2019

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Tracey Hamlet
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Abstract

Affirming social relationships and belonging in community are known to have positive mental and physical health benefits. Unfortunately, citizens with intellectual and developmental disabilities (IDD) have significant barriers to being included in their community. Over the past half century, various policies and legislation have been enacted in the United States in an effort to address the changing societal belief that individuals with IDD should be engaged as part of their community rather than separated, receiving institutional care. These policies influence funding and program designs for nonprofit organizations supporting people with IDD. This article offers (a) a literature review of research regarding effectiveness in measurement of community inclusion for people with intellectual and developmental disabilities, (b) an analysis of several U.S. policies intended to improve community inclusion, (c) considerations of the impact of Michigan’s implementation of the most current federal legislation, and (d) associated recommendations for nonprofit organizations to create public value by affecting progress in community inclusion.

Key words: community inclusion, effectiveness, public policy

Introduction

Feeling that you are part of a community may be one of the most powerful indicators of being human as “we are biologically, cognitively, physically, and spiritually wired to love, to be loved, and to belong” (Brown B., 2017). People with intellectual and developmental disabilities (IDD) are at much greater risk of social isolation than the non-disabled population. Increased isolation occurs for various reasons, including the long history of institutionalization, limited access to employment and leisure, and expectations from persons with IDD about themselves. Disabled persons may also have communication barriers, interpersonal skill deficits, and mobility challenges imposing barriers to forming connections. To widen the
gap further, non-disabled community members often perceive individuals with IDD as different from themselves, putting up barriers to relationships.

In 2006, recognizing this global challenge, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) whose purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights as fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity” (World Health Organization, 2007). This wide acknowledgement of the need for people with disabilities to be respected community members is long overdue. For more than 50 years, there have been various policy and legislative efforts to affect improvement in the lives of people with IDD so they may be included in their communities. Despite decades of efforts and increased opportunities to live in community, over 40% of people with IDD continue to express they either need more friends or have no friends (Petroutsou, Hassiotis & Afia, 2017).

Since U.S. policies and legislative actions have focused on increasing inclusion for people with IDD, it is important to ask the question of whether public policy has actually led to improvement. Additionally, how might nonprofit organizations increase their effectiveness at supporting inclusion for people with intellectual and developmental disabilities? A review of research revealed a variety of measures and definitions of the word inclusion, including several terms intended to describe the same concept. In the literature, as in policy language, community inclusion and community integration are the most frequent terms used interchangeably.

Community ‘inclusion’ was chosen over ‘integration’ for use in this article because the former more effectively captures individualized aspects of belonging. The World Health Organization describes inclusion for people with disabilities as “equal opportunities to live stimulating and fulfilling lives in the community with their families, alongside their peers” (World Health Organization, 2007). This is the definition adopted within this article in order to assess effectiveness of policy interventions. The meaning manages to recognize there are no two people likely to define their vision of a ‘fulfilling and stimulating life’ in the same way.

The definition also addresses barriers imposed by the community, described as “equal opportunity” (World Health Organization, 2007). These barriers can take the form of societal attitude, environmental, financial, or social capital. The description is broad enough to include peers as well as others who do not have an intellectual and developmental disability. This is
crucial because “relationships with other people who have intellectual and developmental disabilities is a great source of belonging” (Lysauht, Petner, Arrey, Howell-Moneta, & Cobigo, 2017).

This paper proceeds by presenting justification for why inclusion is critical for both individuals with IDD and for the community, including examination of the themes in the literature about the effectiveness of community inclusion for individuals with IDD. One component of this literature review includes an assessment of the effectiveness of past public policy aimed to improve inclusion. Finally, after considering Michigan’s implementation of the most current federal policy, recommendations are made to nonprofit organizations supporting persons with IDD on ways to continue progress towards the goal of community inclusion.

The Case for Inclusion

Health and Safety

According to Lloyd, Tse and Deane (2006), lack of inclusion in society can lead to more physical and mental health problems. Social isolation has been studied since the late 1970’s and has been repeatedly shown to predict frequency of death and illness in the general population and in people with disabilities (Berkman, 2000). Additionally, for people with IDD who have a long history of institutionalization, community inclusion is a path to personal safety. Despite years of living in heavily regulated settings, reports indicate that “an adult with a developmental disability is at 4-10 times greater risk of being physically assaulted than adults without a developmental disability” (Wisconsin Disability Rights Association, 2011). It seems like segregation has not kept people safe. To reduce abuse and assaults, efforts to support full inclusion must address the need for people to make choices and engage in reciprocal relationships.

