

Public Conversations: A Model for Supporting Equitable Change in Policy and Services for People with Intellectual and Developmental Disabilities

Mayra Lopez-Humphreys^{1*}, Paul Archibald¹, Selena T. Rodgers²

¹Department of Social Work, City University of New York, College of Staten Island, New York, United States

²Department of Social Work, City University of New York, York College, New York, United States

Received on: June 14, 2020 Accepted on: December 30, 2020

ABSTRACT

Throughout the United States, people with intellectual and developmental disabilities (IDD) continue to experience inequities in educational, employment and community outcomes. Drawing upon the World Café process, an asset-based approach, this article presents study findings from a Public Conversation for Change (PCC) forum with 73 stakeholders living on Staten Island, New York. Data analysis revealed three themes that identified domains of critical importance in promoting local and equitable change for residents with IDD: (a) Community Awareness & Allyship, (b) Housing Resources & Employment Services, and (c) Collaboration, not Isolation. The need for integrated voices of people with IDD plays a critical role in the PCC forums. This study offers recommendations for hosting spaces that seek to leverage change to inequities experienced by historically marginalized populations.

Keywords: Community conversations, intellectual, developmental disabilities, policy, promoting change, deliberation, dialogue,

INTRODUCTION

Persons with intellectual and/or development disabilities (IDD) are assured equal opportunities in education and employment by the American with Disabilities Act (ADA). However, socio-economic inequities, such as lower educational achievements and poor employment, affect people with IDD at an alarming rate. The overall prevalence of IDD has been documented as 38.2 per 1,000 for persons aged 0 to 5; range from 11.0 to 69.9 per 1,000 for children aged 6 to 18; and 7.9 to 41.0 for adults (Anderson, Larson, & Hall-Lande, 2019). This widening prevalence in IDD has many implications for the exclusion of persons with IDD including, many of the socio-economic benefits offered our society, which ultimately affects the micro, mezzo, and macro aspects of their lives.

For people with IDD living in the United States, the routine practice of social exclusion has repercussions that extend beyond their lack of participation in society (Vargaset al., 2017). Compounding the segregation of people with IDD including, many of the psychological, economic, and social outcomes of exclusion. People with IDD are less likely to engage in community participation due to few opportunities to form supportive relationships. Research shows decreased

community involvement among people with IDD is related to reduced access to social services, disparities in healthcare, low rates of educational attainment and employment (Bumble et al., 2017; Corbett, 2011).

Efforts to increase employment and community access for individuals with IDD have expanded to include advocacy for workforce initiatives such as the Employment First and the Workforce Innovations and Opportunities Act of 2014 (Carter & Bumble, 2018). Despite these concerted efforts to increase employment outcomes, the 2017 Disability Status Report confirms that only 17.8 percent of individuals with "independent living difficulties" - a physical, mental, or emotional need that makes it challenging to conduct daily living activities on their own (e.g. visiting the doctor's office), were employed (Erickson et al., 2017). Collectively, when compared to the general U.S. population, reports link employment outcomes with discriminatory dimensions of social exclusion, which inevitably place people with IDD at a higher risk of health and income disparities (Krahn, & Fox, 2014; Nicholson & Cooper, 2013).

Researcher have also argued that for people with IDD living in urban cities, the movement towards reintegration within the broader community has resulted in new forms of social exclusion and discrimination (Jones & Payne, 1997). Such inequities are difficult to overlook in the state of New York (NY). Despite the state's historic closing of Willowbrook State School being a crucial catalyst in the deinstitutionalization revolution, the employment of NY residents with disabilities ranks 40th among the 50 States (Lauer & Houtenville, 2019). For example, in 2015, the employment rate for New York

*Corresponding Author's Email:

Mayra.Humphreys@csi.cuny.edu

Cite as: Lopez-Humphreys, M., Archibald, Paul., & Rodgers, S. T. (2020). Public Conversations: A Model for Supporting Equitable Change in Policy and Services for People with Intellectual and Developmental Disabilities. *Journal of Disability Studies*. 6(2), 56-64.

©IS Publications ISSN: 2454-6623 <http://pubs.iscience.in/jds>



residents aged 21 to 64 with a disability (33.4%) was lower than without a disability (77.6%), a rate that is lower than 80% of cities in the U.S. (Lauer & Houtenville, 2019).

The Islands: Deinstitutionalization, Social Exclusion, and Discrimination

The history of urbanization for people with IDD cannot be separated from institutional segregation, policies condoning sterilization, and the pathologizing of stigmatized populations. By framing the historical context, the practices, policies, structures and institutions that have contributed to disenfranchising stigmatized populations, this section underscores the importance of community action initiatives with stigmatized populations. This section also investigates the factors associated with employment and housing disparities on Staten Island and its effects on people with IDD, with Willowbrook State School as an exemplar.

