Article

The importance of dignity and choice for people assessed as having intellectual disabilities

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Abstract

Individuals assessed as having an intellectual disability often spend a significant amount of time in day treatment/day habilitation programs after they graduate from school. The quality of these programs varies widely and is not federally legislated. The purpose of the current study is both to explore factors that lead to higher satisfaction for participants in these programs and to better understand what participants want in a program. Using a grounded theory approach, researchers interviewed 25 participants, staff, and family members in focus group settings to collect qualitative data. Interviews focused on what worked and what could be improved at a program located in Western New York. Using the constant comparative method, themes emerged from the data that pointed to the importance of dignity and choice in a day program to facilitate empowerment, higher levels of satisfaction and self-confidence.

Keywords

intellectual disability, day treatment program, day habilitation, dignity, choice, grounded theory

The importance of dignity and choice in day programs

A major factor impacting quality of life among adults with intellectual disabilities is the type of supports available during typical weekdays (Reid et al., 2001a). Although individuals with intellectual disabilities progress more slowly across a range of learning tasks, research shows that they continue to learn after completion of their secondary schooling in areas of reading

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(Pershey and Gilbert, 2002), mathematics (Ballard and Calhoun, 1991), and self-management (Browder and Minarovic, 2000). In the last 40 years, the shift for services provided to people with intellectual disabilities has moved from institutions to the community. Such services include respite, residential housing, behavioural supports, day programs, and supported employment, as well as a wide variety of other services designed to help individuals with intellectual disabilities stay in the community and out of institutions. The change has increased the overall quality of life for individuals being served (Emerson et al., 2000a, 2000b; Neely-Barnes et al., 2008). Before the advent of deinstitutionalization, day programs were held either in-house on the institution grounds, or were nonexistent. The first-day programs to come into existence were often held in a house, and organized by parents wanting more for their children. According to a 2006 report to the United States Congress, day programs across the nation totaled 3,400 in 2002, a substantial increase from 40 years ago (Kaufman, 2006b). Of those 3,400 programs, 78% are operated by nonprofit, private, or public organizations. Each day, these programs care for approximately 150,000 individuals. Of the total number of adult enrollees, 67% are women. The population served ranges in age from 18 to 91 (Congressional Research Service, 2006).

Congregate day programs or day treatment centers for people with intellectual disabilities have grown from parent-formed workshops held in kitchens or garages to current activities that include art programs, community-centered activities, sheltered workshops and even job-readiness skills (Parsons, 2004). While the prevalence of programs has grown, there is a lack of research in the literature assessing their effectiveness, purpose and outcomes (Parsons, 2004). Most studies continue to focus on outcomes in residential services or schools (Datta and Talukdar, 2017; Hendrickson et al., 2015; Mariz et al., 2017) with day program outcomes considered an afterthought, leaving a significant gap in the literature. In addition, while residential services are highly regulated, up until 2006 there were no federal standards for day treatment centers (Kaufman, 2006b). Most state-wide regulations have more to do with types of funding provided rather than with ensuring a quality program (Friedman, 2016; Hall et al., 2011; Kaufman, 2006a; Petner-Arrey and Copeland, 2015). However, the literature does suggest important elements that should be in place for a quality day program (Crites & Howard, 2011; Hawkins, 1999; Luckasson and Spitalnik, 1994; Parsons and Reid, 1993; Reid et al., 2001b).

Functional supports

According to Luckasson and Spitalnik (1994), having program models that focus on individual planning in conjunction with providing functional supports is central to achieving community inclusion. A primary determinant of the quality of day treatment activities is the degree to which individuals are involved in activities that are functional and purposeful. Kleinert and Kearns (1999) state that participation in activities involving functional skills, in contrast to nonfunctional behaviour, has become a standard. For example, sitting or lying around with no apparent purposeful activity is considered nonfunctional (Parsons and Reid, 1993). Functional activities can be described as skills taught to individuals that they can use in a purposeful manner outside of the classroom or congregate environment. Furthermore, individuals should be able to use these skills frequently (Reid and Parsons, 1999). One study showed that adults with intellectual disabilities were engaged in purposeful activities during 48% of the observation intervals (Reid et al., 2001a). Unfortunately, non-functional activity was observed 49% of the time.

Active engagement

Becoming actively engaged with other people helps support community inclusion and, therefore, is another important element in day treatment centers. Relationship building is an essential piece of day habilitation programs, as described above. Another important factor is staff engagement with participants (Crites & Howard, 2011). Specifically, respectful engagement between staff and consumers is essential (Mahoney and Roberts, 2009). In addition, studies have analyzed engagement as it relates to other purposeful activities within programs (Parsons et al., 2004; Petner-Arrey and Copeland, 2015; Vlaskamp et al., 2007).

