People with intellectual and developmental disabilities have begun to experience increased participation and inclusion in boards and policy-making bodies. They have, however, faced challenges in gaining full acceptance similar to those experienced by other marginalized groups. To date, the experience of board participation by individuals with intellectual and developmental disabilities has typically been examined through the narrow lens of leadership development. The purpose of this study, which is part of the National Beyond Tokenism Research Study, was to seek the viewpoints of experienced leaders within the self-advocacy movement regarding the prevalence of tokenism and practices they have found effective for inclusive leadership. Implications for future research and practice are discussed.

Keywords: self-advocacy; board inclusion; intellectual and developmental disabilities; leadership; tokenism; focus group; board development

**Introduction**

Over the past decade, policy makers have begun to include people with intellectual and developmental disabilities on boards and policy-making bodies (Caldwell & Hauss, 2009). This increase in board inclusion can be attributed to several factors, including: 1) the requirement in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 that one third of the members of developmental disability councils be people with developmental disabilities, 2) growing demand by self-advocates and self-advocacy organizations for full participation, 3) increasing pressure by funding entities that the people served should be represented on the board of directors, and 4) a growing awareness by organizations of the benefit of having people with disabilities serve on their governing bodies (Administration on Intellectual and Developmental Disabilities, 2000).

Despite this shift toward inclusive board practices, research regarding the leadership experiences of people with intellectual and developmental disabilities is lacking. For example, Banks and Mona (2007) decried the lack of data regarding the experiences of women with disabilities in leadership roles. And, when women with disabilities engaged in an informal online forum created by Banks and Mona, they reported challenges similar to those experienced by other marginalized groups. These included tokenism, not being seen or recognized as leaders, and having their leadership roles defined by others.
People with intellectual and developmental disabilities have faced similar challenges in gaining full acceptance as those experienced by other marginalized groups. To date, the experience of board participation by people with intellectual and developmental disabilities has typically been examined through the lens of personal leadership development (Caldwell, 2010). This focus has emphasized the impact of board membership on the individual, under the assumption that the greatest benefit of participation will accrue to the individual rather than the organization. Further, the measure of this benefit has often been determined through conversations with the organizations' nondisabled board members, with limited input from the board members with disabilities themselves.

Bradshaw and Fredette (2011) defined inclusivity with regard to serving on boards of directors and other policy-making bodies as, "the degree to which individuals of diverse and traditionally marginalized backgrounds are engaged in the governance of their organization, acting specifically within the context of a board of directors" (p. 22). While reflecting on interviews they had conducted with board members, Bradshaw and Fredette noted that "it seemed that our informants were talking about two different types of inclusión -- which we came to call "functional inclusion" and "social inclusion" -- and about how the two can work together to create something transformational" (p. 22).

Bradshaw and Fredette held that functional inclusion occurs when an organization uses "goal-driven and purposeful strategies for the increased inclusion of members of diverse or marginalized communities" (p. 22). Functional inclusion provides individuals from marginalized communities with the opportunity to have a voice as well as influence, but can result in tokenism if its only purpose is to satisfy arbitrary benchmarks for diversity. On the other hand, Bradshaw and Fredette defined social inclusion as "the participation of members of diverse groups in the interpersonal dynamics and cultural fabric of the board, based on meaningful relational connections" (p. 22). As with functional inclusion, it is important to note that social inclusion can result in tokenism if those relationships lead to the organization failing to heed or utilize the voice or influence of individuals from marginalized communities.

Bradshaw and Fredette stressed that both types of inclusion were necessary if transformational inclusion is to take place. Transformational inclusion in this context is characterized by authentic exchanges between board members and an altered board culture in which diverse voices are valued and supported. Transformational inclusion alters both the perceptions of the individual board members of one another as well as their role in governing their organization. Transformational inclusion was more likely to occur when functional and social inclusion efforts worked together. Inclusivity in this regard fundamentally changed the way individuals from marginalized communities were engaged and expanded their capacity for influence. Likewise, inclusivity fundamentally changed the way organizations embrace, support, and benefit from expanded diversity. Transformational inclusivity appears to be the antithesis of tokenism. As such, transformational inclusivity is a reasonable goal for people with disabilities and disability-related organizations engaged in the struggle to move beyond tokenism.