Studies have found that islands across the NYC region (e.g., Blackwell's Island, Hart Island, Randall's Island, Riker's Island, Staten Island, and Ward's Island) are used to house and exclude its "undesirables" including people with IDD (Goode et al., 2013). In 1930, after many years of repeated charges of physical abuses and exploitative labor practices with immigrant youth living in the Randall's Island House of Refuge, the reform school for "juvenile delinquents" was deemed unfit and forced off the island by state legislators (New York State Archives, 1989). Currently, both Randall's Island and Ward's Island house large mental institutions (Goode et al., 2013). In addition, Blackwell's Island - currently known as Roosevelt Island - has an extensive history of operating as a prison, a "lunatic" asylum, and a workhouse, all of which were notorious for the horrors of abuses committed (Horn, 2018). By the beginning of the 20th century, the transfer of prisoners from Blackwell's Island to NYC's Riker's Island and Hart's Island was initiated (New York Correction History Society, n.d.). In 2017, after decades of noted corruption and horrendous incidents of violence (e.g., Kalief Browder), NYC Mayor Bill de Blasio announced plans to close Riker's Island by the year 2027 (Haag, 2019). Similar inhumane conditions are attributed to the calculated use of Staten Island's unoccupied land and limited infrastructure (bridges and tunnels) into the island and gave way to one of the largest mental institution in the history of the United States, the Willowbrook State School (Goode et al., 2013). The institution became notoriously known for the inconceivable horrors and cruelty towards children and adults with disabilities. In 1987, the uncovering of these atrocities led to state-led reforms and the eventual closing of the Willowbrook State School (Ely, 2015).

Staten Island and People with IDD

The closing of Willowbrook, led to the development of numerous state and city policies affirming the right to community-based supportive living and meaningful employment opportunities for people with IDD. However, there remain significant inequities in policies and practices that meaningfully support the full participation and flourishing of people with IDD. Of the five NYC boroughs, Staten Island, also often referred to as "The Forgotten Borough" of NYC, has the

highest percentage of students with an Individualized Education Plan - a plan to support the learning needs of students with a disability. Moreover, a disproportionate number of students living in Staten Island's poorest district, located on the North Shore of the island, are far more likely to have a disability than students' citywide (Mehrotra et al., 2018).

Similar disparities emerge in employment and housing on Staten Island. As confirmed in the book, *Raymond's Room: Ending the Segregation of People with Disabilities*, author and esteemed Staten Island disability advocate, DiLeo (as cited in Langton, 2007) writes, "People with disabilities are the last minority group in which legal segregation for housing and employment is still routinely provided" (p. 62). Dooha (2015) provided statistics on the population with disabilities in New York State and found that New York City residents with IDD are, for the most part, segregated within low-wage jobs. The widespread segregation of employment has resulted in the city's highest employment gap in the boroughs of Manhattan (43.6%) and Staten Island (43.5%). The report showed that for individuals with IDD living in U.S. urban cities, a lack of accessible and affordable public transportation is a critical barrier to employment. Among NYC's five boroughs, Staten Island residents with IDD have the lowest ridership of public transportation (25.3%).

NYC residents with IDD who live in one of the five boroughs where one-bedroom rents exceed 100% of SSI in every housing market area is a predictably distressing reality (Schaak et al., 2017). Equally alarming is the lack of access to safe, affordable, and supportive housing for independent living, further preventing the possibility of equitable deinstitutionalization (Schaak et al., 2017). The housing crisis has spread to the smallest NYC borough Staten Island, which comprises 479,458 inhabitants. Despite the sixty community residencies on the island allocated for hundreds of people with disabilities, a recent report documents many are still waiting for residential placement (Dalton, 2017). For many Staten Island residents with IDD, the denial and disregard for their rights to accessible, safe human living conditions are an on-going struggle that impedes their ability to live productive and connected lives.

Inter-professional Education and Academic-Community Partnerships

Staten Island has a thriving constellation of advocacy efforts with and for people with IDD, there are also legislative lobbying initiatives within agencies, and educational training for self-advocates and their families (Damiani, 2018). However, few opportunities and spaces exist to foster collaboration across and among diverse stakeholders, including self-advocates (people with IDD), students, family allies, agency staff, human service professionals, and academics. Similarly, several scholars have noted the lack of opportunities to promote deliberation and conversation across a broad community of local stakeholders to work together towards systemic and equitable change (Quick et al., 2012; Schaak et al., 2017).