Choice and dignity

Older studies (e.g. Wehmeyer and Bolding, 1999) have assessed self-determination, autonomy, life-choices and lifestyle satisfaction for adults with intellectual disabilities, matched by the level of intelligence, age and gender but differing in the type of residence or working environment. The findings suggested that people who lived or worked in community-based settings were more self-determined, had higher autonomy, had more choices and were more satisfied than were IQ and aged-matched peers living or working in community-based congregate settings or non-community-based congregate settings. This suggests that the first step in promoting self-determination is to support people living, working, learning and playing within their community. If individuals are supported in their choices, able to participate in decisions, set goals for themselves and experience more control in their lives, they will become more self-determined.

Research shows that opportunities to exercise choice and participate in meaningful day and leisure activities for elderly people with intellectual disabilities are lacking (Hawkins, 1999). Because of discriminatory ageist attitudes, they often encounter financial, physical, contextual and attitudinal barriers that interfere with their exercise of choice (Cooke and Long, 1999). Interestingly, research shows that older people with intellectual disabilities value continued active engagement including the desire to continue in their day programs (Bigby, 1997).

Unfortunately, newer studies have mostly focused on student-aged individuals (Chou et al., 2017; Cook et al., 2017; Hendrickson et al., 2015). There have only been five studies (Curryer et al., 2015; McDermott and Edwards, 2012; Petner-Arrey and Copeland, 2015; Shogren and Broussard, 2011; Wong and Wong, 2008) that have focused on choice or self-determination in day treatment centers over the last 10 years. One study (Wong and Wong, 2008) was conducted in Hong Kong and focused on knowledge staff have in relation to helping individuals make choices. Other studies (e.g. Shogren and Broussard, 2011) explored the importance of self-determination and choice for individuals assessed as having intellectual disabilities, supporting older studies (Cooke and Long, 1999; Hawkins, 1999; Whehmeyer and Bolding, 1999) which showed increased satisfaction when individuals were given more choices in their daily lives. The current study seeks to build on previous studies by exploring ways to increase choice for individuals in their day treatment settings using qualitative, grounded theory methods.

Qualitative study

Setting

The current study was conducted at a day program for adults assessed as having intellectual disabilities, located in Western New York, 18 months after it opened. The program was created in

cooperation and collaboration with family members and the participants assessed as having intellectual disabilities whom it was designed to serve. Due to the nature of the program, it was called a Co-Op. The program was created for the people receiving supports, their families and others in their circle of support, to create, direct and oversee the day-to-day operations of the program so that it could better suit their changing needs. The organization that created the program states, "the pilot program is designed to support up to eight (8) people daily and provides personalized opportunities for growth and new experiences that will ensure each person can be a valued member of their community." The purpose of this study was to examine the perceived effectiveness of the program 18 months after its inception, to identify ways to enhance it and enable participants, family and staff to express their experiences of it.

Sample

A convenience sample was drawn from one program located in Western New York, which included staff, participants and family members. The Co-Op recruited family members to be part of a focus group. All families received a written letter from the program, detailing the study and asking for their participation in the focus group. For follow-up, they were called individually by the program manager and asked if they would be interested in attending. Seven family members agreed to participate. All were female and either mothers or sisters of current members of the program.

Next, the Co-Op recruited members (a term used to identify participants with a diagnosis of intellectual disabilities who participated in the Co-Op) of the program. During the daily activities of the program, members were asked, in groups of 3–5, to participate in a short focus group. Before recruiting members, the person hired by the agency to conduct the study spent a month observing the program and becoming familiar with the members. The staff and administrators of the program felt that this was the best way to develop rapport with the members and gain their trust to the extent that they would feel comfortable opening up in a focus group. There were 15 members in total who participated in focus groups ranging from 3 to 5 members at a time. The focus groups for the members lasted anywhere from fifteen min to one hour depending on the ability level of those participating, and their personal comfort level with the interviewer.

Staff who work directly with the members were recruited next. There were three staff working as direct care workers at the time of the study; all three were invited to participate and were given overtime pay by the administration for their time. The administration felt that it was important to give the staff an incentive to participate and were highly motivated to have their input regarding how well the program was developing.

Method

The Co-Op conducted the focus groups as part of their program evaluation. An employee of the Co-Op with experience in research conducted all focus groups at various locations. The focus group for families was held off-site at the main administration building of the company. Member and staff focus groups were held at the Co-Op either in private offices, the kitchen area, or the main area. The exact place was determined based on the level of privacy available at the time. A recording was made of each group and then transcribed. Thereafter, the Co-Op provided the research authors with a transcript of the focus groups with all identifying information redacted. The redacted information included details such as gender, age, ethnicity, and diagnosis thus ensuring confidentiality of the people in the focus group. Gender was known for the family focus group

simply because only females were present. The study was approved by the Institutional Review Board at University at Buffalo (State University New York), where the analysis took place.

