This article summarizes the results of a literature review conducted as part of the National Beyond Tokenism Research Study. People with intellectual and developmental disabilities have begun to be included on boards and policymaking organizations, but the roles given to them have often been tokens -- symbolic gestures that result in presence without genuine inclusion. To better understand the advances that have been made and the barriers that people with developmental disabilities still encounter, a comprehensive review of the literature on how people with complex and high support needs are engaged in leadership development, public policy advocacy, and community activities was conducted. The analysis identified key gaps in information about the degree of influence in leadership and organizational decision making exercised by people with complex needs. These results reflected the need for additional research to better understand how far people with developmental disabilities have moved "beyond tokenism" and into authentic leadership roles, which informed other activities conducted as part of the National Beyond Tokenism Research Study.

Keywords: tokenism; intellectual and developmental disabilities; leadership roles; National Beyond; Tokenism Research Study; self-advocacy

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. (Obermayer, 1999)

Over the past 20 years, disability organizations, self-advocacy organizations, developmental disabilities councils, state developmental disabilities agencies, and others have embraced multiple strategies to increase the number of self-advocates serving 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 people with disabilities at the table.

This Special Issue includes five articles that emerged from the National Beyond Tokenism Research Study, which was conducted to better understand how people with intellectual and developmental disabilities and complex needs were being included and experienced being included in leadership roles. This article presents results of a review of the literature that informed activities conducted as part of the study, and subsequent articles discuss (a) National Survey of disability organizations on the inclusion of people with intellectual and developmental disabilities and complex needs in leadership roles (Conroy, Friedman, & Beckwith, this issue), (b) follow-up interviews with organizations who participated in the survey (Friedman, Beckwith, & Conroy, this issue-a), (c) focus groups with self-advocates who served in leadership proles was conducted to describe involvement of people (Friedman, Beck-with,
Beyond Tokenism: People With Complex Needs in Leadership Roles: A Review of...: EBSCOhost

Generally, a growing body of information has emerged that describes the progress in leadership development activities. Unfortunately, information regarding the provision of supports to people with intellectual and developmental disabilities and complex needs has yet to be adequately developed and disseminated. This gap in information on how best to provide supports within the context of promoting inclusive leadership frequently leaves individuals who desire leadership opportunities with experiences of tokenism instead. Tokenism in this instance can be viewed as only symbolic gestures at inclusion, rather than genuine efforts of engagement and integration.

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 the women's movements were noted in a number of early histories about the evolution of the disability rights movement (Driedger, 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 with its predecessors, the disability rights movement's early objective of claiming a positive collective identity challenged two 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" (Charlton, 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 people with disabilities given admittance have encountered the same degrees of tokenism as other marginalized groups. The present review of relevant literature therefore began with past civil rights struggles, including the literature on the women's movement, yielding the most salient insights into the challenges of gaining respected places "at the table" on companies and boards.

Subsequent to the early formation of collective action by people with sensory and physical disabilities, people with intellectual and developmental disabilities began to demonstrate that people perceived by society as the most dependent, vulnerable, and in need of total external direction by others, could attain and exercise self-determination (Hayden & Nelis, 2002). As Weh-meyer (1998) stated,

When the emphasis is not placed on self-determination as an independent performance, absolute control, and success, and instead on (a) providing individuals with adequate opportunities to be the causal agent in their lives, make choices and learn self-determination skills; (b) enabling them to maximally participate in their lives and communities; and (c) ensuring that supports and accommodations are in place, people with significant disabilities (emphasis added by authors) can be self-determined. (p. 10)

The purpose of this review, therefore, was to identify approaches and resources that have been found useful in supporting people with intellectual and developmental disabilities in leadership roles with a particular emphasis on people with complex needs. In order to do so from a civil rights perspective, contemporaneous definitions of "complex needs" are provided and concepts such as "tokenism" and "participation in civil society" are given a contextual basis within the parameters of leadership in an organizational dimension. This framework was then employed to examine publications that specifically focused on approaches intended to promote organizational inclusion and diversity with regard to people with disabilities and more specifically, those with multiple and complex support needs.

Methods
This review presents the results of an extensive search of the literature including journals, web pages, and training manuals and documents. The process of conducting the review was carried out in two distinct phases: (a) identifying, compiling, categorizing and determining the relevancy of items for inclusion in the review, and (b) synthesizing and reporting the results of the analysis; and evaluating the process for accuracy and reliability. The second author carried out the process for Phase One. The first and second authors completed Phase Two. Finally, the evaluation of the results for accuracy and reliability was carried out during each phase in consultation with the third author.
Phase One: Identifying, Categorizing, and Determining the Relevancy of Items for Inclusion

The process of identifying relevant items for inclusion in the review began with compiling and reviewing the existing resources held by the authors in their private collection of materials related to prior self-advocacy activities. The authors then contacted via email four authors of the most recent works in the authors' possession (Blisard, 2003; Caldwell, Hauss, & Stark, 2008; Moseley, 2006; Patterson, 2012) to solicit their input for expanding the list of possible items to include. Informants in leadership positions in the national self-advocacy organization Self Advocates Becoming Empowered (SABE) were then approached as well as the executive directors of the technical assistance centers for Developmental Disability Councils (DDCs) and University Centers on Excellence in Developmental Disabilities (UCEDDs) and The Arc of the United States to assist with identifying relevant material.