Within a range of educational institutions, collaborations between people with IDD are often regarded as valuable partnerships that support the improvement of social care for

people with IDD through the provision of knowledge and expertise, and the development of allies who can challenge exclusionary attitudes towards people with IDD (Carter & Bumble, 2018). Despite the acknowledgment and noted beneficial opportunities for collaboration, the literature on academic-community partnerships has seldom examined initiatives with the inclusion of people with IDD as a model for building productive learning relationships (Mandy et al., 2004). Even among professional programs in higher education, with required practice internships that necessitate partnerships within local communities (e.g., social work, medicine, teaching, and nursing), the promotion of a learning culture that integrates the resources of its service users can often be limited to perfunctory and tokenistic forms (Marini, Glover-Graf, & Millington, 2011). This suggests that the involvement of historically stigmatized populations, including people with IDD, is often passive, at the convenience of the academic leaders, and that the promotion of anti-oppressive practice in professional educational programs may be jeopardized (Mackelprang & Salsgiver, 2016).

Academic-community partnerships involving people with IDD also provide opportunities to strengthen inter-professional learning and foster thriving networks that enhance the sharing of skills and resources across professions practicing within the local community (Mcclimenset al., 2012). Community conversations are an evidence-informed approach for leveraging the expertise of local service-users and professionals with a wide range of professional and life experiences. For academic institutions, community conversations can create a space to obtain the varied perspectives and ideas of local interest groups and encourage social networking that can generate meaningful partnerships (Parker-Katz et al., 2018).

In a study examining an inter-professional dialogue and deliberation initiative, with social work and nursing program students and self-advocates with IDD, students reported that the knowledge gained through dialogues with self-advocates contributed to a greater understanding about the importance of learning from self-advocates in critically reflexive ways. The study also showed an increase in students' awareness of how their professional decision-making impacts stigmatized groups (Terry et al., 2015). Adopting democratic approaches to academic-community partnerships is inclusive and can provide equitable change that centers the voices of people with IDD within the inter-professional education of local professionals (Moxham et al., 2011). This current study reports on the design and implementation of a community conversation model as a part of inter-professional education and academic-community partnership's strategy for countering the exclusion of people with IDD, living in Staten Island, NYC.

METHOD

Conceptual Framework: Theory of Deliberative Capacity

This study is guided by the theory of Deliberative Capacity (Fishkin, 2009), which is grounded on Habermas' Theory of Communicative Action (Habermas, 1984; Vargaset al., 2017). A deliberative framework promotes inclusive spaces for belonging (Kapai, 2012). Moreover, deliberative capacity aides

public value through decision-making processes (Sandfort & Quick, 2015). A central principle of modern democracy is citizens' abilities to deliberate with each other about social values and public policy, a process described by Reich (1990) as the "civic discovery" of public interests. Palumbo, (2017), extends private and restricted conversations to build deliberative capacity and create public value in two ways. First, deliberative capacity both advances democratic participation in governance. Second, deliberative capacity provides opportunities to produce efficient policy solutions.

Deliberative processes are particularly conducive to moving citizens with stigmatized identities beyond a role as either consumers or recipients of policy decisions, to being active partners in both defining public issues and developing strategies to solve shared problems (Vargas et al., 2017). People with IDD hold essential knowledge and experience that is valuable to communities when seeking to address local change. However, when communities come together to work on IDD related issues, stakeholders with IDD are often left out of discussions. Deliberation models that place a high value on affirming and welcoming voices that are often stigmatized have been implemented as an effective strategy for increasing the participation and integration of disenfranchised populations (Aldred, 2011; Fouche & Light, 2011).

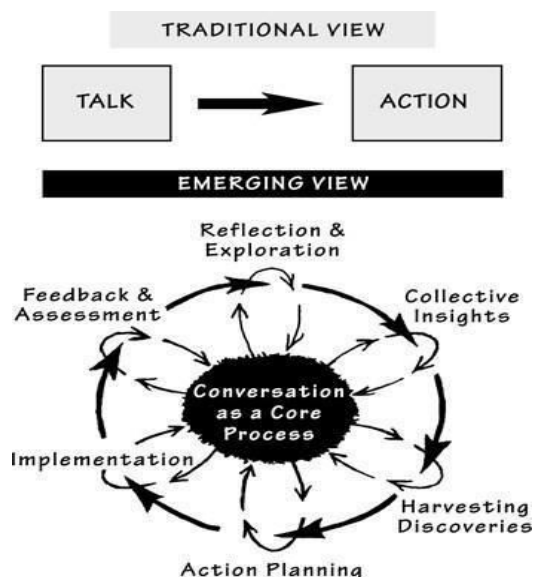
The Public Conversations for Change: World Café Dialogue and Deliberation Practices

