Tokenism From the Eye of the Beholder

Gail Bottoms, Liz Weintraub, and David Taylor

Abstract

In this article, self-advocates express their perspectives on social inclusion (and exclusion) in a variety of ways. Poetry and essays penned by self-advocates provide insight into internal thoughts and feelings that may rarely be expressed outside of their personal circles. The poetry and essays focus on leadership, both supported and thwarted. As such, they provide critical information on what works and what doesn’t, and how best to assure that both the individual and the organization benefit from the opportunity of self-advocates to serve.

Key Words: self-advocacy; intellectual and developmental disabilities; leadership; board inclusion

This article in the special issue of *Inclusion* on the National Beyond Tokenism Research Study includes the perspectives of individuals with intellectual and developmental disabilities (IDD) on leadership. The National Beyond Tokenism Research Study examines the inclusion of people with disabilities serving on boards and committees. The five articles included in this special issue consist of a comprehensive review of the literature (Beckwith, Friedman, & Conroy, in this issue), the results of a national survey (Conroy, Friedman, & Beckwith, in this issue), the results of in-depth interviews with 37 organizations (Friedman, Beckwith, & Conroy, in this issue-a), the results of a focus group with leaders of Self-Advocates Becoming Empowered (Friedman, Beckwith, & Conroy, in this issue-b), and this article, the perspectives of individual self-advocates who have experience serving on boards of directors.

One of the purposes of the comprehensive review of the literature, described more fully Beckwith et al. (in press), was to identify the degree to which people with IDD were included in leadership roles on organizational boards of directors. The initial search of the literature yielded a total of 356 items. However, despite the increase in representation on boards of directors by individuals with IDD, only six items focused on how people with disabilities experienced tokenism first hand. As such, two self-advocates—one member of the project advisory board and one an employee of the study—were invited to submit essays regarding their experiences in leadership roles serving on boards of directors. One of the previously published pieces, *Inside Out* (Bottoms, 2004) was also selected for inclusion, as it is a clear commentary on the overarching theme of the study.

TOKEN

by Gail Bottoms, Past President, People First of Georgia

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.
FAQs on Tokenism
by Liz Weintraub, Advocacy Specialist, AUCD

Are People Able to Recognize Tokenism?
I know you might be saying tokenism is an idea, not something you can see or feel, but you can. I believe people need and should understand how you can see the signs of it. I believe that people won’t admit to themselves or even others that they treat people in a way that the person will feel like a “token,” because they will feel bad and upset that you will feel that way; however, if a person feels like you are treating them that way, then you, as a professional need to respect and honor that.

One of the biggest ways to show that you are treating the person as a token is to just invite them to the table without a reason, just to be nice, or just to make you or your organization look good. You or your organization need to figure out why you want the person at the table. Perhaps, take a meeting or two to figure out these questions:

- What would you gain from me from having me on the board?
- Is there a specific reason why you want me to be at “table”? If the reason is that you will “look good to others” ask yourselves, is that a reason to invite me?
- Also, don’t just think about disability issues; people with disabilities could be good at other things, and might be useful to the board in other ways. For example, a friend of mine is good at fund raising, and when I was on a board, I was one of the first persons to donate to the board.

I am too busy if you don’t have a good reason to invite me at the table, but most people I know with disabilities are not busy and feel flattered to be asked to be on a board, so people jump at the opportunity to be at the table, especially because it’s quite an honor to be asked. When I was first on a board, all I could think about was, "WOW, they want me" rather than “why are you asking me”...now I ask that question. I think people often tell me things I want to hear so I can be on their board, sometimes to make them look good. However, I think people should have an opportunity and feel “safe enough” to ask, “Why do you want me?”

Am I the “Right” Person to Be at the Table?
I remember a few years ago, I was on a board for two or three meetings, and then I told the Executive Director that I wanted to resign because I didn’t understand why I was on the board. We talked and she didn’t understand and I think she got angry, and asked, “Why are you leaving?” “Aren’t we supporting you?” “Aren’t you happy?” Well, I was and the organization is a good one, but if I don’t understand why I am at the table, then even if I have all the time in the world to be on the board, in my mind I was just wasting my time and maybe taking up a seat of another advocate that would enjoy the board more than I would. You know, I am NOT the only person with a disability in the state, and maybe that board doesn’t match my interests or skills. I know people think of me as a great advocate and I am flattered, but guess what, I am not that great. I should not be on ALL boards.

Based on what the organization needs and wants, the organization should find “the right” person to be on a board,

- With you or someone that the person feels comfortable with, look at the mission/belief statement and explain it to the person, so the person, can decide if the board is “right” for them. If the person DECIDES that the board isn’t “right” for them, then,
- The person should feel comfortable in saying, “Thank you for thinking of me, but I not really interested in the board” and It’s YOUR job to make the person feel comfortable and at ease in saying that.
- The Executive Director should say something like, “if you decide that you are not interested in the board, I will still respect you and maybe you can help us in this way instead.”
- If the person is just on a board, because it’s a “cool thing” to do, or it gives the person something to do, “tokenism” can happen, as the person could not be interested in the subject.