Given the population’s history of isolation and societal attitudes, many people with IDD have missed opportunities to develop, utilize, and assert their own choices. They have experienced limited control over smaller and larger life decisions, often expected to follow someone else’s directions. The system of care for people with IDD has emphasized teaching how to comply with rules and institutional norms. There has been insufficient effort to teach decision-making or critical thinking. This “culture of compliance surrounds people with disabilities and those who support them (and) is so
ingrained that we fail to grasp the detrimental and sometimes dangerous effects this culture has wrought on people, giving license to anyone in authority to misuse, exploit or abuse those who are expected to comply—people with disabilities” (Wisconsin Disability Rights Association, 2011). A vision for change is a community where people with disabilities are free to express themselves, act on choices, and enjoy full citizenship and belonging.

Community Benefits

While inclusion is critical to a person’s wellness and safety, it is also essential for a healthy society to embrace each citizen as an equal member. In his book *Becoming Human*, Jean Vanier (1998) addressed the emotional pain of loneliness and called for community response when he wrote, “the discovery of our common humanity liberates us from our self-centered compulsion”. Vanier’s call for action is to open ourselves to people we may view as different or weaker from ourselves so that we can achieve true personal and societal freedom (Vanier, 1998). He makes the case that healthy human relationships are interconnected as well as interdependent.

When the community fails to engage with people who have intellectual and developmental disabilities, “it makes itself an impotent place, a place that doesn’t help each of us live through disappointment, and failure, and sickness, and sorrow, and death — experiences that cannot be isolated because they come to everyone” (O’Connell, 1988). Human experiences are truly more similar than different; therefore, including everyone in community enriches the human experience. In her book, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America*, Allison Carey (2009) argues:

Citizenship cannot occur on an individual level…The need for an interpersonal and community infrastructure that supports the practices of rights and citizenship is important not only for individuals who are considered to have intellectual disabilities or disability more broadly. This is not a matter of “special rights”. The exercise of rights is inherently relational; we all exercise rights within the context of our communities and we all must be supported in doing so (page 228).

Carey also emphasizes the interdependence of humanity. A fully developed society supports inclusion of all members; this is part of exercising citizenship. Key point. While it is evident that people with IDD
have multiple health benefits from being included in their community, they are more than capable of adding value to their community as well. These words should appeal to nonprofit organizations to provide the necessary leadership towards the transformative goal of inclusion.

**Literature Review**

Research on community inclusion efforts revealed a number of challenges to making headway. Much of the literature identified a lack of shared terminology as a key barrier to measuring inclusion, including the absence of a comprehensive, uniform definition. This issue was a common theme addressed in the research and recognized as an obstacle to measuring effectiveness (Simplican, Kosciulek, & Leahy, 2015). Most researchers recognize that inclusion is a complex concept too often narrowly defined in policy or practice. There were different methods and sample groups used to address the topic of community inclusion. Sample groups included persons served, families, or provider organizations. Methods included surveys, standardized measurement tools, and review of existing data. The various approaches to researching the topic of community inclusion were guided by the researchers’ definition.

Some articles addressed societal perceptions and the impact the community has on feelings of belonging for people with IDD. One researcher primarily focused on barriers in environments in order to expand beyond the physical aspects of ADA requirements (Sherman & Sherman, 2013)). This research mainly addressed lack of financial means, poor community attitudes and inadequate access to transportation. While community attitudes and accessibility are important barriers challenging inclusion, the majority of articles focused on strengths of relationship or shared interests in activities.

**The Many Components of Inclusion**

Some literature attempted to address the many components of inclusion (Shogren et. al, 2009), while others proposed new models for measuring the various aspects (Lysaught & Cobigo, 2017; Simplican, et. al 2015). One researcher evaluated 5 different inclusion scales (Baumgartner & Burns, 2013). In their research on defining inclusion for people with IDD, Simplican et. al (2015) proposed an ecological model that addressed 2 major
domains of inclusion: relationships and participation in activities. Hall’s (2009) research identified 6 themes as crucial to inclusion, such as community acceptance, reciprocal and significant relationships, being involved in activities, living conditions in community, being employed, and receiving both formal and informal supports. This perspective addressed community behavior as well as more subjective outcomes related to how people with IDD experience community.