Community conversations are an asset-based strategy that has been used to center the inclusion of people with IDD in the brainstorming and identification of targeted, localized solutions for increasing access to services, as well as the advocacy for policy change with collaborating community stakeholders (Dutta et al., 2016; Trainor et al., 2012). The Public Conversations for Change (PCC) forums examined in this study employed a community conversation design that draws upon World Café approaches where community stakeholders come together for facilitated small group discussions centered on specific questions to generate solutions (Brown & Isaacs, 2005). World Café practices involve structured conversational processes that assist diverse stakeholders in engaging in constructive dialogue around critical questions; it also fosters collaborative learning, towards a collective intelligence that prioritizes local, contextualized solutions. Figure 1 illustrates the World Café's integration of talk and action as a single cohesive process for engaging a collaborative change process (Brown & Issacs, 2005). Concerning other collaborative and iterative learning approaches, the World Café is particularly useful in the cross-pollination of ideas through evolving rounds of "conversations that matter" (Brown & Issacs, 2005) and the use of a cafe-style social context. The World Café method (Figure 1) is inherently complementary to work that is seeking equity and access, together with marginalized groups (Aldred, 2011).

Setting and Sample

As a progressive call and response to bridge Staten Island community stakeholders together with people with IDD, the Geraldo Rivera Fund (GRF) for Social Work and Disability

Figure 1: World Café's Emerging View of Conversation and Action



(Brown & Isaacs, 2005)

Studies, was established in 2014, at a City University of New York Public University campus. The campus is also the former site of the Willowbrook State School, which has a Master of Social Work program that has disability studies as its sole specialization. A convenience sample of attendees participating in the two-hour PCC forums were invited to join in the research study. A convenience sample was best suited for this study because the PCC forums were designed to involve a broad cross-section of allied community members. Therefore, the diverse members within the Leadership Cohort were responsible for inviting IDD stakeholders within their circle of influence, including self-advocates with IDD, family allies, students preparing for professional degrees in health and human services, agency staff, professionals and executives, local politicians and academics. Participants were recruited using social media, electronic and paper invitations, as well as word of mouth. The Cohort outreached to local community members within the university, independent living centers, IDD advocacy councils, faith-based organizations, human service agencies, public schools, and hospitals.

Both forums included in this study were delivered in 2017 and 2018 at a Department of Social Work in Staten Island, NY. Participants included attendees who represented a total of 25 different institutions and agencies, including colleges/universities, advocacy coalitions, human service agencies, and school systems. A total of 73 individuals participated in the *first* PCC forum. A survey was only distributed at the end of the *second* PCC forum. A total of 51 individuals participated and completed the second PCC forum, and a total of 36 agreed to participate in the evaluation for a response rate of 70.5%.

Data Collection

This explanatory and evaluative pilot study employed a one-group mix-methods design to answer two research questions: 1). *What are the insights and opportunities about creating*

collaborative change for people with IDD on Staten Island?; and 2). What are the participants' attitudes about PCC forums and advocacy with people with IDD? IRB approval was obtained from the authors' university, and participants provided consent prior to data collection.

PCC Leadership Cohort and Planning Process

The PCC forums were designed, organized, and facilitated by a PCC Leadership Cohort that involved 12-15 members, including self-advocates, family allies, MSW & BSSW students at CSI, staff, and professionals in health and human services and CSI academics in the department of social work and disability studies. The Leadership Cohort served in the role of community organizers, strategically inviting their network of community members who could speak to the issues and share their community's assets. The Cohort met two times a month and was responsible for (a) designing a collaborative process of change and advocacy with and for people with IDD and coordinating forum logistics; (b) collectively co-leading the PCC participants in developing and implementing a plan of action. A faculty member within the Department of Social Work was also selected to coordinate the GRF. The faculty member was selected on the basis of experience in developing and facilitating equity-minded, person-centered, community-academic partnerships. Two project consultants trained in facilitating community conversations using World Café practices, and both possessing more than 20 years of experience in the field of disability services, provided training and guidance to support all pre-event planning and logistics. The consultants also provided Cohort members with a one-day training in World Café practices.

World Café Procedures

Using round tables, 8-10 participants were randomly seated. A 20-minute panel discussion included a self-advocate with IDD, a caregiver of two children with IDD, and a director of a disability justice program. The remainder of the time was focused on facilitating the World Café process, with the Leadership Cohort serving as the host at each table, facilitating introductions, providing guidance for the process, and encouraging participants to use colored markers and the butcher-block paper covering the tables as a canvass for writing/drawing notes that related to their ideas or discoveries during.

As the PCC forum 'ambassadors of meaning,' attendees participated in three successive rounds of small-group conversation in which they identified ideas, resources, and personal connections that could be drawn upon when deciding on a collaborative plan. The following "powerful" questions guided each 20-minute round of conversation: (1) *Why is it so important to come together at this time to have a conversation about people with IDD on Staten Island?; (2) What opportunities are emerging that can create vital change for people with IDD on Staten Island? What is getting in the way (i.e., barriers)?* After the first round, the participants were asked to move to another table with different people. However, during the second and third rounds of conversation, the host at the table remained to summarize the previous discussion with new

participants. Upon the completion of the three rounds of conversation, a 25-minute harvesting session invited all attendees to “gather” and share the most meaningful ideas they heard at their tables. The second PCC forum also employed World café practices to prioritize theme/s –identified through the first PCC-- that were most conducive to collective action.