Analysis. The focus group transcripts were analysed using the constant comparative method of grounded theory designed by Glaser (Glaser, 1978) and Strauss (Charmaz, 2007) at the University of California. An alternate form of grounded theory was later developed by Kathy Charmaz (Charmaz, 2007) who felt that there should be a more constructivist approach as opposed to the positivist philosophy which Glaser and Strauss espoused. The grounded theory components employed in this study were open coding, focused coding, axial coding, theoretical coding and memoing. The researchers utilized the important aspect of comparative analysis inherent in grounded theory by comparing each of the transcripts, as well as comparing coding and memoing, with more than one researcher.

Two researchers conducted initial open coding of the transcripts while meeting regularly to discuss and compare the codes that were evolving. Open coding consisted of analysing the data line by line and establishing words that captured the meaning of each line. In addition, the researchers produced memos as they analysed the data to conceptualize the data and to work toward an ultimate theory that best described what the data said.

As analysis of the transcripts progressed, the researchers began selective or focused coding (Charmaz, 2007) of the transcripts while continuing to memo and meet regularly to compare memos and codes. Charmez (2007) defined focused coding as "using the most significant and/or frequent earlier codes to sift through large amounts of data" (57). The researchers had to identify the initial codes and themes that were found most often and made the "most analytical sense" to "categorize (the) data incisively and completely" (Charmez, 2007: 57). Once initial and focused coding of all the available data was finished and no new information was being elicited from the transcripts, the researchers utilized axial coding (Charmez, 2007; Glaser, 1978) to group the main themes together to derive the main theory behind how the program was operating and what factors might drive the continued success of the Co-Op. Once the main themes were grouped together, a workable theory emerged.

In grounded theory, researchers usually keep interviewing new subjects until they achieved saturation of data; a process called theoretical coding (Glaser, 1978). In other words, new subjects are interviewed until no new information emerges from the data. In this instance, the researchers only had the data that were given to them and were not able to interview any additional subjects. However, the number of participants and the number of interviews conducted and provided to the researchers by the program were sufficient enough to elicit saturation of data. By the time the last transcripts were analysed, they elicited only confirmatory information that previous transcripts had already discussed.

Results

The grounded theory constant comparative method of analysis produced an overarching phenomenon focusing on the positive relationships that helped the Co-Op continue with their initial vision for the program 18 months after inception. The model that emerged from the data also happened to correlate with the current theory of social role valorization (Race et al., 2005). Social role valorization states that the degree to which people are integrated into society dictates how valued they are as members of that society (Farrell, 1995). For people with intellectual disabilities, being valued means being accepted (Farrell, 1995). A grounded theory analysis is not an analysis of particular concepts and theories. Rather, it seeks to derive theories from the
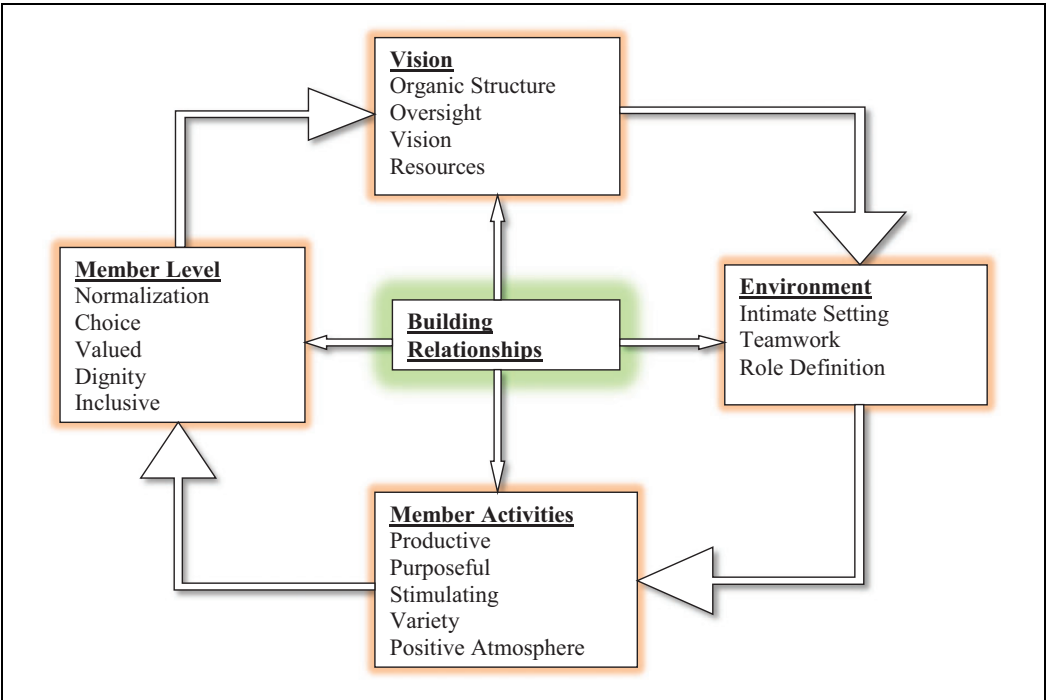
Figure 1. Mapping dignity and choice.