There were common themes in the literature related to the aspects that should be measured as part of inclusion. While Lysaught & Cobigo (2017) focused on the benefit of employment pertaining to feelings of being included, other literature identified employment as an avenue to be included (Hewitt et. al 2013; Hall, 2009). Table 1 (below) provides an overview of the literature reviewed including researcher, year, population sampled, how inclusion was measured, and effectiveness.
### Table 1.
**Research on Community Inclusion**

<table>
<thead>
<tr>
<th>Researcher(s)</th>
<th>Year</th>
<th>Sample</th>
<th>Measure</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hewitt, et. al</td>
<td>2013</td>
<td>Families of IDD</td>
<td>National Core Indicators</td>
<td>limited</td>
</tr>
<tr>
<td>Baumgartner &amp; Burns</td>
<td>2013</td>
<td>General Pop.</td>
<td>5 Scale measure</td>
<td>not broadly</td>
</tr>
<tr>
<td>Bigby et. al</td>
<td>2017</td>
<td>IDD pop.</td>
<td>Interaction</td>
<td>limited</td>
</tr>
<tr>
<td>Hall</td>
<td>2009</td>
<td>IDD pop.</td>
<td>Qualitative Analysis</td>
<td>partial</td>
</tr>
<tr>
<td>Hall</td>
<td>2009</td>
<td></td>
<td>Surveys</td>
<td>partial</td>
</tr>
<tr>
<td>Martin &amp; Cobigo</td>
<td>2011</td>
<td>IDD pop.</td>
<td>RAI (5 domains)</td>
<td>partial</td>
</tr>
<tr>
<td>Petroutsou et. al</td>
<td>2017</td>
<td>IDD pop.</td>
<td>Loneliness scale</td>
<td>limited</td>
</tr>
<tr>
<td>Simplican et. al</td>
<td>2015</td>
<td>IDD pop.</td>
<td>Life domains intersect</td>
<td>limited</td>
</tr>
<tr>
<td>Sherman &amp; Sherman</td>
<td>2013</td>
<td>Community</td>
<td>Community attitudes</td>
<td>unclear</td>
</tr>
<tr>
<td>Jones &amp; Gallus</td>
<td>2016</td>
<td>Families of IDD</td>
<td>Survey</td>
<td>partial</td>
</tr>
<tr>
<td>Williamson et. al</td>
<td>2016</td>
<td>Family caregivers</td>
<td>Survey</td>
<td>limited</td>
</tr>
<tr>
<td>Shogren et. al</td>
<td>2009</td>
<td>IDD pop.</td>
<td>Practice/policy interact</td>
<td>limited</td>
</tr>
<tr>
<td>Lysaght et. al</td>
<td>2017</td>
<td>Cargivers/IDD ind.</td>
<td>Impact of employ.</td>
<td>partial</td>
</tr>
<tr>
<td>Mirenda</td>
<td>2014</td>
<td>IDD pop/Comm. aug.</td>
<td>Survey</td>
<td>limited</td>
</tr>
<tr>
<td>Friedman &amp; Rizzolo</td>
<td>2017</td>
<td>IDD pop.</td>
<td>POM</td>
<td>partial</td>
</tr>
<tr>
<td>Siska et. al.</td>
<td>2018</td>
<td>Provider org.</td>
<td>Review Data</td>
<td>partial</td>
</tr>
</tbody>
</table>

**Employment as a Path to Inclusion**

One path to increased inclusion described in the literature is employment. Many people identified that the “lack of access to work is a barrier to social inclusion” (Lysaght, Petner-Arrey, Howell-Moneta, & Cobigo, 2017, p. 922). Individuals with IDD continue to be underemployed, with over 57% of people with IDD in Michigan indicating that they would
Belonging in Community

like a paid job but do not have one (National Core Indicators, 2017). In the literature, employment was described as an avenue to inclusion because work is often a source of meeting people and gaining relationships. However, when a person does not earn income this often equates to poverty, a factor which adds more challenges to inclusion.

Due to underemployment, people with IDD often do not have financial resources to enjoy sharing a meal out with a friend or transportation to a community activity. While most of the literature identified the need for people to form reciprocal relationships in order to be included in community, none of the research addressed challenges with reciprocity related to scarcity of financial resources. Lack of funds is a legitimate obstacle to sharing a community experience if there is persistent resource dependency on others.

Relationships Matter

Various standardized assessments have been used to measure the emotional and personal aspects of inclusion. The impact of having relationships— not those based on altruism, but reciprocal and affectionate connections— was identified in much of the literature as a path toward inclusion (Baumgartner & Burns, 2013; Bigby, Anderson & Cameron, 2017; Petroutsou, Hassiotis, &Asia, 2017; Simplican et. al, 2015; Hall, 2009). Relationships are a critical aspect of inclusion and “function to provide multiple kinds of social support…including emotional, instrumental, and informational” (Simplican et. al, 2015). All people, especially those most vulnerable, need all three levels of support experienced through relationship with others.