Two data sources were collected during and after the PCC forums. For purposes of this article, we analyzed the harvested notes from the first PCC forum and responses from the post surveys, from the second PCC forum. This approach allowed us to gather a variety of data focused on the PCC forums and centered in examining the ideas of all attendees, with an emphasis on assuring that the contributions of participants with IDD are cultivated.

PCC Notes. The first author and research assistants compiled a comprehensive list of all of the ideas shared within the rounds of conversations. Data from the PCC harvest was collected in various formats, including, participant notes on paper tablecloths, final group write-ups on chart paper, group themes discussed on post-its, and observation notes recorded by table hosts. This study includes notes from the first PCC forum, 136 distinct ideas were shared.

The Community Attitudes Response (CAR) Survey. The CAR survey is a 32-item questionnaire that consisted of eight demographic variables (e.g., age; gender; race and/or ethnicity; the highest level of education; organization/agency affiliation, involvement with people with IDD, role in the community [e.g., human service agency support staff and self-advocate with IDD]). Eight items from the participant feedback survey were adapted from Carter et al. (2012). In this study, Cronbach’s alpha indicated a high level of internal consistency for the CAR survey scale at ($\alpha = .91$). Twenty-two items examined the participants’ perceptions related to the benefits of the PCC forums and rated using a 4-point Likert-type scale ranging from 1 (strongly disagree) to 4 (strongly agree). Five of the statements examined the participants’ perceptions about the *awareness* benefits (e.g., “My awareness about the needs of people with developmental disabilities has increased because of this forum”); four statements focused on the benefits of *learning about people with IDD* (e.g., “I have a greater understanding of the biases that affect the well-being of people with developmental disabilities”); five statements captured participants’ views about the *value of World Café practices* (e.g., “The dialogue approaches used were beneficial to my learning in this forum”); four items examined the benefits related to *commitment to participating in change for people with IDD* (e.g., “I am more committed to participating in efforts to change policies that negatively impact people with developmental disabilities”). The CAR survey also included four items that explored participants’ satisfaction with the PCC (e.g., “I would like more public dialogues like this one to keep me involved in changes needed for people with developmental disabilities on Staten Island”).

Data Analysis

Qualitative Analysis: The six steps of thematic analysis (Braun & Clarke, 2006) were used to analyze the data. The data

analysis began with the researchers reading the PCC notes in full and noting initial ideas. The notes were then re-read, and initial codes were generated that provided a summary or explanation of each data extract. After initial coding, revisions were made to tighten definitions, collapse overlapping codes, and add new codes. The themes were refined further by collating related subthemes and discarding themes that did not have enough support from the data. The final list of codes of 81 codes was clustered into an overarching framework of three broader themes. The desired outcome of this qualitative data analysis was to identify multiple perspectives on creating change and increasing belonging for people with IDD from the initial PCC. The three main themes were further reviewed to examine the specifics of each theme and determine each theme’s significance in relation to the study question. Each theme is described and includes participants’ quotes.

Quantitative Analysis: The data were analyzed in IBM SPSS, version 24, using descriptive statistics to determine percentages, frequencies, and central tendency for the demographic variables and the items within the CAR survey.

RESULTS

Table 1: Demographics of PC Forum Participants

Variable	n(%)
Race and/or Ethnicity (36)	
White/European –American	16(44.4)
Black/African –American	5(13.9)
Hispanic/Latino/a/x	5(13.9)
Asian/Pacific Islander	3(8.3)
Other Ethnicity	2(5.6)
No Response	5(13.9)
Gender (36)	
Female	22(61.1)
Male	14(39.2)
Highest Level of Education Completed (35)	
High School	5(14.3)
Undergraduate	11(31.4)
Graduate	14(40)
Doctorate	4(2.9)
Other	1(2.8)
PC Stakeholder Identity	
Identifies as a Self-Advocate (35)	12(34.4)
Identifies as a Professional or Staff (34)	19(55.9)
Agency Affiliation	
College of Staten Island	4(21)
Non-Profit Serving People with IDD	5(26.3)
Received services for yourself or a family member (35)	
Yes	18(51.4)
No	17(48.6)
Involvement with People with IDD (34)	
At least once a month	20(58.8)
At least once a year	8(23.5)
Some involvement over the last 5 years	3(8.8)
Has not been involved	1(2.9)
Don’t know	2(5.9)

Table 1 reports the full demographics of the participants. Study participants ($n = 36$) consisted of adults who ranged in age from 18 to 73 years old. The majority of participants were female participants and from diverse ethnic and racial backgrounds - more than half of the PC participants identified

as either a self-advocate or an allied family member. The means and standard deviations for each item after the second PCC forum are reported in Table 1.