available data without having preconceived notions of past literature or theories. As this particular study progressed, it became more apparent that the overall theory emerging aligned with the grand theory of social role valorization.

Dignity and choice theory

With Building Relationships at its core, the mid-range theory (Figure 1) that emerged from the grounded theory data describes how, for the Co-Op, relationships come together and work congruently with each level of a day program, from the top administrators to the staff, the members themselves and family members to create and foster a positive environment that helps members increase their independence and provides them with stimulating activities during the day. In turn, this has the profound effect of giving the members of the program a sense of value and dignity as described by social role valorization theory.

The model describes how the building of relationships is fostered and developed at four distinct areas of the organizational theory: the Vision, which consists of the parent company overseeing the Co-Op; the Environment, which encompasses the environment of the Co-Op; and giving the members Purposeful Activities, which include the overall daily activities of the program. At the top of the model is providing a sense of Dignity and Choice for the members, which is considered to be the ultimate purpose of the program and what the other three areas are working toward. The present study discusses what happened within one agency but can also be used by other day programs to model quality services.

Vision

The Vision (Figure 1) of the emerging theory encompasses those parts of the program that set the stage for how it operates, from the initial creation to daily activities that can last for a long time. Day programs for people with intellectual disabilities often begin with positive, innovative ideas but get bogged down in the day-to-day operations and the initial vision becomes lost. Generally speaking, family members like how the organization strives to provide unique experiences for their loved ones that more closely resemble everyday life. One parent said it best by pointing out that the parent organization of the Co-Op " . . . seems to think outside the box and that is very impressive." Family members feel such an organization is " . . . extremely impressive and person-centered, and that is real important."

However, family members experienced programs in the past that started out with creative ideas that fell far short with the actual implementation of their vision. One parent stated their son

> . . . had been in another agency program 5 days a week and I just felt that (the Co-Op) could do a better job because I felt there were a lot of glitches (at the other program) and I wasn't hearing about those glitches at (the Co-Op).

Another family member said,

> The program we were in before was from another very popular agency and I was extremely disappointed in it. They touted the program as being a growth and development type program, and it was not. It was just the opposite. The kids . . . sat all day long. That is all they did was sit, and they moved them in groups and in busses with large groups of people and (the Co-OP) does not do that. When they go out in the community they go in small groups, not big huge groups of people. It is a more normal situation.

The vision of the program created at the outset sets the scene for a snow-ball effect that is ever-changing and growing. The upper level organization creates and drives the initial vision. The overall vision of the Co-Op started off with the idea that the Co-Op is "more focused on quality, not quantity." Parents see the overall vision as "an open community or a place where you can be you, and you are allowed to try new things. If you fail (at something) everybody is there to help pick up the pieces. You aren't frowned upon." The administrators set the tone for the vision for management who set the tone for staff. Senior staff set the tone for new staff. The vision also includes a feeling that the program is,

> more person-centered. Each individual is taken into account a great deal more than I had been experiencing before. Basically, I just think (the Co-Op) tried harder. I think they care more, and I am just more comfortable with the way any situations are handled. I just think (it is) a better-quality program than what is out there, from my experience as a parent.

The Co-Op seems to have been able to continue with its creative vision through the first 18 months of operating. At the Vision Level, the themes that evolved from the data to suggest why this may have happened include the organic structure of the program, oversight from top administrators available to the program and commitment and ability to continue to provide the resources needed for operation as initially envisioned. Built within each of the described themes is the way that each one depends on the ability of the program to establish good relationships at all levels of the Co-Op. Parents stated, "It is just a much better program, and I like to think that they consider our thoughts as parents."

Organic structure. Built within the vision of the Co-Op is an organic structure that allows it to change in conjunction with the needs of the members being served. Everyone is involved in how the Co-Op functions on a day-to-day basis. As such, its structure grows and changes constantly. This depends on the input of those around but always maintains the overarching mission and each person's role in the organization. The staff and members of the program both expressed this in the same sort of terms. Staff stated, "Everyone brings something different." The members shared similar sentiments, " . . . we all carry and bring something different that is not what we normally would do" in relation to other programs they have attended in the past.