Connected to lack of relationships, one article focused on a negative outcome of community exclusion using loneliness scales as a measure (Petroutsou, Hassiotis, &Asia, 2017). Loneliness is an emotional pain that describes the difference between a person’s expectations and their experiences in relationships. It is for this reason a loneliness scale measurement could capture a highly relevant aspect of how excluded a person may feel. Physical health research has uncovered a powerful connection between the emotional pain of loneliness and physical illness. The loneliness scale measurement may gain increased attention as the support system for people with IDD progresses to an integrated care coordination model.
Another researcher addressed the impact of friendships on quality of life using the Personal Outcomes Measure (POM) (Friedman & Rizzolo, 2018). The POM was developed by the Council on Quality and Leadership (2017) and is an interview tool designed to measure 21 indicators with a focus on 5 factors. These factors include personal safety, community, relationships, choice, and personal goals. There are several life dimensions addressed in the POM in common with other measurements of inclusion including community engagement and relationships. A prevailing theme in the literature review is when people have access to healthy and supportive relationships they are more likely to be included.

Policy Impact on Living in Community

While not all the articles reviewed provided a policy connection, those that did indicated it was limited in impact or provided too narrow a scope in measuring results of inclusion. The deinstitutionalization movement, OBRA, and the Olmstead Act identified the ‘place’ the person lives as a success indicator for inclusion. Deinstitutionalization represented the closing of institutions for people with IDD. While the national movement began in 1968, Michigan closed the door on its last institution for people with IDD in 2010.

Since the deinstitutionalization movement began, over 150 U.S. institutions have closed, including all Michigan facilities. This course of action “has produced dramatic changes in the places people with IDD live in the US” (Mirenada, 2014). The success of the movement was acknowledged in surveys with families who were initially concerned about the impact of deinstitutionalization on their loved one, and later realizing the benefits their family member enjoyed following a move to a community setting (Jones & Gallus, 2016).

Similar to deinstitutionalization, the implementation of OBRA produced significant results when people exited nursing homes to live in community. In one study, people who entered other supported community living arrangements “received more vocational programming, participated in more hours of direct clinical service, and had more family contact than they had in the nursing homes” (Speart, Conroy & Rice, 1998). There is a positive link between both employment and family contact with living in community. While the place you live is too narrow a concept to capture the complexity of what it means to be included, there is evidence that when
people live in smaller communities the likelihood they will engage more frequently with others improves.

Families and Inclusion

Some researchers focused on the families of people with IDD as their sample population (Hewitt et. al, 2013, Williamson et. al, 2016, Jones & Gallus, 2016). This concentration recognized that over 70% of people with IDD, including adults, are cared for within their families. Federal and state policies have directed funding and service delivery towards this majority group of people with IDD. This policy aim presumes that services provided in families are lower cost. However, less public spending does not equate to individuals being included in community. This aspect was not adequately addressed in the literature reviewed.

Another concern with this federal funding bias is the risk of a blind spot with the changing population demographics. It should be noted “more than 25% of family care providers are over the age of 60 years and another 38% are between 41-59 years” (Braddock, Hemp, & Rizzolo, 2008). Since many people with IDD also have a mental health diagnosis or complex medical conditions, the preference to fund family programs may result in service gaps, as aging parents of people with IDD are no longer able to provide care. The research did not adequately address the complexity of care for people with IDD, particularly as they and their caregivers’ age. Public policy focuses on funding the 70% of people with IDD cared for in family homes yet fails to address individual needs when families are no longer able. Nonprofit organizations will continue to be relevant in the provision of necessary services.

Policies Directed Toward Inclusion

Nearly all seven policies selected for assessment were chosen because of a stated goal to improve inclusion or integration for people with IDD. However, Self-Directed Service 1915(j) was included because some of the reviewed literature indicated this policy as a path to support inclusion efforts. Table 2 (below) provides an overview of the assessment of the United States policy or legislation aimed to shape efforts to improve community inclusion.
Some widely known policies such as the Adults with Disabilities Act (ADA) were not included in this review because this legislation intended influence on the broader disability community, not specific to individuals with IDD.

