

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	<input type="text"/>
Primary Contact	<input type="text"/>
Position	<input type="text"/>
State	<input type="text"/>
Telephone	<input type="text"/>
E-Mail	<input type="text"/>

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	<input type="text"/>
Second Most Important	<input type="text"/>
Third Most Important	<input type="text"/>

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	<input type="text"/>
Use a communication device	<input type="text"/>
Use a personal attendant	<input type="text"/>
Have difficulty hearing what is said	<input type="text"/>
Have difficulty being understood by others	<input type="text"/>
Have difficulty reading the meeting materials	<input type="text"/>
Have difficulty seeing the meeting materials/ presentations	<input type="text"/>
Have difficulty understanding the discussion at a meeting	<input type="text"/>

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

Under 25 years old	<input type="text"/>
26-55 years old	<input type="text"/>
56 plus	<input type="text"/>

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

1 year	<input type="text"/>
2-3 years	<input type="text"/>
4-5 years	<input type="text"/>
More than 6 years	<input type="text"/>

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	<input type="text"/>
Second Biggest Impact	<input type="text"/>
Third Biggest Impact	<input type="text"/>

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	<input type="text"/>
Low support needs	<input type="text"/>
Moderate support needs	<input type="text"/>
High/complex support needs	<input type="text"/>

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	<input type="text"/>
Person to Contact	<input type="text"/>
Email or telephone	<input type="text"/>
Reason for nomination	<input type="text"/>

18. Success Organization #2

Organizational Name	<input type="text"/>
Person to Contact	<input type="text"/>
Email or telephone	<input type="text"/>
Reason for nomination	<input type="text"/>

19. Success Organization #3

Organizational Name	<input type="text"/>
Person to Contact	<input type="text"/>
Email or telephone	<input type="text"/>
Reason for nomination	<input type="text"/>

Part 8: Other Resources

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

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

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