Oversight. The vision of the Co-Op is maintained and kept going by providing daily oversight and support. The oversight established by administrators has helped foster good communication between management, staff, members, and families. The staff appreciate how the oversight of administrators and management helps guide them in their job duties. "The other program (I worked at) was a little different because there wasn't a lot of guidance as far as my job duties went", she said. "Here is your paper work; have at it." The staff also appreciate that the Co-Op building is "very open and at any given point, your managers are there." They feel that in organizations "when management is gone, it is all over" in terms of the quality of services for the members being served. The members of the program agreed and felt other programs where managers were absent were "not organized," and so they "dropped out and decided to do the Co-Op." The provided oversight also helped foster relationships with family members. Parents have faith the Co-Op will "continue to have a high-quality staff" because "both (supervisors of the program) really know what is happening" and that administration is not "so far removed" as in other programs.

The visible oversight of the program helped family members feel it was a safe, constructive place. One parent showed her concern with other programs by stating,

> I can't tell you how many times my (child) would call me from the cell phone to tell me that at transportation they had pulled into a gas station to get coffee and cigarettes, and everybody was sitting in the van and drivers were off having a cigarette.

The overall attitude and supportive nature of management was very appreciated. One person also stated of one individual involved in running the program, "(she) is great. She brings in a different sort of energy. She takes insane pride in her job. This is her purpose, and she fits great in whatever she is doing. She goes above and beyond her job." The communication set up by administration and managers being available helps family members and members of the program feel valued. That value translates to strong relationships between everyone.

Environment

Participants of the study felt that the way the Co-Op operates was the reason the vision had been carried out for the last 18 months. The way the site was designed and managed is an important factor in building the necessary relationships to keep it going. The main areas participants brought up were the intimate setting, the teamwork built into the Co-Op and the role definition and flexibility provided for staff.

Intimate setting

The Co-Op is situated within a larger business complex where a variety of organizations and retail businesses exist. The interior of the Co-Op has an open yet small feel to it that provides an intimate

setting appreciated by staff, members and family alike. The participants of the study indicated that not only the size of the site but also the high staffing ratios and the number of members being served lead to higher quality of services. "It is personal. With the less number of individuals, we are very close. It is all open and everyone knows where everyone is," one member stated. A parent stated, "One of the good things about the Co-Op is that they don't have as many young adults as they might have had" and as other programs are apt to have. The staff of the program expressed the same concepts and included how the intimate and open setting works with oversight from supervisors.

> Plus like it is very open and at any given point, your managers are there. I think, especially, in day programs where it is like classrooms, your managers are on the opposite end of the building they don't know . . . I have walked into rooms where staff are on the opposite end of the classroom where you couldn't see them throughout the door and they are playing cards. People are sitting up toward the T.V.

Teamwork

The intimate and open setting of the Co-Op helps to foster a strong sense of teamwork and is considered part of the environment factor of the model in Figure 1. A program might have the best setting but lack an intimate feel. The teamwork starts at the staff level but is structured by the administrators of the program. The members commented that, "without the right staff, you are just like blahhhh." Family members agreed and expressed how they feel that the staff is an integral part of the Co-Op's success. While they saw the way the physical environment of the Co-Op worked, they "also think personalities" are important and that "this can change because they are basically direct care staff, and I am sure they don't get paid enough. But the present personalities (at the Co-Op) seem to work so well with the members." Family members also felt "the people that created the program are very much involved in the implementation, so I have faith that it is going to continue to have high quality staff."

Participants felt that the teamwork went beyond just staff working well together. There was also recognition of the teamwork involved among the members of the program. One aspect of the vision in creating the program was to include the members being served in the hiring process of new staff. "After each interview, (the supervisor) asks the consumers their opinions. They are a big part of picking who gets hired." When members were asked how they felt being included in the process, one stated, "that was awesome! They were asking me questions. It was very cool." Overall, the way the staff work together and with the consumers leaves the consumers feeling, "staff are nicer and they help us a lot. I just like being with the nicest staff here."

Hiring obviously influences this teamwork-based environment. One staff member discussed another program they had worked at where "a lot of people I worked with don't give a crap." The staff further stated they felt attitude "has a lot to do with" being a quality staff member. "It really has a lot to do with the person you are hiring to work." The prevailing attitude of the staff in the focus group feels "we are working for them." Overall, the staff said,

> we have had some bumps and it is hard to find the right person and nobody is perfect, but I think they have done a good job meshing the staff personalities. We all feed off each other; and we all carry and bring something different. That is not what we normally would do.