Are You Inviting Me to Be “at the Table” Just Because I Am a Woman, Jewish, and a Person With a Disabilities?
Can the person contribute to the conversation? If the answer is “No” then don’t invite the person to the table.
Why Do People Need a Letter Behind Their Names Just so People Can Be Recognized?

Letters like PHD or MD or BS doesn’t mean everything. Yes, it means something, but it just makes people feel “bigger” and “smarter” than others. People without letters feel bad if they don’t have them.

What Advice Can You Give About How to Avoid Being Treated or Treating Someone Else as a Token?

There are three main questions in my mind:

1. Why are you in this field?
2. Whose voice are you trying to include?
3. Whose voice is really powerful?

If you really want people’s voice heard then you need to figure out ways to include people. You need to figure out money and transportation. When the national self-advocacy organization, Self-Advocates Becoming Empowered (SABE), was just starting, they realized talking on conference calls wasn’t working and that they needed to get together. SABE was saying, “lets figure out a way to make this work.” If you really want the voices of people with disabilities heard, then you really need to make it happen. It’s really hard.

Step 1 is knowing that this is the right thing to do. You need to figure out a budget to make this happen. You may need to shift money around. You need to really listen with your heart, your mind, and your soul. You need to really want to do this. You need to really think out why you want the person to participate. What does the person really have to offer?

Making Our Voices Heard

by David Taylor, Council Member, Michigan Developmental Disabilities Council

I joined my first Board of Directors when I was 20-years old and I was invited to join the Board at Community Living Services. Initially, I went into it feeling like it would be easy to feel like a token (that I was only on the Board to fill a quota as someone with a disability and that my opinion didn’t really matter). This was only because I grew up having those feelings, based on messages I had received from others in society. However, the members of that Board of Directors quickly changed my perspective, by directly telling me that my input was important and that I do have a voice on the Board. I was told up front that if there was anything I didn’t understand to please ask for help to understand. During each meeting, there was an atmosphere that no one person was better than the other.

Since then, I have participated in 11 committees that all serve to advocate for the rights and needs of people with developmental disabilities (including Public Policy Committees, Executive Committee through the Michigan Developmental Disabilities Council, the Oakland County Regional Inclusion Community Coalition, the Stomping Out Stigma Committee through Community Mental Health, Family Voices through the ARC of Michigan, the Youth & Leadership Committee through the Impass Michigan Coalition Advocacy Group, and the Citizen Advisory Committee through Community Living Services of Oakland County). I also served as the Vice-Chair on the Board of Directors of Community Living Services, as well as a member of the Michigan Developmental Disabilities Council (which advocates for people with developmental disabilities to have opportunities and supports to achieve their life potential in the community under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000. Members on this council are appointed by Michigan’s Governor).

During this time, I slowly gained experience and became familiar with issues pertinent to each group. I carefully read through meeting agendas and meeting notes, and with time I increased my confidence to speak my opinion on each issue. I also learned what accommodations I need in place to help me be successful; for example, letting the members know up front that it helps me to be mailed their meeting agenda in advance, so I have time to review it and make sure I understand it. I also ask for the meeting materials to be sent to me in large print, with all of the acronyms spelled out. It’s also important for me to let my fellow members know up front that it helps me to be driven due to my disability. Many fellow board members, as a result, have offered to pick me up on their way there and then drive me back home. There were times when this was not an option, so I also developed my skills using public transportation. I am now an expert at using the bus system.
Through the years, I have seen fellow members who also have disabilities not speak up because they were used to feeling like their opinion didn’t matter. Seeing this saddened and motivated me to educate my peers with disabilities on steps they can take to increase their involvement and confidence in their voice. As a result, I have provided presentations on this subject, as well as on the benefits and empowerment that comes with Self-Determination. I enjoy educating people on the potential those with developmental disabilities have to live a meaningful and involved life in their community and how they can tailor their own supports to help them do this. I have done public speaking at conferences throughout the state of Michigan, as well as in Ohio, Delaware, Wisconsin, Maryland, Alabama, Georgia, and Texas. I also became a Peer Support Specialist at Community Living Services of Oakland County to provide education and support to my peers on a one-on-one level—sitting in with them during meetings where they are setting personal goals and expressing the dreams they want for their life. I provide encouragement and ideas on how they can use their supports to achieve their goals and dreams for their future.

I know I have a voice that is important to share with the others. I offer a unique perspective of how someone who is receiving services feels about the issues being discussed. I have a voice on how I would like to live my life in my community. I know people (with or without disabilities) can benefit from my voice on these committees, boards, and councils, as I can also learn from them. We all have a voice that is important to be heard...our role is FAR beyond tokenism.

References

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