Searches of scholarly databases, internet sites and publication source databases were conducted using keywords such as: complex needs and disability, board inclusion, tokenism, women and boards, disabilities and leadership development, public policy advocacy, community activities, and leadership training. Databases searched included ERIC, EBSCOhost, HathiTrust, Professional Development Collection, PsychARTICLES, PsycINFO, SAGE Journals, SocINDEX, and Women and Social Movements.

Items for possible inclusion in the review were then entered into an online database (Mendeley) to aid in tagging, categorizing, and identifying those items felt to be relevant for inclusion in the review. Items that received 100% agreement were noted. The authors then discussed the items that were not in agreement to reach a consensus on whether to include the item and the most appropriate category for its analysis. Finally, an analysis was conducted of the completed sort for gaps and deficits from citizen participation and organizational development perspectives, two key elements of leadership expression (Wandersman & Florin, 2000).

Phase Two: Synthesizing and Reporting the Results of the Analysis

Phase Two focused on developing themes representing the key findings aligned with the purpose and objectives of the study. To generate a list of themes, the authors conducted separate reviews of the items within each category by identifying repetitions, examining similarities and differences, and using a cutting and sorting procedure for nontextual data (Ryan & Bernard, 2003). These themes were then compared and those that received 100 percent agreement were noted. The authors then discussed the remaining items to establish a consensus or establish that no apparent theme could be determined.

Subsequent to the identification of themes, rubrics were created in the form of tables to evaluate individual items with regard to (a) the presence of relevant themes; (b) the purpose of the material or publication; (c) the target audience(s) of the material, including people with and without complex needs; (d) the ways in which people with and without complex needs were included; (e) the supports provided to enhance the influence of people with and without complex needs; and, (f) the presence of descriptions or discussions of efforts by people with disabilities, women, or other minorities to identify, define, and address tokenism.

Results

Phase One Results

The activities carried out during Phase One of the search of the literature resulted in a total of 356 items identified as possibly relevant for inclusion in the review. These 356 articles were then entered into an online bibliographic database (Mendeley). Each item within the Mendeley database was tagged with descriptors relevant to this review. The subsequent sort of the database by tags resulted in 14 categories with a total of 186 items. Tags with the highest returns included training manuals, citizen participation, women, research with people with complex needs, and intellectual disability.

Items that focused primarily on service users giving input outside of leadership roles, participant driven research, and those that could not be readily obtained by research or request (such as out-of-print training materials) were excluded. Remaining items were then analyzed for gaps and deficits from citizen participation and organizational development perspectives. Those items felt to be in keeping with the purpose and objectives of the study were then categorized by primary area of focus.
Ultimately, 60 items were categorized into the four primary focus areas of the review for analysis. These items include four prior national overview studies of overlapping categories of disability focused organizations, 15 qualitative 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.

**Phase Two Results**

The analysis and synthesis of the search results were carried out using the rubrics designed for this purpose. The rubrics were constructed in the form of tables to aid in the overall synthesis and reporting of the search results.

Definitions of multiple and complex support needs. The use of the rubric to evaluate and categorize the items yielded varying results with regard to the definition of multiple and complex support needs. Nonetheless, it was determined that despite the small number of items, the similarities between each definition warranted analysis and further discussion.

Four distinct definitions of multiple and high, complex needs pertinent to this review were identified. The earliest of the four definitions was developed for the purpose of recruiting people to participate in focus groups who used assistive technology as their sole means of communication (Clare & Cox, 2003). Their definition targeted people with cognitive impairments whose communication difficulties made it difficult for their views and preferences to be understood.

More recently, the Michigan Developmental Disabilities Council (MDDC; 2012) defined complex or high-support needs as those that were present in the most vulnerable members of the community and were due to either the breadth or depth of their needs. In particular, the MDDC definition included people who were least likely to get the supports they needed to experience ordinary life; who spent most of their time in segregated settings; who would experience discrimination, social exclusion, or isolation without supports; and who were usually unable to exercise choice unless specific opportunities and appropriate assistance were made available.

Last, as with the definition created by Clare and Cox (2003), Patterson (2012) described people with complex needs as those who did not use spoken, signed, or typed words to communicate. This definition also included people with significant behavior challenges that served as barriers to being included. Finally, it noted that people with complex needs found participation in traditional forms of information gathering, such as focus groups, meetings, and surveys, to be particularly challenging.

All three definitions share a common component -- a need for being deliberate and specific when reaching out to an extremely marginalized segment of the developmental disability population. This also includes collaboratively developing individualized means for inclusion of this population in the larger community as a whole and in leadership roles within organizations.