In a larger context, Fredette, Bradshaw, and Inglis (2007) described practices that organizations can adopt to mitigate barriers to the functional and social inclusion experienced by marginalized groups that are in keeping with what are considered to be best practices within the disability community. In doing so, they included a particular emphasis on the value of social inclusion with regard to successful board integration:

To us, the message was clear, if you want to have diversity in the boardroom you need to find a way to speak to people from marginalized communities, support these members through the transition phases of board entry and authentically engage them in social domains that build strong relationships. (p. 62)
Notwithstanding this explication of social **inclusion**, Fredette et al. (2007) go on to state that the maximum benefits of board diversity will only be realized when functional as well as social **inclusion** result in transformational consequences to both the individual as well as the organization:

From our perspective, organizational groups, teams, and boards of directors, which functionally and socially integrate individuals from marginalized and disparaged communities, possess an opportunity to reach a state of authentic transformational inclusivity. (p. 63)

The expectation that the **inclusion** of people with intellectual and developmental disabilities will result in individual and organizational transformational benefits has yet to be articulated in the disability-related literature. Nonetheless, it was hypothesized that aspects of this phenomenon would be evident in the responses of people with intellectual and/or developmental disabilities to questions regarding their experiences on serving on boards of directors. In order to ensure **inclusion** moves beyond tokenism, research is needed to explore the full implications and benefits of the involvement of people with intellectual and developmental disabilities.

As people with individual and developmental disabilities have increasingly assumed leadership roles on boards of directors, researchers have likewise begun to involve people with intellectual and developmental disabilities directly in research through action research projects where the people with intellectual and developmental disabilities are active agents in the research rather than simply subjects to be acted upon (Beresford, 2003; Heller, Nelis, & Pederson, 1995). More recently, researchers have begun to ask people with intellectual and developmental disabilities their opinions directly through individual surveys and focus groups (Llewellyn, 2009). Focus groups, in particular, have been found to be an especially effective method of including individuals and groups that have been previously excluded, such as ethnic minorities, young people, old people, and people with disabilities (Kass, 2001). Fern (2001) identified such data gathered from focus groups as experiential information that "refers to the thoughts, feelings, and behavior shared by members of a culture, race/ethnic group, community, or familial group" (p. 174).

The current study is one part of the larger National Beyond Tokenism Research Study. Other parts of the study, described in this special issue, included a comprehensive review of the literature (Beckwith, Friedman, & Conroy, this issue); a quantitative national survey of 160 disability organizations (Conroy, Friedman, & Beckwith, this issue); and individual interviews with 37 leaders of disability organizations (Friedman, Beckwith, & Conroy, this issue). The purpose of the current study was to seek the viewpoints of experienced leaders within the national self-advocacy movement regarding the prevalence of tokenism and practices they have found effective for inclusive leadership.

**Method**

**Participants**

To obtain the perspective of self-advocates with intellectual and developmental disabilities who had experience on disability-related boards and councils, a focus group was held with the board of directors of Self-Advocates Becoming Empowered (SABE), the national self-advocacy association. All SABE board members had extensive experience and involvement with serving on boards associated with State Councils on Developmental Disabilities (DDC), State Protection and Advocacy Systems (P&As), and University Centers for Excellence in Developmental Disabilities (UCEDDs), as well as other disability organizations, including SABE. The majority of the participants had served on multiple councils, boards, committees, and task forces, with the average being 3.6 groups per participant.
Inclusion Is Transformative: Self-Advocacy Leaders’ Perspectives on Board Inclusion

SABE board members are elected by geographical region at meetings held during biannual national self-advocacy conferences. The focus group was held following a regular board meeting at a national conference, with the entire membership of the board (13 people) participating. The participants were from 10 states: Texas, Georgia, New York, New Mexico, Arkansas, Vermont, California, Minnesota, Oklahoma, and Utah. All of the individuals self-identified as people with disabilities. Eight participants were male and five were female. Ten were White, two were African American, and one was Hispanic. Two-thirds of the participants were considered to have high support needs; the remainder had moderate support needs. Six of the 13 participants had previously participated in a focus group.