**Policy Goals and Measurements**

<table>
<thead>
<tr>
<th>Major Policy Initiatives</th>
<th>Date</th>
<th>Stated Goal</th>
<th>Measured in what way</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deinstitutionalization</td>
<td>1968</td>
<td>community integration</td>
<td>place (where you live)</td>
<td>Yes</td>
</tr>
<tr>
<td>Person Centered Planning</td>
<td>1979</td>
<td>community integration</td>
<td>choice/participation</td>
<td>Mixed results</td>
</tr>
<tr>
<td>OBRA Legislation</td>
<td>1987</td>
<td>community integration</td>
<td>place (where you live)</td>
<td>Yes</td>
</tr>
<tr>
<td>Self Directed Service</td>
<td>1998</td>
<td>control and choice</td>
<td>direct control of funding</td>
<td>Partially</td>
</tr>
<tr>
<td>1915(i)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Olmstead Act</td>
<td>1999</td>
<td>community integration</td>
<td>place (where you live)</td>
<td>Yes</td>
</tr>
<tr>
<td>Managed Long Term Care</td>
<td>2012</td>
<td>community inclusion/lower cost</td>
<td>place/no segregated options</td>
<td>Mixed results</td>
</tr>
<tr>
<td>HCBS</td>
<td>2014</td>
<td>community inclusion</td>
<td>place/no segregated options</td>
<td>TBD</td>
</tr>
</tbody>
</table>

Different words are employed in policy goals to describe inclusion, just as the challenge highlighted within the literature review. This adds to the confusion in measurement progress. In addition, the policy on Self-Directed Service 1915(i) focused aim on increasing choice and control for persons with IDD, and not specific to integration or inclusion. However, this policy was included in the review because it was referenced in literature as having potential to influence community inclusion (Petroutsou, Hassiotis, & Asia, 2017, Friedman & Rizzolo, 2018). Increasing ability to exercise personal
control and choice are linked to improving community inclusion. It is interesting to note the policy intention was to increase control and choice through a specific means - direct control of funding. However, it is unclear whether direct control of funding leads to social inclusion, or whether there is, another aspect related to this policy that influences inclusion.

Another policy that emphasizes individual control is the Person-Centered Planning (PCP) initiative, which underscores increased personal choice and control for people with IDD. This policy was introduced during Michigan’s most active era of deinstitutionalization, the late 1970’s through 1980’s. This process of shifting to individual control and choice was accommodating to the societal transformation recognizing people with IDD should be engaged participants in their community. PCP was frequently mentioned in the literature as having the capacity to influence and improve community inclusion efforts as well as an impetus within the current HCBS policy (Shogren et. al, 2009; Bigby, Anderson, & Cameron, 2017; Hall, 2009; Jones & Gallus, 2016).

It is worth noting there are legitimate challenges with the effectiveness of implementing person-centered plans. The practice assumes people with IDD will safely express their dreams and there is an avenue to align funding and support. These two assumptions are challenged by a long history of expectations for people with IDD to be compliant, and the limitations of both human and financial resources. To add to the PCP implementation challenges, the Managed Long Term Care Act appeared on the landscape in 2012; this legislation is based on a medical model.

The intersection of the PCP initiative with the Managed Long Term Care Act often represents a funding conflict. This is because the medical model does not give preference to choice and control but rather service coordination and cost containment. The two policies are incongruent with each other, yet are simultaneously active in Michigan. In fact, one identified limit of managed care is the potential to restrict choice, which is a primary emphasis of the PCP initiative (President’s Comittee for People with Intellectual Disabilities, 2012).

Managed Long Term Care. Families interviewed about their views of the impact of Managed Care approach to services shared concerns when ‘place’ was used to measure progress if this eliminated segregated options (Williamson, Perkins, Fitzgerald, Agrawal, & Massey, 2016). Segregated options are those services that only include people with disabilities. Several families expressed program options that include people with disabilities
support their family member’s well-being in terms of relationships. They conveyed reservations that an integrated community would be as supportive to their family member. This feedback is an indicator that societal attitudes continue to be perceived as a barrier towards the acceptance of people with IDD as equal community members.

**Deinstitutionalization, OBRA and Olmstead.** The impact of people living in their communities after deinstitutionalization, Olmstead and OBRA legislation, has been historic in terms of the numbers. It is straightforward to conclude these policies are effective by using the quantitative measure of the number of people who moved from institutions to homes in the community. It was noted in the literature that living in community homes affords more access to activities in the community. Often people gain exposure that they did not have living in institutions. However, it is also clear that where a person lives has not always resulted in belonging in community for persons with intellectual and developmental disabilities.