The use of the term "complex needs" in Australia and Great Britain has generated similar overlapping definitions. For example, while conducting a review of the literature on multiple and complex needs, Rosengard, Laing, Ridley, and Hunter (2007) found that "often there was an assumption that complex and/or multiple needs are a matter of fact and can be understood without definition, and a strong thread through the literature was that the terms are used interchangeably" (p. 6). Nonetheless, in going forward they elaborated on one definition (strikingly similar to the Michigan DDC definition) as the basis for their review.

Having arrived at a similar conclusion, Rankin and Regan (2004) usefully identify the essence of complex needs as implying both: breadth -- multiple needs (more than one) that are interrelated or interconnected; and depth of need -- profound, severe, serious, or intense needs. Rather than use the term "complex needs" to describe an individual's characteristics, Rankin and Regan (2004) define it in terms of an active framework for response (p. 8).

Shifting the focus from individual characteristics to the creation of a framework describing the presence of complex needs was particularly relevant to understanding the support needs of people with complex needs in leadership roles. Inasmuch as the purpose of this review was to identify useful approaches and resources, the authors included these factors for further analysis of the literature adopting the definition of an "individual with complex needs" as
someone whose developmental disability required multiple or intense supports to be included in leadership roles and/or their community.

Parallels from the women's movement. Two seminal articles (Arnstein, 1969; Kantor, 1977) served as a starting point for examining tokenism as it relates to both citizen participation and the experience of women seeking entrance to the corporate boardroom. Arnstein's "ladder of citizen participation" concept is still useful as a tool with which to examine the effect of tokenism on marginalized groups, including those with developmental disabilities. The eight-rung ladder begins with nonparticipation as the result of any number of factors, including apathy or oppression and concludes with degrees of power such as citizen control over decision making seats, or full managerial power. As such, degrees of participation can be used to describe both the experience of the individual as well as the extent to which an organization has embraced diversity.

In 1977, Kantor began to analyze other factors that influenced the successful integration of corporate boards by women, including how altering the overall ratio of women to men transformed the experience of the individual along with the level of influence they had on organizational decision making. Kantor found that when serving alone, women struggled to cast off the male stereotypes of women's lack of leadership capabilities. However, when the ratio increased as much as by fifteen percent, the culture of the board became more balanced and women found they had greater influence on both the agenda and the outcomes being debated.

Currently, a ratio of 30% is considered to be the minimum level of inclusion needed to create a shift in the balance of power among the board members (Erkut, Kramer, & Konrad, 2008; Kristie, 2011; Torchia, Calabro, & Huse, 2011). The transformational impact on women and organizations that consistently have three or more women serving on their boards has been shown to be both statistically (Torchia et al., 2011) and anecdotally significant (Kramer, Konrad, Erkut, & Hooper, 2007).

As there were more women, the first woman became more active. They were all more active as the number of women increased. It's a group dynamic. When you bring on one of any demographic group, they're trying to figure out how they fit. With more, that's not an issue. (Konrad et al., 2008, p. 146)

Finally, a Catalyst survey of Fortune 500 companies found that between 2005 and 2009, those with three or more women directors outperformed those with fewer by achieving an average of 43% return on equity over time (Carter & Wagner, 2011).

The 30% ratio for representation is in keeping with the number of members of Developmental Disability Councils required to be people with developmental disabilities (Developmental Disabilities Act, 2000). However, such a mandate does not exist for other disability related organizations and investigations into the impact of board participation by people with developmental disabilities on the corporate bottom line has yet to be formulated. Even so, in a blog post, "Return on Disability," Donovan (2009) put forth the need for a board of directors to include directors who have a disability in order to reflect the diversity among its shareholders and to position itself to expand market share (Donovan, 2009). Consequently, exploring whether differences in influence and outcomes exist between U.S. Administration on Intellectual and Developmental Disabilities (AIDD) funded programs will be an important focus of subsequent investigations along with emerging interest in attaining corporate leadership roles.

Moving to transformational inclusivity and diversity. Shifting paradigms in how and where services and supports are made available have created greater demands on the capacity of communities to fully embrace and plan for the inclusion of people with disabilities. In addition to recalibrating systems to accommodate the logistics of carrying out what has become an ever-widening decentralization of service delivery, person centeredness, self-determination and inclusion are now viewed as key components of progressive service system designs (Kendrick, Petty, Bezanson, & Jones, 2006).

The extent to which these components will ultimately manifest in opportunities for leadership roles commonly assigned to citizens in civil society has been examined from the perspective of the members of community organizations that have accepted participation (Amado & Boice, 2012) along with qualitative research as to how the limitations created by complex needs can be impediments to political empowerment (Redley & Weinburg, 2007).
In 2002, Reinders cautioned that the current reliance on regulations to hold service systems accountable for inclusion is insufficient.