Session Facilitation
The focus group was facilitated by the first author, who has extensive experience conducting research with people with intellectual and developmental disabilities, including focus groups, surveys, and directed interviews. The facilitator began the focus group by explaining the purpose of the study. 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 a consent form. The focus group lasted 2 hours.

Focus Group Questions
A set of 17 questions was developed by the research team and used to guide the focus group (see Table 1). The questions were generated with input from a review of the literature on people with complex needs in leadership roles (Beckwith et al., this issue), input from the project’s advisory board (that included people with intellectual and developmental disabilities), and experience gained from previous focus groups on this topic conducted with people with disabilities by the co-authors.

Data Collection and Analysis
Fusch and Ness (2015) described focus group data collection as an alternative means for achieving data saturation that is comparable to conducting multiple individual interviews. Data saturation is desirable in either instance to ensure that the ideas and opinions captured are comprehensive in nature while allowing for the expression of lesser known or understood viewpoints. The fact that the focus group members in this study were well known to one another was also advantageous in that each person’s ideas and experiences could more confidently be shared and expanded upon by other group members (Kitzinger, 1994). Finally, as evident in the transcript, focus group members felt comfortable backtracking to respond to questions more fully that had been asked earlier in the session. The full transcript can be viewed at http://www.beyondtokenism.com/292-2/.

The first author facilitated the focus group in a hotel meeting room. The session was audio recorded and the recording of the session was transcribed verbatim. The first author reviewed and verified the transcript for accuracy. The first and second authors independently categorized the responses as representative of the "themes" of functional, social, or transformational inclusion as described in the article introduction. As previously discussed, these aspects of board participation relate to the extent to which inclusion is evident in practice as well as outcome. Focus group data that did not appear to fall fully within one of the three categories were placed into a subcategory of "other issues." The authors then met to compare and gain consensus on the separate analyses and reach agreement on the distribution of all of the responses.

Results
Altogether, a total of 75 responses were elicited in response to the 17 focus group questions. The results of the categorization of responses by the type of inclusivity yielded an even distribution of responses across the three categories: functional = 25 responses, social = 24 responses, and
transformational = 26 responses. Table 2 provides the categorization totals and examples of the types of inclusivity apparent in the focus group members' responses.

In terms of social inclusion, focus group members viewed supports for social inclusion as highly important to effective board membership. The self-advocates expressed a need to feel comfortable and at ease when serving in leadership roles. Navigating complex social settings is difficult under the best of circumstances, and supports for doing so were viewed as critical. Putting one's best foot forward and reaching out to fellow board members was perceived as a challenge -- one that had to be met in order to be accepted in a new leadership role. As such, support for building relationships amongst board members and staff must be treated as a critical element for attaining true social inclusion.

In terms of functional inclusion, focus group members likewise viewed the provision of supports for functional inclusion (such as preparing and attending meetings) as highly important to being able to fully participate as a board member. Again, the need for supports for reviewing, synthesizing, and formulating opinions was clearly articulated. The types of supports focus group members described were varied and, in some cases, appeared idiosyncratic to the organization. However, support for fulfilling board member responsibilities must be treated as a critical element for attaining true functional inclusion.

Finally, with regard to transformational inclusion, focus group members' responses to the question about being able to influence fellow board members or the organization were brief, particularly compared to the other domains. The examples of transformational inclusion also tended to be less concrete than other dimensions and focus more on what could be done to enable this outcome rather than examples of it actually occurring.

Conclusion
The statements made by self-advocate leaders during the focus group yielded rich insights into the leadership opportunities experienced by leaders within the self-advocacy movement. As noted earlier, collectively, the focus group members had tremendous depth of experience with serving in leadership roles. The focus group members also knew one another and, as such, were less likely to feel inhibited in responding to the questions. Finally, although the number of participants was small and the timeframe for the focus group was limited to 2 hours, the analyses of the focus group results suggested the importance of functional, social, and transformational inclusion, although the self-advocates described more concrete examples of functional and social inclusion and fewer opportunities for transformational inclusion.