Policies that aim to improve choice and control, in addition to location, are inherently more challenging to measure in terms of inclusion. In order to address the gap, Michigan and federal legislation are adept at adding policy but less effective at eliminating or revising. This practice may impede progress because policy initiatives do not always reinforce each other. Therefore, it is important to reflect on past legislative challenges while considering how current or future policy impacts progress toward inclusion.

**Current Policy – Home and Community Services (HCBS)**

The Home and Community-Based Services (HCBS) implemented by the Center for Medicare and Medicaid Services (CMS) is intended to help citizens with disabilities or other health issues to live at home or in the community (Stiffler, 2018). While the policy is federal, Michigan’s multi-year implementation is a transition plan to bring current Medicaid funded programs for people with IDD into compliance with the CMS rule. While there are many aspects to how CMS defines inclusion, essentially it means a person with IDD will receive services in non-segregated locations affording the level of choice and control available to non-disabled members of community.

There are clear benefits to policy focused on increasing choice and control as part of gaining ground toward inclusion. As stated in the case for inclusion section of this paper, as people with IDD become stronger
participants in their own lives, they lower their risk of victimization. It is notable progress that the final HCBS rule shifted “away from defining home and community based settings by ‘what they are not’ and toward defining them by the nature and quality of participants’ experiences (CMS, 2014). The HCBS policy boldly attempts to address the limitations of previous policies by expanding the definition of inclusion beyond ‘place’. Getting it done, however, is no simple task.

The Transition Plan in Brief

Michigan’s plan includes an electronic survey process of people with IDD who receive their services in specified settings with the purpose of identifying whether the service is community based, as defined by CMS. The multi-year process reflects the administrative challenge of adding another audit process to an already heavily monitored system of care for people with IDD. The survey is a series of questions addressed to the person served, their guardian (where applicable), and the service provider. More than one viewpoint for each person is solicited through a set of similar questions, and all perspectives are expected to align. If there is lack of agreement between the stakeholders on the responses, the person is considered out of compliance with the federal rule (HCBS) and the provider is responsible for implementing a corrective action plan. The risk to both the person receiving services and the service provider is a loss of funding at the location determined to be out of compliance.

The 70% of people with IDD who receive services by a family member are deemed in compliance with the CMS rule and therefore no survey process is implemented. This is true even if family homes implement more restrictions to community access than service organizations. Some examples of restrictions include locked up food, an inaccessible laundry area, or failure to support the individual access to community. Michigan’s focus for the HCBS compliance plan is on the (roughly) 30% of people who receive services in provider organizations whose services are usually considered costlier.

Michigan’s transition plan also conflicts with aspects of the State’s Adult Foster Care Licensing and Regulatory Agency (LARA) in several areas. While collaboration has occurred between the two organizations, there continue to be significant differences, leaving nonprofit organizations caught in the confusion. While LARA is primarily focused on health and
safety, the HCBS transition plan emphasizes community living with importance placed on choice and the participant’s experience.

**Analysis of potential HCBS policy impact**

Past policy has generated some progress for people with IDD through focus on where the person lives. Location of services to the community was a good start towards increasing opportunities for access as well as increasing contact of people with IDD with non-disabled members of the public. However, since outcomes are not measured by a shared definition it remains unclear how much has been achieved for people with IDD in feeling they belong, have friends, and experience less isolation. It is partly for this reason that improvement is only possible if people with IDD, their families, advocates, and nonprofit leaders remain active in the policy discourse on how to influence advancement for people to be included in their communities.

**Inadequately Addresses Resource Gaps**

The complexity of the concept of what it means to be included adds to the challenge of measuring progress. Michigan’s HCBS implementation plan is focused on services occurring in integrated places, greater choice, and community access. Choice is defined as ability to select housing options, community access, roommates, and other aspects of control many take for granted. Access is defined (in part) as unrestricted access to food, privacy, community, and relationships. However, Michigan’s plan fails to consider that some choices are limited by individual resources or housing services available in the community.

For example, one question on the HCBS survey explores whether the person can choose to leave the home whenever they desire. Yet often people require staff support or transportation to leave home. In many cases, resources are limited or unavailable; therefore, a lack of choice is related to a resource barrier rather than intention to limit access. In fact, there is no recognition within the survey process of the direct care staffing shortage crises currently facing people with IDD, their families and community providers (President’s Committee for People with Intellectual and Developmental Disabilities, 2017). Michigan’s HCBS transition plan does
not acknowledge this significant workforce shortage’s impact on inclusion, but simply focuses on compliance.