To be part of a social world is to be included in the bonds of civic friendship. 'Civic friendship' in this connection means a type of relationship between citizens that goes beyond the legal sphere and includes the social sphere. People who enjoy civic friendship live and work together in the pursuit of shared ideals. To be included in these kinds of relationships is what makes human life worth living for everybody, not just people with ID. (p. 3)

Inclusion and the attainment of leadership roles in governance and advisory capacities, is being increasingly embraced by people with disabilities as a means to exert greater control over the institutional structures that impact their lives. Within the context of non-profit and voluntary boards, Brown (2002) defined inclusivity to be the degree to which people of diverse and traditionally marginalized backgrounds are engaged in the governance of their organization.

As people with developmental disabilities are identified for potential leadership, a consideration of the factors that are most likely to encourage both initial engagement and long-term participation is necessary. Ife (1997) identified five key conditions that are important to promoting community participation; (a) people will participate if they feel the issue or activity is important, (b) people must feel that their action will make a difference, (c) different forms of participation must be acknowledged and valued, (d) people must be enabled to participate, and supported in their participation, and (e) structures and processes must not be alienating. Boyce et al. (2001) expanded on these conditions as they pertain to organizations run by non-dominant groups such as disability groups to include 1) representatives must develop the personal capacity to resist power, 2) groups must occupy organizational positions in which power can be exercised, and 3) groups must be situated within norms and networks where the exercise of power can achieve its purpose. Without these conditions, one can presume that tokenism can and will play a role in preventing individual and organizational capacities to reduce the advantage of privilege and number to gain both respect and influence.

In a larger context, Fredette, Bradshaw, and Inglis (2007) described practices that organizations can adopt to mitigate the 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) goes 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)

Even though the expectation that the inclusion of people with developmental disabilities will result in individual and organizational transformational benefits has yet to be articulated in the disability related literature, it was anticipated that aspects of this phenomenon would be evident in the literature gathered for this review. In order to assure inclusion moves beyond tokenism, the full implications and benefits of their involvement must be fully understood beyond the disability community as well.

Developmental disability (DD) leadership involvement. Four central themes relating to DD Leadership Involvement emerged as the result of the Phase One categorical sort. These included articles and materials regarding the perspectives of people with IDD; literature specific to leadership roles; research studies of the issue; and training manuals and materials.
Perspectives of people with IDD. Only six items about having experienced tokenism first hand as people with developmental disabilities were located despite an expansive search for such work. Carlson noted the lack of such perspectives in his 2010 article, stating: "not surprisingly, the voices of persons with IDs themselves are virtually absent from philosophical discourse about them."

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), poet Gail Bottoms (President of People First of Georgia, Inc. from 1997 to 2000) succinctly describes her experience with tokenism in her 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.

In an earlier work published by the Oregon Council on Developmental Disabilities in 1999, Liz Obermayer (Weintraub), a national leader in the self-advocacy movement, showed 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," Obermayer went on to identify three ways to stop tokenism: (a) involve people with disabilities on boards of directors, (b) involve more than one self-advocate, and (c) 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 (Robinson, 2006; Shoultz, 2003). Nelis (President of Self-Advocates Becoming Empowered, and Research associate at the Rehabilitation Research and Training Center and Aging with Developmental Disabilities located at the University of Illinois at Chicago) describes her efforts to help make the process of research and its findings accessible to people with intellectual and developmental disabilities, "If it's going to be disseminated to people with developmental disabilities, we talk about it with people with developmental disabilities first" (Shoultz, 2003, p. 6).

Robinson (2006), former Chairperson of the Michigan Developmental Disabilities Council, provided extensive examples of how to make presentations that everyone can understand at a Leadership Retreat.

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 (2011, Peer Trainer for the Beyond Tokenism project funded by the Pennsylvania Developmental Disabilities Council, 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 people with developmental disabilities have given their commitment to broader representation in civil society. The experiences of
other people 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 to enhance within the professional discourse the richness of first-hand authenticity and passion.

Literature specific to leadership roles. The first effort to identify organizations that included people with disabilities in leadership roles also included people 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 used to promote participation. This study also identified barriers to inclusion and collaboration with self-advocates. 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 people with disabilities as directly involved.

Blisard (2003) compiled the responses to a written survey obtained from 26 states along with seven state self-advocacy organizations. The report described how different organizations pay for expenses; accommodations needed and desired by self-advocates; the use of mentors and support people; the provision of premeetings to review agendas and prepare for active participation; transportation assistance; and the need to develop a culture of inclusion.

Moseley (2006) included information from compilations of resources developed and gathered by state developmental disability departments in the development of the NASDDDS Handbook on Inclusive Meetings and Presentations. Finally, Patterson (2012) conducted interviews with UCEDD staff and representatives, along with other organizations and individual experts, that focused less on the barriers to leadership and more on the type of supports believed to be effective.

As shown in Tables 1 and 2, all four publications identified different as well as overlapping strategies for overcoming barriers to leadership roles. This pattern was present throughout all four categories of items included in this review with similar recommendations for further research provided in the qualitative and quantitative research.