Role definition. The staff of the Co-Op talked a lot about the purpose in the program. They stated their goal was "getting (participants) out of their houses, stimulation, social interaction and learning something. It is giving them more than what they would get at home or in the group

home." They seemed to take pride in their jobs and the fact that they were given clear, defined roles and the responsibility and trust to carry them out. The staff made several comments during their focus group about how they interact with parents, the members of the Co-Op and the supervisors. Overall, having their roles defined well gave them a feeling of accomplishment and purpose.

Member activities

Another area of focus was the activities provided during the day for the members of the Co-Op. The focus groups discussed what the vision of the program was from the outset and how, while the environment was important, the most essential aspects of the program were the actual activities provided. All of the focus groups agreed that the necessary components of activities include productivity and purpose and that they are stimulating and offer variety. This finding is consistent with previous research (e.g. Reid et al., 2001b; Vlaskamp et al., 2007).

Productive activities. When comparing the productivity of the Co-Op to other programs, one family member stated,

> Their time is well spent, and one of the problems that I experienced with another program was that most of their time was down time; all day was down time, and I never get that sense here. They are always doing something that is age appropriate and that helps with learning and social skills.

The members of the Co-Op talked about the things they did during the day, including "doing the artwork," "we go to fair," "went to the Jello museum" and "doing goals." The staff felt that being productive was "a big part of the program." They further stated that the biggest part of being productive was giving the members an outlet for "self-expression."

Purposeful. While being productive was important, most felt that the activities needed to have a purpose. However, there was a difference of opinion between focus groups regarding which types of activities had purpose for the members. Family members expressed a desire to have more concrete purposeful activities. One parent said, "I am a big promoter of some kind of academics; I like (my son) to be doing a little bit more reading" or learning "money skills." The intellectually disabled members who attended the program were happy "doing artwork," or as one person stated, "I like to go out and help out other people in the community. I like to volunteer." However, there were a number of members who did mention that they liked doing "their goals," which are set academic areas members work on such as learning to read more proficiently or how to manage money.

All of the study participants felt that being social was also a productive skill.

> (Members) and staff get together, and they are able to actually talk about common problems or situations that are normal at this time of life, and it is facilitated in such a way that everybody is encouraged to talk about boyfriends, girlfriends, dating, whatever. Then the appropriate ways in which to participate in those activities is discussed. I like that because it is not like sitting down and having a teaching session. It is a bunch of age appropriate people all sitting down and talking about things that are happening.

Stimulating. One consumer made it clear how stimulating the Co-Op is by describing being able to paint with her hands. "That was cool because we got our hand into it. Some of us do not know exactly what it feels like, but once you get the feel of it, it is not really disgusting." This particular

member was also pleased that there was a variety for the members, meaning that they all didn't have to do the same thing.

> I mean some people like (finger painting) and some people don't. Some people don't mind getting their hands filthy. Now me, I don't care. If I get dirty, who cares? If you don't want to get dirty you don't have to.

It was the overall experience that was desirable, and the fact that they could choose to participate was part of the experience. Overall, there was a feeling the program provided "more life" in the members' day compared to other types of day programs, as one participant so eloquently put it. The daily experiences reassured family members that their son or daughter was benefiting from his/her time at the Co-Op. One family member said, "I think there is a lot of variety. They don't get bored doing the same thing every time they go there. It is something to look forward to, and I think they do. At least my son does."

The staff of the Co-Op found that the variety of daily activities helped them to stay interested in their work and as such, they looked forward to working at the Co-Op each day. "I feel like I use (my degree) more here as far as I feel like I use my brain more here." Another staff stated,

> I like it because it is not the same thing every day. And you get hugs and high fives all day. You get paid for hugs and high fives. And the simplest little thing that you could accomplish in one second and once you work with that person and once they accomplish that it is like, a really cool feeling.

By providing an environment that encouraged growth for members, the staff, in turn, felt appreciated.

Member level

The purpose of any day program is to provide an environment that adds to the overall growth of the individual being served. Built within this paradigm is the theory that growth is achieved by providing an environment that helps people assessed with intellectual disabilities become normalized into society rather than isolating him or her. The members of the day program expressed how being given choice and being treated with dignity helped them to feel similar to "normal" people who do not have a disability. Overall, being treated with dignity helped them to feel like valued members of society. The vision of the program, the environment of the program, and the individual activities are all focused on providing the dignity and choice the members strived for to feel valued. Most programs start off with a good vision, but without the ability to treat the members of the program with dignity and respect through choice, the program fails. The members of the program expressed their desire for normalization in subtle ways such as saying they wanted to "buy things" when asked what they liked about the mall. One parent stated more clearly that they "like the attention that the program gives to different aspects of persons' life; academic, physical, social, emotional, artistic. It really reflects more of our lives."