Compliance Focus

While this HCBS transition approach may cause modifications in a nonprofit organizations’ programs, without frequent public discourse around the purpose of the policy there is a risk that nonprofits will perceive it as another audit devised to reduce funding. The survey practice has potential to limit the effectiveness of impact on organizations because if the correct box is checked then the organization is viewed as compliant. To be clear, there is misaligned incentive for the service providers to check the correct box as opposed to using the survey for a critical evaluation of their own services. If the agency is deemed compliant, there is no need to go through further reviews and no risk to funding. The heavy orientation to conformity, which includes stated threats of funding losses, may cause unintended consequences for people with IDD.

If an organizations’ response is primarily compliance driven when completing HCBS surveys, this can lead to the failure to question when processes do not result in inclusion and may actually cause harm. For example, some of the questions could instigate the elimination of a restriction that is necessary to support individual health and safety. As cautioned by Adams and Balfour (2015), “When compliance is wedded to organizations and institutions within a culture of technical rationality, we begin to see the social and political dynamics that can result in eruptions of evil”. Given the design of the survey, nonprofit organizations need to be mindful of the HCBS intended outcomes and be vocal allies to assure people with IDD are actually gaining inclusion to meet their individual needs.

What about Friends?

HCBS focuses on place, choice and community access but less on other subjective aspects of what it means to be included in community. For the service delivery culture to affect increase to community inclusion, there is a need to address the prevailing complaints of loneliness and the lack of friends. Another dilemma presented by the HCBS transition is that without a focus on healthy relationships there is failure to acknowledge people may
meet their relationship needs through affiliations with other people with disabilities. HCBS does not support segregated locations, however if a segregated location closes because of HCBS findings of noncompliance, this may shut the door to existing and critical friendships for people with IDD. While certainly not an argument for the State or Federal government to fund segregated service options, failure to address the need for human connections can have damaging impact.

Despite the many challenges, there is promise for Michigan’s HCBS transition plan to generate positive movement toward community inclusion. Michigan is intentionally engaging the public throughout this transition phase; this dialogue has been instrumental in supporting adjustments to the survey questions. The survey questions create potential for properly motivated nonprofits to revisit and revise any legacy practices that limit people they support. The final HCBS rule integrates “person centered planning which draws particular attention to community participation, employment, education, and healthcare” (Friedman, 2017). This focus has capacity to influence how Michigan and other States will direct future resources. However, given the current political landscape, progress towards inclusion will require the nonprofit organization remain resolute in support of people with IDD to be included citizens.

**Recommendations for Nonprofit Organizations**

Since the deinstitutionalization movement, nonprofit organizations have engaged in a critical role, formerly managed by government, to provide a public service to people with intellectual and developmental disabilities to assist inclusion efforts. Much of the expansion of nonprofit organizations in Michigan in the 1970’s and 1980’s was related to the demand, and corresponding funding, for community homes for people with IDD. Progress toward inclusion is evident from early policy efforts affecting places people live. Yet, we know that living in community is not the same as belonging. Therefore, in order to create public value, it is necessary for nonprofits to engage in a strategic plan to go beyond supporting where people live (Bryson, 2011).

Organizations must recognize the limits of policy, and implement strategic action to influence improvement in inclusion for people with intellectual and developmental disabilities. If an organizations’ mission statement identifies community inclusion as a significant focus, leaders
should evaluate the actions taken to support these efforts as well as how progress is evaluated. Based on themes identified in the literature, and the HCBS imbedded values of person-centered planning (community participation, employment, education and healthcare), organizations may consider the program initiatives summarized in Table 3 (below).

**Table 3. Program Initiatives**

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<tr>
<th>Recommendation</th>
<th>HCBS Emphasis</th>
<th>Special Considerations</th>
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<td>Promote employment</td>
<td>Employment</td>
<td>Strength Based Approach</td>
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<td>Supportive Work Culture</td>
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<td>Competitive Wages</td>
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<td>Community-based</td>
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<td>Expand relationships</td>
<td>Health/Comm. Participation</td>
<td>Expand social networks</td>
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<td></td>
<td></td>
<td>Increase community engagement</td>
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<td></td>
<td>Educate on healthy relationships</td>
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<td></td>
<td>Cultivate reciprocal relationships</td>
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<tr>
<td>Increase self-advocacy</td>
<td>Education/Health</td>
<td>Strength based approach</td>
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<td>Disability Pride movement</td>
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<td>Leadership training for IDD</td>
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The first recommendation is supported by the literature and is a HCBS emphasis area. Specifically, nonprofits should actively promote programs for successful employment for persons they serve. As stated earlier, more than half of the individuals who have a desire to work have been unable to achieve or maintain employment. Given the current low unemployment rates in Michigan, timing is right for collaborating with local employers to design programs that help people find and keep jobs. The literature addressed concerns that individuals did not feel as though they belonged when they were placed in non-supportive work cultures (Hall, 2009). Therefore, the employment program design should emphasize the strengths of the person with IDD as well as confirm a culture match with the employer. This match is necessary to maximize the potential for employment to be a path for increased reciprocal relationships, as well as a paycheck.