Table 2: Community Attitudes and Response Survey (N = 36)

*Statement	n	M	SD
My awareness about the needs of people w/ IDD has increased because of this forum	36	4	.79
I am more aware of the issues affecting people w/ IDD	36	4.4	.64
I have more awareness on the different ways I can support people w/ IDD	35	4.3	.75
I am more aware of the importance of collectively organizing to promote changes in IDD policies	35	4.4	.61
This forum helped broaden my awareness of approaches for promoting change with/for people w/ IDD	36	4.4	.65
Benefits of Learning			
By attending this forum, I learned something about IDD that has changed my perspective	36	3.9	.85
I can see ways of incorporating some of the learning from this forum into my engagement with people w/ IDD	36	4.2	.71
I have a greater understanding of the biases that affect the well-being of people with IDD	36	4.1	.59
Overall, I found this activity to be informative; it provided me with new learning about people w/ IDD	36	4.4	.69
Value of World Café Methods			
The dialogue approaches used were beneficial to my learning in this forum	36	4.3	.79
Regarding your own observations at today's event the PCC forum was helpful for balancing different points of view	35	4.2	.77
Assuring the conversation was not dominated by a few participants	35	4.5	.74
Encouraging respectful listening	35	4.5	.74
Thoroughly examining questions and ideas with a diversity of people	36	4.5	.65
Commitment to Participating in Change			
I am more committed to participating in efforts to change policies that negatively impact people w/ IDD	36	4.5	.61
I am more motivated to support people w/ IDD	36	4.6	.61
I am more committed to promoting change in policies and services for people w/ IDD	35	4.4	.61
I will tell others about some of the issues I became aware of through this forum	34	4.4	.66
PCC Participants' Satisfaction			
I would like more public dialogues like to keep me involved in policies & service changes needed for people w/ IDD on Staten Island	36	4.5	.69
After today's meeting I believe our suggestions will be used to make change in policies & services for people w/ IDD on Staten Island	36	4.3	.7
I have a greater sense of expectation for the changes that can be made to promote the policy & service needs of people w/ IDD on Staten Island	36	4.2	.77
Overall how would you rate your experience in this PCC forum	36	1.26	.65

Note: Percentages are based on number of persons completing each item. *Means and standard deviations based on a 5-point, Likert-type scale: 1 = strongly disagree (SD), 2 = disagree (D), 3 = neutral (N), 4 = agree (A), 5 = strongly agree (SA). **Means and standard deviations based on a 4-point, Likert-type scale: 1 = very positive (VP), 2 = positive (D), 3 = neutral (NEU), 4 = negative (NEG), 5 = very negative (VNEG).

Table 2 reports the results from the Community Attitudes and Response (CAR) survey. Most of the participants agreed that the community conversation helped to increase their awareness of issues related to the needs and concerns of people with IDD and that it was a good use of their time (averaging between 4 and 4.4 on these items). Likewise, participants agreed that the forum was beneficial to learning about people with IDD (averaging between 3.9 and 4.4 on these items). Most attendees rated the World Café methods as a valuable approach (averaging between 4.2 and 4.5 on these items). For the most part, participants expressed a commitment to participating in change for people with IDD (averaging between 4.4 and 4.6 on these items). Furthermore, most participants responded with a favorable satisfaction rate about their participation in the PCC forums (averaging between 4.2 and 4.5 on these items).

After analyzing the notes from the PCC forums, significant topical areas were developed from the cluster of themes that developed. Three major themes emerged labeled as 'Community Awareness and Allyship,' 'Housing Resources & Employment Services,' and 'Collaboration, not Isolation' (see Table 3). These three themes served as the overarching themes for corresponding categories related to opportunities and barriers. Together these themes and categories generated core ways to create change for people with IDD by drawing from their specific life experiences and uncovering descriptions of opportunities and barriers in a broader, holistic context.

