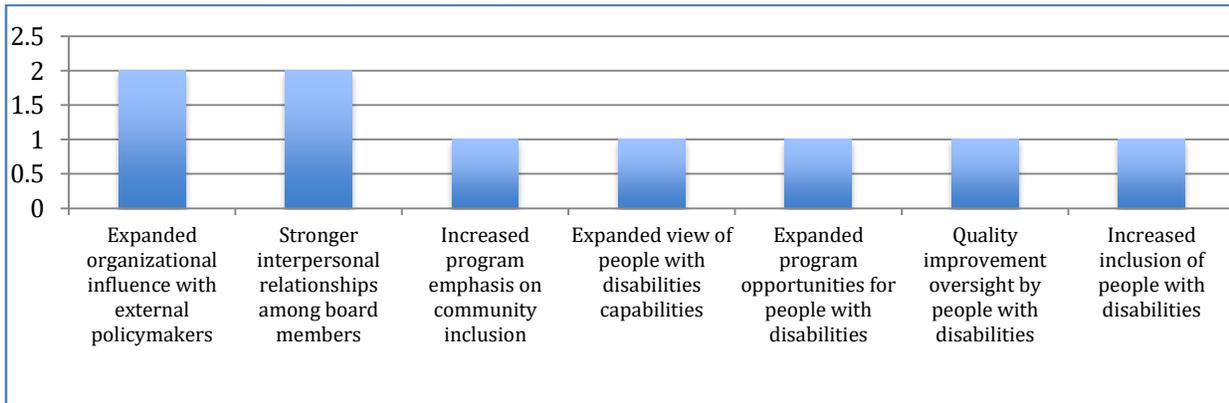


Table 5: Greatest impact by three groups with 5 or more individuals



Part II: Findings of the Best Practices In-Depth Interviews

The purpose of the Best Practices In-Depth interviews was to identify and examine the techniques and methods found to be most successful in including people with complex and/or high support needs in their governance and organizational activities. Interviews were conducted with 35 organizations; including 21 organizations identified from the National Overview Survey and 18 from the snowball recommendations (See list of organizations at www.beyondtokenism.com).

Effective Practices and Transformational Outcomes

The Best Practices interviews provided many examples 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. Some of the examples identified included:

Effective Practices for Authentic Membership

The use of mentors: A mentor/mentee relationship is established; as soon as that person is appointed, a more seasoned Board/Council member becomes their mentor. They are responsible for making sure the new member has everything they would need for the meeting. The mentor is selected by the chair or Executive Director or the person themselves. Almost all organizations provided mentors either formally or informally. Sometimes, everyone with or without a disability was provided with a mentor that often faded out over time.

Effective Practices for Deliberate Communication

The use of technology: Devices with voice capabilities are made available and someone is responsible and often paid to prep it for the meetings.

Bridging understanding: When a person's comments appear off the mark, an effort is made to connect it to the current content. The chairperson makes sure everyone gets the chance to speak and asks members for their opinion.

Meeting management: When voting, the motion is made and the meeting stopped while the mentor explains to the person what is being voted on to be sure that they fully understand the upcoming vote. Each person has access to the microphone. One Council uses two paddles (similar to table tennis) during the Council meetings for voting. One is green and one is red. One paddle has an exclamation on one side and question mark on the other so everyone has the same opportunity to speak.

Effective Practices for Full Participation

Setting: Councils/Boards meet at round tables with microphones. This helps people feel more willing to speak up. Facilitators are used to help elicit ideas from everyone and to make sure everyone gets to participate.

Materials: The packet and agenda are simplified; a picture agenda is used that includes boxes at the bottom that explains the anticipated action or outcome. A tab sheet in the meeting binder references the tab number with the item behind it.

Pre-Meetings: Pre-meetings occur before the general meeting. Mentors are encouraged to attend. The agenda is reviewed ahead of time and explanations are provided as to here's what will be discussed at the meeting, what input is needed and wanted from members. The pre-meeting provides a time for the new person to ask questions.