The second recommendation is to address the severely under met need that people with IDD have expressed for friendships and relationships.
Aristotle conveyed a high regard for the importance of friendships in *Book VIII of the Nicomachean Ethics* (Burton, 2012),

> For without friends no one would choose to live, though he had all other goods; even rich men and those in possession of office and of dominating power are thought to need friends most of all; for what is the use of such prosperity without the opportunity of beneficence, which is exercised chiefly and in its most laudable form towards friends?

While Aristotle indicated life was not worth living without friends, it is now known that having friendships improves physical and mental health. Nonprofit organizations might address this critical need by offering programs intended to facilitate development of relationships. This may also include designing services in order to expand opportunities for people to participate in community experiences. However, organizations should be mindful of the IDD population’s long history of abuse and incorporate education on the development of healthy, reciprocal relationships.

The third recommendation, noted in the literature as a path to support inclusion, is promotion of self-advocacy. The power of self-advocacy was evident during a recent personal experience. In August 2018, Michigan Disability Rights Coalition (MDRC) hosted Disability Pride training in Grand Rapids, Michigan for a group of people, both with and without disabilities. The audience was highly engaged in the participatory learning experience. Following the training, the individuals with intellectual disabilities gathered and discussed what they learned. One young man described what he gained from the training as simply, “I learned I don’t have to be ashamed.” Learning not to feel disgrace for who you are seems like a necessary step towards knowing you are worthy to be included in society.

The final recommendation for nonprofit organizations is directed at administrative leadership rather than suggestions on program design. Nonprofit leaders must actively engage the community in dialogue to champion inclusion efforts. In her book, *Turning to One Another: Simple Conversations to Restore Hope to the Future* (2009), Margaret J. Wheatley reminds us “there is no power greater than a community discovering what it cares about”. Wheatley’s assertion is evident in a review of the nation’s history of effective advocacy for individuals with IDD. In fact, many U.S. institutions closed during the decade following the Peabody award winning Geraldo Rivera expose, “Willowbrook: The Last Disgrace” (1972). The unmasking of the horrors of institutionalized living generated community awareness
and became the impetus of a class action suit, resulting in mandated reforms for people with intellectual and developmental disabilities.

While Rivera exposed Willowbrook’s inhumane conditions to the nation, divulging these atrocities also required efforts from families, courageous leaders inside the institution, and community advocates. The Willowbrook story caused a sweeping shift in societal intolerance of people with IDD living in institutions, influencing the closing of institutions across the nation. It is important to reflect on the past efforts that function to remind the community what ‘they care about’. Therefore, future improvement to include people with IDD will require the dialogue continue.

Conclusion

Nonprofit organizations must respond to the changing needs of a population, including changing societal values, and changing demographics. Now that they are more likely to live in community, people with IDD are also experiencing a longevity that was never predicted, increasing the demand for services and resources (Katz, 2003). While the percentage of people with IDD living with families continues to grow, people receiving services outside of family homes depend upon support from nonprofits. Public resources are simply inadequate to meet the rising demand in services; community support and involvement is essential. It is for these reasons and the justification put forward in this article’s case for inclusion, that nonprofit organizations are obligated to implement strategies to pursue the public value of community inclusion for people with intellectual and developmental disabilities.
References


About the Author

Tracey graduated from Michigan State University with a Bachelor of Science in Psychology in 1987. She began her professional career as a direct support professional for people with intellectual and developmental disabilities during one of Michigan’s peak periods of de-institutionalization. She recalls one of her first days on the job as impactful as she helped an individual leave his institutional home carrying a garbage bag of personal belongings into his new “home” in the community. Motivated by a keen sense of justice for people to be, not merely accepted, but truly included in their community, Tracey continued her career with that population. While working as a Director of Programs for MOKA non-profit corporation, and after raising three children to adulthood, Tracey returned to school to advance her education and earned her Master of Public Administration degree from Grand Valley State University in 2018. Tracey currently serves as the Interim executive director for MOKA Non-profit.