Research studies of the issue. The literature search identified 15 distinct research studies that directly involved people with developmental disabilities, four of which focused on people with complex needs in accordance with the previously identified definitions. Within this body of work, the prevailing approach for investigations in the area of supporting people with complex needs and developmental disabilities in leadership roles was qualitative. However, it is important to note that reports relating to the substantive thesis work of one author, Frawley (2006), accounted for no less than five articles, thus constituting close to 20% of this body of work.

Following the identification of research articles, an analysis was conducted to identify and evaluate three key components: (a) the characteristics of the people engaged in the study, (b) the types of barriers and strategies used to overcome them, and (c) any recommendations that might have been made based on the researcher's findings.

As shown in Table 3, this analysis identified four studies that included a focus on people with complex needs and, more specifically, people with communication difficulties as defined by being nonverbal or the use of an augmentative or alternative form of communication.

Radermacher, Sonn, Keys, and Duckett (2010) provided a useful categorization of barriers -- intrapersonal (such as lack of skills or areas of competence), interpersonal (such as individual and team dynamics), and organizational (such as lack of resources and rigidity). Frawley and Bigby (2011) classified such barriers within the context of supports that would address them as being either tangible (such as meeting practices and lack of training) or intangible (such as being overlooked and low expectations). Finally, conclusions and recommendations put forth by the authors fall within one or both of these constructs (such as provision of training for the individual and adapted materials).

While conducting the initial review of articles and materials, common themes regarding participation and inclusion with regard to leadership roles emerged as particularly relevant. For example, as part of their research on participation on advisory boards, Caldwell and colleagues (2008) identified five major themes: (a) Individualized
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In this review, 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 described with regard to individual transformation as the result of having a leadership role. Finally, factors relating to the theme of Value and Outcomes were found to be in keeping with the need to attend organizational transformational outcomes put forth by Fredette et al. (2007).

To provide for a systematic analysis of the research as well as the training manuals and handbooks, five elements essential to inclusive board practices were subsequently synthesized from the quantitative and qualitative research. The five elements, described in Table 4, 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.

The ongoing assessment of what types of supports and forms of mentorship are needed and how best to provide them to maximize successful inclusion can then be viewed as a critical component of assuring individual and organizational success across all five elements. The responsibility for making this assessment fell across a wide spectrum of roles including the people with intellectual and developmental disabilities, professional staff within the organization including management and support personnel, specifically appointed facilitators for board and committee meetings, and mentors who were also in leadership roles on the various boards and advisory committees along with those who were external to the organization.

An analysis of the supports identified or referenced by the 15 studies based on a categorization by essential elements and transformational outcomes is also provided in Table 4. 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 within these studies followed by those relating to full participation and meaningful contributions. Less attention was given to the effect of support provision on individual or organizational transformation. However, when considering the challenges people 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.

Training manuals and handbooks. Initial training regarding the participation of people with developmental disabilities on boards of directors, advisory committees and other decision making entities focused primarily on enhancing the leadership and self-advocacy skills of the individual (i.e., Hoffman, 1992; Pederson & Chaiken, 1992). Little or no attention was given to the role of the other non-disabled board members or the respective organizations as a whole. Since that time, more expansive manuals and handbooks have been developed that include training for the individual, other board members, mentors, and organizational personnel, as well.

This review focused on materials that were previously received by the authors from the source group (i.e., People First of California, 2012) and by contacting the primary source for newer publications. Taken as a whole, the characteristics and content are highly similar in nature. The types of approaches, supports, and processes recommended for successful inclusion in organizational functions have varied little across time. Beginning with an initial focus on leadership development (Hoffman, 1992), people with disabilities continue to be the primary focus of training efforts. Differences among the resources fall primarily in the utilization of current terminology and the degree to which the targeted audience is actively engaged in the learning process.

When compared to generic board and leadership development resources, they appear to have “face validity” in as much as components of commonly accepted board practices such as board recruitment, orientation, and the duties...
of board members are included (Gottlieb, 2008, 2009a, 2009b). It is important to note that only one training approach, Patterson (2012), included Internet-based multimedia instruction -- an increasingly important method by which adults acquire information in our society.

An analysis of the 11 training programs and manuals suggested that only two, Facilitating Consumer Leadership in Service Systems: A Toolkit for (Holt, Jones, & Petty, 2007) and Beyond Tokenism: Partnering With People With Diverse Abilities on Consumer Advisory Boards (Stevens & Ibanez, 2004) include content that addresses all seven elements of board participation. These two training programs also address the effective use of mentors, a support described as instrumental in facilitating board participation, particularly for people with complex needs. Ironically, these two manuals target participation on policymaking entities and not on boards that have governing and oversight responsibilities.