Theme 1: Community Awareness & Allyship

Community Awareness & Allyship was defined as a method for increasing awareness and interest in humanity, legal rights, and the individual and collective needs of people with IDD within the local community. Many participants

Table 3: Harvest Responses Generated by PCC Participants

Opportunities	Barriers
Themes: Community Awareness & Allyship	
<ul style="list-style-type: none"> Growing interests in the needs of people with IDD. Creating disability allies in the community for a better understanding of people with IDD. Not allowing our past (Willowbrook) to define our future. The MSW Program & Disabilities Studies minor at CSI shows the values of our lives, and sets a positive example for our community. Linking awareness of individual need with an understanding of structural barriers and connection with people with IDD. 	<ul style="list-style-type: none"> The need to educate the community. No one size fits all. Assumptions and stigmas within the community. Non-Disabled people need to get out of their box & out of our way! The social perceptions of disability is getting in the way. In general, we need awareness, knowledge, and understanding about people with IDD.
Themes: Housing Resources & Employment Services	
<ul style="list-style-type: none"> Adequate, fair funding can improve opportunities for all. Sharing knowledge of "how funding works." Providing meaningful employment training supports. Quality training as a means for reducing high turnover with direct staff. Educating new, experienced and future professionals together; crossover trainings. 	<ul style="list-style-type: none"> Changing funding climate. Inequitable funding for services, appropriate housing & skilled staff. Few employers are invested in hiring people with IDD. Minimum wage employment is not a livable wage. The need for more programs that build supportive employment opportunities (e.g., Project Search) & residential supports. Self-Direction Services: not user friendly & a lack of training on how to use it. Concerns for a sustainable future--when parents are in their senior years, and when parents are deceased.
Themes: Collaboration, Not Isolation	
<ul style="list-style-type: none"> Removal of physical and other barriers is bringing us more and more together each day. A close-knit community. Provider agencies connecting with schools. Fostering powerful relationships challenges and empowers one another. Creating meaningful employment training supports for direct staff. 	<ul style="list-style-type: none"> Fighting for resources—People get lost. Bridging disconnect between academia & direct services. Transportations issues and isolation. Increase communication to break down boundaries between agencies. Need more collaboration between service providers. Disconnected services between systems.

acknowledged, "Growing interests in the needs of people with IDD" on Staten Island. However, non-disabled people, who understood that ableism exists, but did not accept their responsibility to actively engage in allyship with people with IDD, were described as being hindrances and obstacles. Participants identified this core belief about non-disabled persons' inability to fully ascribe to disability allyship as an influence on the continued challenges and disrupted services for persons with disabilities. They proclaimed, "non-disabled people need to get out of the box and get out of the way." Community awareness was described as an opportunity to "link awareness of individual need with an understanding of structural barriers and connection with people with disabilities." In fact, the term 'opportunity' was most heavily associated with the topic of community education. Seeking ways to cultivate community allies was identified as a central strategy for creating a greater understanding of people with IDD. Breaking through stigma, stereotypes, and public perception was reported as barriers that were getting in the way of emerging opportunities.

Theme 2: Housing Resources & Employment Services

PCC participants conceptualized resources and services in terms of the role of funding in providing the education, training, and ancillary services for people with IDD in the community. In contrast to the opportunities identified for community

education, funding was the most significant barrier identified to improved quality of life for individuals with IDD. The challenges of funding also presented a broad and persistent impact on the well-being of people with IDD. Barriers frequently identified included “changes in funding” for the growing numbers of people with IDD on Staten Island, “inequitable funding” for services and reduction in training programs.

Another common category that emerged as a part of this theme was the opportunities and barriers related to services provided to individuals with IDD. This included employment support, self-direction, and residential services - all of which were discussed as a source of several barriers to an optimal high quality of life. There was also a call to revamp self-direction services so that services would be more user friendly and less overwhelming for self-advocates. Services were also discussed in relation to incentives that could be utilized to increase the number of community residencies/supported apartments. Concerns for the future relative to employment, housing, elderly services, and when parents are deceased. They were also very concerned about caregiving across the lifespan, especially for those who were aging while caregiving. Creating sustainable employment strategies that addressed the minimum wage and incentivized the hiring people with IDD were critical issues that were linked to this theme. Participants identified the need for more programs like *Project Search* - described as a workplace immersion program that serves as a school-to-work transition process for graduating high school students with IDD. Concerns for the future with employment, residential, and plans as caregivers age, particularly the long-term stability of adults with IDD when parents are deceased.

Theme 3: Collaboration, not Isolation

Values and beliefs about “moving away from isolation and moving toward collaboration,” emerged as a common theme, which permeated the discussions of training, services, community outreach, and more. Participants reported that there were “lots of good services being provided,” but felt a lack of collaboration among service providers.

An emphasis on strengthening relationships between service providers and among interfacing systems (e.g., education and mental health) as resources for networking, improving communication, and the “cross-pollination” of ideas among varying professional roles were identified who desired to bridge the gap between academia and direct services. Ideas included academic-direct service partnerships that would encourage seasoned professionals, mid-career, newly hired, and emerging professionals to learn and develop together. Productive discussions centered on support systems, and new training opportunities as a means for reducing high turnover among staff within the disabilities sector can help decrease the stigma of employment with individuals with disabilities.