The key to normalization for the members were the choices they were given during the day. One member articulated that he felt "more challenged because you have more options on what you want to do." Another member stated, "I like that there's so much flexibility. You get to do things when you want instead of having someone tell you when you have to do something." It was the flexibility of daily activities and choices, which gave the members the feeling of being treated just like everyone else. Some members did express dissatisfaction with being denied their choices at times. "It is hard sometimes because of everybody's schedule." Parents appreciate choice but in a safe environment. They would prefer members were guided to make safe and appropriate choices. For

instance, one parent said they liked "the idea of independence" but wanted to make sure whatever choices made led to improved skills. Family members wanted purpose to the choices made too.

> For example, they said on Thursday they were going to Super Walmart. But I'm thinking what is the purpose of going there? Are they buying something? Does she have a list? She will write it down, but she doesn't really know the reason why she is going. I think that would be important for the young adults to know the purpose of taking a trip. What are they basically going for?

Value/dignity. The process of developing the Co-Op and creating a good vision, environment, and productive member activities drives the ultimate purpose which is to provide members assessed as having intellectual disabilities with a sense of value and dignity in the community. The members of this program expressed feeling valued by mentioning that staff take the time to "help me through stuff" or "I like when they smile at me and I smile back" along with the other comments about feeling that the program is flexible in meeting their needs and provides them choices. Being valued is a sentiment shared by other stakeholders as well. Family members also expressed feeling valued by the program in that "with (the Co-Op), when I met with them, they told me what it was going to be like. It has lived up to my expectation. The other programs basically lied." At other programs, they had experience with

> we had meetings with all kinds of people within the agency and no one paid any attention at all. They would give us lip service and they would turn around and walk away with the same thing happening over and over again.

Despite feeling valued, family members also expressed some frustration with a lack of communication during outings as well as the purpose of specific outings.

Relationship building

Relationships are at the center of the model because during the focus groups, participants made comments about how it is the relationships within the organization that create a positive environment. The staff shared that they feel trusted to do their jobs and are able to communicate with the supervisors and administrators easily. The family members felt the Co-Op discusses things with them more than other programs and so have a higher degree of trust for the welfare of their intellectually disabled family member. For instance, one parent felt the Co-Op "attracted me because of the people, and any time I had a question, it was answered immediately. Anytime I had a concern, it was addressed immediately." The relationships between the members and the staff and supervisors are what helps them feel the staff "are helping me with stuff" and empowers them to feel valued members of society.

Discussion

This study had two main purposes: to evaluate the program and to explore how participants experienced the program as compared to other programs, which they had been a part of. While exploring their experiences, it became apparent that they were highly satisfied with the program. As such, the study sought to determine what factors made this program so successful. The evaluation portion of the study provided the organization with the feedback they used to find out what was working, so the administrators could plan continued success of the program. The study goes

one step further and gives meaningful examples for how to include individuals assessed as having intellectual disabilities into society as a whole.

Social role valorization

Social role valorization stems from Nirje's (1994) normalization theory, a response to conditions prevalent in institutions in 1969. The principle of normalization has been used as a blueprint for bringing people out of institutions into community settings (Kumar et al., 2015). Nirje (1994) defined normalization as "patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 19). The term is used to explain why it is so important to have people live in the community rather than in institutions. In layman's terms, it means ending the practice of putting people who are not considered "normal" out of sight into institutions, so that society does not need to see them and can ignore their existence. Institutionalizing made those institutionalized "the other" or "not human" and ultimately dehumanized by society.

According to Kumar et al. (2015), Nirje's colleague, Wolf Wolfensberger (2011), felt that the term "normalization" was too easily misunderstood and so came up with social role valorization, a term based on role theory in sociology. This study was not meant to be an extensive analysis of social role valorization versus normalization theory or to delve into the debate if they are the same or different theories. In fact, this study did not consider either theory as a possible theory when the study began. The authors simply wished to explore how the Co-op made participants feel more included. Grounded theory studies do not start with preconceived ideas that are tested. Instead, the data are supposed to lead the researchers to the conclusion through inductive reasoning. The data from the study led the authors to social role valorization. In assessing the New York day habilitation program, the authors discovered how important it was for the individuals served in day program-like settings to be treated like everyone else and to be included in decision-making and daily choices. Ultimately, the idea of giving members the role of decision maker by asking them what they want and following through with what they want was key for them in feeling included. While Nirje (1994) and Wolfensberger (Kumar et al., 2015) supported the idea of choice in their formulations of both theories, the authors felt, like Kumar et al. (2015), that social role valorization fits better than normalization in this study. Participants made it clear that just being in the community was not enough, that they needed specific things to feel fully included, such as choice, respect, equity, and, above all, the dignity of having those around them include them in decision-making in their day to day activities.