Limitation of the Review
This literature review applied qualitative methods to existing documents and publications. It attempted to identify common threads and concepts that may inform future researchers. As with all qualitative research, the process of pattern recognition, whether in the phenomena of behavior, writing, speech, or video materials, is influenced by the observers’ experience, knowledge, and attitudes. The patterns we have perceived (categories) of barriers, strategies, elements of transformation, and essential elements of board inclusion are thus qualitative interpretations. Though we used independent analysis by the primary researchers, followed by comparison and reconciliation of the categorization schemes, it is possible that other scientists would create categories in somewhat different ways. What is offered in this article is not a definitive set of findings, but rather modest findings of common values and issues mentioned in the literature. We encourage our colleagues to modify and enhance our "first draft" categorization schemes. The topic is important enough, and challenging enough, to justify serious efforts to gain deep understanding. Another limitation of this work is that there is so little literature directly relevant to our subject -- so little that we had to reach into other civil rights movements to seek common patterns and issues. This was particularly true for the literatures on race and gender, which are fairly well developed, whereas the literature on board involvement of people with disabilities, particularly significant ones related to cognitive processing and communication, is in its infancy. Again, we must caution the reader that what we have analyzed is just the beginning of a developing understanding of how agencies concerned with disabilities, and all other organizations, can include members with disabilities with dignity and full participation.

Discussion
Since 1992, growing attention has been paid to ascertaining the most effective ways to support people with intellectual and developmental disabilities in leadership roles. The emergence of leadership roles within the disability rights movement led to opportunities for people with developmental disabilities to assert their right to influence decisions that would affect their daily lives. The self-advocacy movement created significant leadership roles and skills among people 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 people with intellectual and developmental disabilities began to take their place at the table.

This review sought to identify the challenges and barriers that have had to be addressed to facilitate greater and broader of leadership opportunities. Important guidance and clues were found in the literature of preceding civil rights movements, particularly that of women. Similar to the efforts of other marginalized groups to gain influence, people within intellectual and developmental disabilities have had to confront tokenism and the lack of commitment to their inclusion.

The foremost finding from this review is that people with complex needs can successfully engage in leadership roles when adequate attention is paid to their individual support needs. However, 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. For example, the body of work reviewed paid little attention to the ultimate outcomes of inclusive leadership practices on the individual or organization. This lack of attention to outcomes as the measure of true influence that occurs as the result of access to leadership roles can be viewed as tokenism in that it fails to hold the organizations accountable for instituting and maintaining change.
Primary themes relating to aspects of board and organizational development did emerge. These themes served as the basis for the creation of a model that includes five essential elements felt to be necessary for the successful inclusion of people with intellectual and developmental disabilities in leadership roles that will result in both individual and organizational transformational outcomes. These elements include authentic membership, deliberate communication, full participation, meaningful contributions, and true influence.

Fredette et al. (2007) suggest that to attain the maximum benefits of board diversity, functional as well as social inclusion must be taken into consideration for transformational consequences to both the individual as well as the organization. As stated earlier, the expectation that the inclusion of people with developmental disabilities will result in individual and organizational transformational benefits has yet to be articulated in the disability related literature. However, the lessons learned from the gains women have attained through expanded leadership opportunities are worthy examples for the disability community to consider.

Research on the leadership roles afforded women has generated outcomes that have great potential for enhancing the inclusion and influence of people with complex needs in leadership roles. The findings that a ratio of 30% is considered to be the minimum level of inclusion needed to create a shift in the balance of power among the board members (Erkut et al., 2008; Kristle, 2011; Torchia et al., 2011) suggests that one or even two people with disabilities serving on a board of directors will not be sufficient to assure their voices will be integrated into the overall dialogue of the organization.

Research and training materials to date have focused primarily on identifying supports and adaptations that enhance the capacity of people with intellectual and developmental disabilities to more fully participate. Many of these resources were created by or in partnership with self-advocacy organizations and have a significant number of concrete and useful supports suggestions. However, training for fellow board or committee members needed to ensure their overall commitment to diversity and the continuation of supports provision has yet to be viewed as an integral element of board and organizational development.

Finally, from among the varying definitions used to describe people with multiple and complex support needs, the definition found to be most useful with regard to providing supports to people with complex needs in leadership roles appears to be the one put forth by Rankin and Regan (2004) as described by Rosengard et al. (2007). This definition is particularly useful for discerning and creating a framework of supports that address both the breadth of interrelated or interconnected needs, as well as the depth of needs, in terms of their severity or intensity.

As greater numbers of people with complex disabilities are included in leadership roles, care must be taken to record their perspectives on what they have found to be most effective approaches and supports. Items authored by or featuring people with disabilities included in this review of literature made it clear that their experiences with tokenism are highly relevant to efforts at assuring inclusion in leadership roles as well as community.