Financial Support and Coordination: Expenses including accessible lift vans and rental cars, drivers both to and from the meeting, airfare and airport assistance, rented mobility equipment, and greeters are covered. Arrangements are made to contract with someone in the community who also gets meeting materials and meets with the individual before meetings to review the materials so that person can more fully understand the content.

Effective Practices for Meaningful Contributions

Presentations use co-presenters who are self-advocates. Self-advocates review proposal notes for Council/Board projects and are part of the discussion team. An oral synopsis is provided in the meeting so individuals can be part of the decision-making around which proposals will be funded. Members are asked how they would like to be engaged. Media such as YouTube, Webinars, audio recordings, and conference calls are also used to share information. Staff contacts are made periodically by phone in advance of meetings.

Effective Practices for True Influence

People write their own messages to their legislator and write a legislative agenda each year focused on what is important to people with developmental disabilities. There is 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 and respond to issues raised at any time during legislative sessions.

Transformational Outcomes for Individuals

Meetings are held with underrepresented groups when Council/Board meetings are in their areas. Members are given the opportunity to share their cultural background or other experiences that relate to the work the Council/Board is doing.

Transformational Outcomes for the Organizations

The fact that the Council/Board has people with high needs serving influences other State agencies to have people serve on their committees, too. Partner organizations may have a glass ceiling for people with disabilities in terms of a leadership role. The Council/Board's example helps people think differently about what is possible in partnership with people with disabilities.

Effective Practices for Need Other Specific Supports

Effective practices for supporting people with communication needs: Many Boards/Councils had people with communication difficulties serving as officers or committee chairpersons that used communication devices. Many devices were pre-programmed with voice commands like, "Welcome everybody," "Do I have a motion," "All in favor," "All opposed." Several UCEDD's were able to receive additional support for communication devices from the State Assistive Technology Projects that were operated by their organizations.

Organizations found that while the hardest issue was waiting for the person to type their responses into their devices, over time they came to value the person's input and were more patient about waiting. People who were very difficult to understand but did not use communication devices posed a different set of challenges for the organizations. Re-voicing, repeating or rephrasing the person's speech was frequently used successfully.

Effective Practices at Supporting People with Attention Support Needs

This is an area where frequent breaks and rest periods has been found to be essential. Extra meeting space or an additional meeting room is made available. 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. 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 abuse or institutionalization). Best Practice 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. Council/Board 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

Results from the National Overview Study 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. They also indicate that some respondents have begun to experience the transformational benefits of moving beyond the provision of token representation to individuals with complex and/or high needs. 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 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 tenacity and "try another way" attitudes. Finally, financial resources and large amounts of staff time are required.

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 as curb cuts were found to be very useful by mothers with baby strollers and runners. 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 Council/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 integrated into the organization’s culture.

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.

See the full report, Easy Read version, video interviews with self-advocates, and additional materials at www.beyondtokenism.com

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.

References

Fredette, C., Bradshaw, P., & Inglis, S. (2007, February). Moving To Transformational Inclusivity and Board Diversity. In *ASAC* (Vol. 28, No. 11).

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. In particular, we would like to acknowledge first and foremost, the Michigan Developmental Disabilities Council for commissioning this study and their patience in awaiting its final outcomes. 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 in simply getting things done. Thanks to you all.

Production of this document was supported by Grant #2012090 from the Michigan Developmental Disabilities Council, awarded pursuant to P.L. 106-402, as amended, The Developmental Disabilities Assistance and Bill of Rights Act, through the Michigan Department of Community Health, the Council's designated state administering agency.

© Mark Friedman, Ph.D. and Ruthie-Marie Beckwith, Ph.D. The Michigan Department of Community Health reserves a royalty-free, non-exclusive and irrevocable license to reproduce, publish and use such materials and to authorize others to reproduce and use such materials