It can be argued that the Co-Op took the extra step to truly "include" members in ways they had not experienced in regular day programs. Members in this study felt fully included because the formation of real relationships was facilitated and encouraged. The current study builds on current research that underscores the importance of belonging and how essential being part of a community is to everyone, including people assessed as having intellectual disabilities (Strnadová et al., 2018). Good relationships help people feel as though they belong and are a part of a community. This would make sense but is surprisingly overlooked when planning day programs. Including people into society, people who are valued, as Wolfensberger (2011) says, can only happen if real relationships occur. What good is it to be in society when there are no meaningful relationships being formed?

Previous research (e.g. Garrote, 2017; Overmars-Marx et al., 2018; Saarinen et al., 2018) found that relationships for people assessed as having intellectual disabilities are generally lacking.

Overmars-Marx et al. (2018) found that neighbors of individuals assessed as having intellectual disabilities perceived them as having behaviour problems and were difficult to approach. A long-itudinal study by Saarinen et al. (2018) found that without proper resources, people assessed as having intellectual disabilities lose what few relationships they do develop. Garrote (2017) found that while children with special needs were perceived to "lack" social skills, "mechanisms" within the special education program helped to facilitate social participation. We cannot assume that simply placing people with those we perceive as "normal" will foster relationships. As Garrote (2017) found, care must be taken to facilitate relationships and appropriate mechanisms need to be in place.

The Co-Op sought to put mechanisms in place that would result in relationships being devel-oped at every level. Administrators worked to be available and instituted regular times to check in with members, staff and family members. A major purpose of the Co-Op check-in was to plan activities that members really wanted to participate in, thereby giving them choices. The envi-ronment was set up to be welcoming and open, further fostering communication and the feeling of being valued and supported. If the members, family members, and staff did not feel the organi-zation valued them, they would naturally hesitate to trust enough to form relationships within the program. Future and current day treatment programs can endeavor to increase the esthetics of the day treatment environment. The staff, participants and family members all indicated that the overall environment helped them to feel respected. This sentiment makes sense when considering that developing a program that is comforting and inviting requires a great investment by the organization. That investment shows staff and participants how much the organization values them. Not surprisingly, work environment has been associated with overall employee satisfaction and intent to stay (Al-Hamdan et al., 2017).

Implications for practice

This study underscores the importance of including individuals assessed as having intellectual disabilities in decisions about their day-to-day life and treating them with dignity and respect. While such a notion seems simple and obvious, individuals have historically not been included in deciding what they do in their daily lives. From a policy perspective, most regulations at state and federal level for day programs or day habilitation programs focus on activities, health care, pro-viding supports for behavioural challenges (Friedman, 2016), teaching skills and becoming independent. There is little or no focus on facilitating relationships and yet, this study shows that it is an essential component to feeling valued in society. While teaching behavioural and independent living skills are important, federal and state regulations should add mechanisms that will facilitate relationships for individuals as well as open communication among staff, family members and members of the program.

The idea of including participants and family members in the creation of a day program con-tinues to be a novel idea and may not be possible in every situation. This program was unique in that they were able to keep their program small and tailored to this particular group. The program also chose individuals to participate based on the likelihood that they would thrive in the program. The success of early institutions was also predicated on being able to control the number of participants as well as choose people who had the highest chance of benefiting from the program (Trent, 2016). Once institutions increased their populations and stopped selecting individuals, the quality rapidly declined (Trent, 2016). History (and this study) indicates the need for small, cooperative type situations where individuals are seen as equal. However, the Co-Op's success was not simply based on the boutique-style environment. As Wolfensberger (2011) foresaw in social

role valorization, individuals also findthe way staff interact with them and the overall environment to be important. The role of the staff here was to facilitate members' choices and feelings of empowerment. In turn, the staff felt empowered by the organization. This helped to maintain the vision, which is to provide choice to members and staff. Staff were then motivated to support and empower the participants and their families. While all-day programs may not be able to keep their groups small and completely tailored to each individual, they can replicate the ways in which staff was treated by management. Previous studies concur on the influential role staff play (Petner-Arrey and Copeland, 2015)

Limitations

The small sample size and specific population being studied limited generalizability. In addition, qualitative data do impact the extent to which we can extrapolate the findings to other programs. While this study has limited external validity, it does give a clear picture for how this program style can lead to an increase in empowerment and ultimately of dignity and worth for participants. Future analysis should work to quantify the key indicators of social role valorization identified in the focus groups to establish best practice parameters (Shogren et al., 2009).

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