Table 1 Barriers to Leadership Roles Identified in Prior Overviews and Surveys

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1 Difficulty recruiting culturally diverse staff and</td>
<td>[Y]</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>participants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Language and communication barriers</td>
<td>[Y]</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>3 Difficulty providing supports and a lack of support</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
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<tr>
<td>providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Lack of leadership opportunities</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>5 Difficulty recruiting individuals for leadership roles</td>
<td>[Y]</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>6 Limited knowledge of leadership training</td>
<td>[Y]</td>
<td>--</td>
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</tr>
</tbody>
</table>
### Table 2 Strategies for Overcoming Barriers Prior Overviews and Surveys

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Expanding outreach to include increased numbers of people with disabilities and cultural diversity</td>
<td>[Y]</td>
<td>[Y]</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>2 Expanded training opportunities</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>3 Increase effectiveness of advisory councils</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>4 Hire more staff with disabilities</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>5 Involve individuals with disabilities more directly in training, planning and policy development</td>
<td>[Y]</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>6 Improve accessibility</td>
<td>[Y]</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
</tr>
<tr>
<td>7 Mentors</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>8 Funding/stipends for transportation and other expenses</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
<td>[Y]</td>
</tr>
<tr>
<td>9 Engage members in active roles</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>10 Pre-meetings</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>11 Materials in advance</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>12 Materials alternative forms</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>13 Leadership commitment</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
<td>--</td>
</tr>
<tr>
<td>14 Opportunities for fellowship and increased interpersonal knowledge</td>
<td>--</td>
<td>[Y]</td>
<td>--</td>
<td>[Y]</td>
</tr>
<tr>
<td>15 Clear, direct communication</td>
<td>--</td>
<td>--</td>
<td>[Y]</td>
<td>[Y]</td>
</tr>
<tr>
<td>16 Tools for alternative approaches to communication; technology and proxies</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>[Y]</td>
</tr>
<tr>
<td>17 Accessible online meeting space</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>[Y]</td>
</tr>
</tbody>
</table>
### Table 3 Summary of Barriers and Recommendations by Research Articles

<table>
<thead>
<tr>
<th>Barriers and Recommendations</th>
<th>Multiple/Complex</th>
<th>Barriers and Challenges</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbott &amp; McConkey (2006)</td>
<td>N</td>
<td>From perspective of person: lack of knowledge and skills, role of support staff and managers, location, lack of community amenities/attitudes</td>
<td>Advocacy</td>
</tr>
<tr>
<td>Amado &amp; Boice (2012)</td>
<td>N</td>
<td>Transportation, communication with provider, members not being accepted, social skills of person, person not having email, lack of flexibility, mentor being asked to &quot;monitor&quot; person</td>
<td>Make sure person could attend and has form of transportation, help person navigate relationship (i.e., cut down on phone calls), sensitivity</td>
</tr>
<tr>
<td>Caldwell, Hauss, &amp; Stark (2008)</td>
<td>N</td>
<td>Difficulty recruiting committee members from diverse ethnic and racial backgrounds, access to services, financial barriers, transportation, communication, lack of clear information, and small pool of potential candidates for involvement</td>
<td>Accessibility of meetings, physically accessible locations, other environmental accommodations (i.e., scent free, communication related such as sign language interpreters, closed captioning devices, amplified hearing devices, and meeting materials in alternative format). *Felt accommodations for individuals with intellectual disability (ID) not well understood, such as materials in advance, support person before, during, and after meeting, plain language, Financial supports, coordination and communication, leadership development</td>
</tr>
<tr>
<td>Frawley (2006)</td>
<td>N</td>
<td>People were underrepresented and underparticipating; will take more than a support work and note taker</td>
<td>Need for accommodations; adjustments; education and training, facilitation for participating in &quot;formal talk&quot;; rethink how forums are structured and conducted</td>
</tr>
<tr>
<td>Frawley (2008)</td>
<td>N</td>
<td>Tangible supports: feeling ill prepared; way governing bodies did business, i.e., long</td>
<td>Identified different approaches to support including individual (external 1:1), shared (internal</td>
</tr>
<tr>
<td>References</td>
<td>Include (Y/N)</td>
<td>Reference Point: Person is Important; How They See Their Role Will Influence Their Participation (i.e., Advocacy, Status, and/or Raising Awareness)</td>
<td>Assure Common Ground; Matching Person's Interest and How They See Their Role with Needs of the Organization.</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Frawley &amp; Bigby (2009)</td>
<td>N</td>
<td>Reference point of person is important; how they see their role will influence their participation (i.e., Advocacy, Status, and/or Raising Awareness)</td>
<td>Assure common ground; matching person's interest and how they see their role with needs of the organization.</td>
</tr>
<tr>
<td>Helmsley, Balandin, &amp; Togher (2008)</td>
<td>Y</td>
<td>Communication barriers, time involved in using augmentative and alternative communication to express ideas and opinions, voices not being included in broader dialogues.</td>
<td>Focus group is a reliable approach to gaining input.</td>
</tr>
<tr>
<td>Llewellyn (2009)</td>
<td>Y</td>
<td>Orientation of support person (i.e., philosophy of care may have profound effect on the support provided and can facilitate or inhibit open exchange of information)</td>
<td>People who provide support need training on how to do so without influencing participant's input.</td>
</tr>
<tr>
<td>Mitchell (2009)</td>
<td>Y</td>
<td>Limited means for communication both non-verbal and speech and exclusion, additional time needed, lack of resources, and knowledge about supports</td>
<td>Used shortened, simplified versions of instruments, symbols-based information, Talking Mats e (choose symbols that match their ideas or thoughts)</td>
</tr>
<tr>
<td>Radermacher, Sonn, Keys, &amp; Duckett (2010)</td>
<td>Y</td>
<td>Intrapersonal: skills and competence Interpersonal: Team dynamics mixed agendas, individual needs superseding those of organization, Organizational: Resources decision making processes historical practices</td>
<td>Recommendations based on Ife's; and they added: &quot;People must trust and respect others and feel safe to speak their mind in public without fear of retribution&quot; and team dynamics</td>
</tr>
</tbody>
</table>
| Reinders (2002)                                 | N             | The issue at stake here has to do with how we understand the concept of inclusion. Rights create space for action and opportunities for individuals to take on new institutional roles. But new paradigm has values that derive moral force from regulation of focused on public morality, respect of which is | Two types of morality which ideally coexist in liberal society: First type is public affairs and our lives as citizens, subject to public authority that protects individual freedom and equality of opportunity; second type deals with our lives as human beings and human fulfillment. "We cannot seriously maintain that we
necessary as a precondition but that it is not the good life itself. "Success of inclusion for people with ID may depend on the strength of their social networks much more than their individual rights."