DISCUSSION

Themes that emerged in this study facilitated a better understanding of how participants in the PCC forums viewed change, opportunities, and barriers to improve experiences for

people with developmental disabilities on Staten Island. Results show that participation in the PCC forums supported an increased awareness of issues related to the life experiences of people with IDD and how community conversations can lead to person-centered solutions that respond to the exclusion of people with IDD. Similar studies have found that community conversations can serve as a means of identifying assets and barriers that encourage change for people with IDD (Molfenter et al., 2018; Raynor et al., 2018). The majority of participants agreed that as a result of attending the PCC forums, they were more aware of the issues impacting people with IDD, and had a greater understanding of the biases that affect the well-being of people with IDD. Results also showed that participants felt more committed to participating in efforts to change policies that negatively impact people with IDD. Many participants believed that the World Café approaches used were beneficial to their learning in the PCC forum. The majority of participants also believed the World Café model could be used to make changes for people with IDD on Staten Island. The inclusion of self-advocates and the ability to collaborate with other disability stakeholders were identified as the most meaningful aspects of the PCC process.

Calls to bring together multiple stakeholders are certainly not new, but pathways for doing so in effective and inter-professional ways have been more elusive within professional education program. It has been found that professional education programs have often focused more on interdisciplinary and transdisciplinary work rather than inter-professional practice (Mackelprang & Salsgiver, 2009). The inter-professional process goes beyond the interdisciplinary and transdisciplinary process (Archibald & Estreet, 2017). During the interdisciplinary process, multiple disciplines interact with each other to solve an issue while focused on their respective theories and practices. The transdisciplinary process goes beyond the interdisciplinary process and develops an agreed-upon paradigm to address a common social problem. On the other hand, the inter-professional process builds upon the transdisciplinary process to establish a collective professional identity that relies on the resources, tools, methods, and procedures available to all the disciplines involved in addressing common social problems (Alberto & Herth, 2009). Findings from this project have generated useful discussion that will help guide future contextual methodologies for bridging self-advocates and their families with inter-professional learning.

The PCC approach described in the present study can contribute to increasing broader stakeholder engagement in generating equitable changes in policy and services that include a deliberative capacity of people with IDD as allies in the decision-making process (Sullivan, 2018). Although professionals play a vital role in providing key information and support with planning and services, it is important to remember that self-advocates and family members must be afforded opportunities to contribute their perspectives. Intentional ways to ensure that happens are needed. Adopting a more democratic approach to involvement by making room for self-advocates or allied family members to outline particular curriculum topics may lead to more relevance and equitable inclusivity, with self-

advocates in a more influential position, increasing the potential for political empowerment (Moxham et al., 2011).

Professional education programs, would be well advised to aim for higher rungs on the participation ladder, engaging self-advocates as equal partners. The literature indicates that self-advocates' involvement should be increased across all aspects of curricula in professional education programs (Moxham et al., 2011). Models of community conversations can offer departments and schools an approach for expanding collaboration to a broader cross-section in support of advocacy change while increasing the inter-professional practice competency of faculty and students.

Strengths and Limitations

One of the strengths of this study is that the methodology serves as a source of gathering information and networking while at the same time eliciting potential local solutions to barriers relating to the exclusion of persons with IDD from socio-economic benefits. Community conversations foster both novel ideas and collaboration for increased social justice expectations and attitudes to empower individuals with IDD. Although this study has several strengths, some limitations should be acknowledged. First, methods for more precisely tracking the types of connections made and resulting outcomes would have enhanced our study. For example, interviews with GRF Leadership Cohort would yield greater information on the effects- of self-advocates on the community conversations. Second, the PCC forums are effective at spurring change but maybe insufficient for sustaining on-going movements. Follow-up studies have focused only on the short-term impact of this approach (Carter et al., 2016). Documenting the changes as a result of these events is a complex endeavor, but an essential next step.

CONCLUSION

This inter-professional education and academic-community partnership utilized community conversations to develop solutions to the systemic practice of excluding people with IDD living in Staten Island, NYC. We combined the social model of disability studies and paradigms presented by self-advocates, family allies, and professionals in health and human services to develop new disability justice content. These community conversations were content-based processes and demonstrated aspects of best practices in experiential learning such as mutual engagement, information sharing, and peer to peer learning among self-advocates, family allies, professionals in health and human services, and faculty (Kickul et al., 2012). The community conversations produced outcomes that demonstrated a commitment to increasing the competency in inter-professional modalities aimed at addressing inequities in educational, employment for individuals with IDD. Policy and services with people with IDD necessitate public conversations to facilitate reform and community engagement. Universal support for innovative strategies that center the lived experiences of people with IDD is critical to implement throughout the wide spread fabric of Staten Island and broader society.

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Source of Funding: None

Conflict of Interest: None