Overall, as with the findings from interviews with leaders of 37 disability organizations (Friedman, Beckwith, & Conroy, this issue), the degree to which transformational inclusion is occurring remains limited. Instead, components of social and functional inclusivity appear more likely to be present, which has the potential to lead to transformational inclusion (Bradshaw & Fredette, 2011), although more work is needed to enable this outcome. In this regard, organizations need to focus on strategies for increasing the comfort levels of self-advocates and expanding the opportunities to exert influence in their role as board members. Failing to do so limits opportunities for the authentic exchange of ideas and opinions, and suggests that organizations have a long way to go to achieve transformational inclusion. Other articles in this special issue provide recommendations for strategies that can be adopted to enhance the focus on transformational inclusion, building on social and functional inclusion (Conroy et al., this issue; Friedman, Beckwith, Conroy, this issue).
One thing is clear -- self-advocates have consistently stressed the desire to serve in leadership roles and the corresponding need for successful strategies that organizations can use to ensure people from marginalized backgrounds experience inclusivity that is intentional and sustained. The findings of this study provide insight into the strategies self-advocates themselves identify as useful, particularly those related to social and functional inclusion. Further work is needed to make transformational leadership a reality for boards including people with intellectual and developmental disabilities.

Table 1 Focus Group Guiding Questions

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>1. Why do you serve on boards or committees?</td>
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<td>2. How do you get involved in these groups; how do you have some say on things?</td>
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<td>3. How many people have been officers of the boards and how did you get to be an officer?</td>
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<td>4. What are some of the things the organizations have done, or should do to help you?</td>
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<td>5. What are some of the things the organization helps you do?</td>
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<td>6. How important is it to get to know each other?</td>
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<td>7. 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?</td>
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<td>8. Some people have talked about being afraid to participate. How many people were afraid when they went to their first meeting? [Everyone raises a hand]. What happens when you are afraid and how do you overcome it?</td>
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<td>9. What else can organizations do to help you serve on their boards and committees?</td>
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<td>10. How is it different from someone taking notes and the minutes that are read?</td>
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<td>11. Why is it important to have more than one self-advocate in the group?</td>
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<td>12. Some people talk about having the material 2 weeks in advance -- why is that so important?</td>
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<td>13. Who helps you be prepared for a meeting?</td>
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<td>14. How many self-advocates should serve on a board?</td>
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<td>15. Let me come back to what we discussed a little earlier -- influence -- a lot of you feel that's why you're on these committees. How do you make a difference?</td>
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<td>16. What can the organization do to better help?</td>
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<td>17. How much influence do you feel you have being on these boards and committees?</td>
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Table 2 Examples of Focus Group Participant Responses by Type of Inclusivity

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<th>Inclusivity Focus</th>
<th>Examples</th>
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### Functional (25 responses): The organization has goals and strategies for including marginalized individuals who see participation as an opportunity to have a voice and influence.

<table>
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<tr>
<th>* &quot;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.&quot;</th>
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<tr>
<td>* &quot;I think that'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 all right. Then, you're starting trouble.&quot;</td>
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<td>* &quot;Standing up for what you believe in -- you may be rewarded, but it's a dirty job.&quot;</td>
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<td>* &quot;I also think that if you're going to have a person with a disability to be on your board or committee 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.&quot;</td>
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<td>* &quot;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.&quot;</td>
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<td>* &quot;I have proper support -- like when I come here, our Council helped me 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.&quot;</td>
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| * "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."

Social (24 responses):
Interpersonal dynamics and cultural fabric of the board are based on meaningful relational connections.

* "Sometimes it's just who you know!"

* "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."

* "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 your name out there and you can talk about the training you've had, presentations given, and get to know them that way."

* "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."

* "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."

Transformational (26 responses): Board culture is altered through authentic exchanges, thus changing both the perceptions of the individual board members of one another as well as their role in governing their organization.

* "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 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.”

* "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 into a meeting more learned because you know what's going on. That 10 minutes of support really does help."

* "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."

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