<table>
<thead>
<tr>
<th>Redley &amp; Weinberg (2007)</th>
<th>N</th>
<th>Speech inaudible, not speaking at all, spoke inappropriately (wrong time, topic)</th>
<th>Focus greater attention on means to empower individuals with supports to navigate complex interactional impediments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Riddington, Mansell, &amp; Beadle-Brown (2008)</td>
<td>N</td>
<td>Co-chairs mainly welcomed people and introduced agenda items, few spontaneous questions/comments, primary means of providing in put through presentations, lack of resources for participation, boards had little real local authority</td>
<td>Establish clear lines of accountability for and responsibility for assuring meaningful participation</td>
</tr>
<tr>
<td>Spear &amp; Kabuga (2002)</td>
<td>N</td>
<td>Demonstration project used community development approach to develop board connections posed challenges for recruitment of individuals with disabilities, mentors, and board members to train, resources for transportation, coordination, approach of systems change increased demands on sponsoring organizations</td>
<td>Identify internal resources available to support potential board members. Match the consumer to a specific board upfront to improve preparation, encourage broader community participation by persons with developmental disabilities such as volunteerism to build greater community connections</td>
</tr>
</tbody>
</table>

**Table 4 Analysis of Research Using Five Essential Elements and Transformational Outcomes**

<table>
<thead>
<tr>
<th>Elements of Board Inclusion</th>
<th>Descriptor</th>
<th>Studies That Referenced Element or Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authentic Membership</td>
<td>Indicators of equal status to, and recognition of, the presence of the individual to be as important as any other member of the board of directors</td>
<td>Frawley (2008); Radermacher et al. (2010); Redley &amp; Weinberg (2007); Riddington et al. (2008)</td>
</tr>
<tr>
<td>Deliberate Communication</td>
<td>Indicators that the ways the individual receives, processes, and expresses information and ideas are accommodated with regard to content and processes.</td>
<td>Caldwell et al. (2008); Helmsley et al. (2008); Llewellyn (2009); Mitchell (2009); Radermacher et al. (2010); Redley &amp; Weinberg (2007); Riddington et al. (2008)</td>
</tr>
<tr>
<td>Full Participation</td>
<td>Indicators that the interests and preferences of the individual are used</td>
<td>Frawley (2008); Llewellyn (2009); Radermacher et al. (2010); Redley &amp; Weinberg (2007)</td>
</tr>
</tbody>
</table>
to establish ongoing involvement with board functions and activities.

Meaningful Contributions

Indicators that the gifts, talents, and experience of the individual are used in ways that expand their responsibilities as board members.

Weinberg (2007); Riddington et al. (2008); Spear & Kabuga (2002)

True Influence

Indicators that the ideas or concerns expressed by the individual are acknowledged and acted on.

Frawley (2008); Radermacher et al. (2010); Redley & Weinberg (2007); Riddington et al. (2008)

Transformational Outcome: Individual

Authentic acceptance of the individual in which the person's functional and social contributions are integrated into the board's activities.

Amado & Boice (2012); Caldwell et al. (2008); Redley & Weinberg (2007)

Transformational Outcome: Organizational

Authentic social acceptance of diverse board members, as well as functional inclusion in issues, processes, and decisions made by the board.

Amado & Boice (2012); Caldwell et al. (2008); Redley & Weinberg (2007)

References


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By Ruthie-Marie Beckwith, City University of New York, N.Y., 1509 Van Cleve Lane, Murfreesboro, TN 37129, empfanatic@aol.com; Mark G. Friedman, City University of New York and James W. Conroy, Center for Outcome Analysis

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