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Reimagining the Role of Human Services Workers: Staff Experiences of a Social Change Initiative

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ABSTRACT

Despite recognition that social inclusion is a primary goal within the field of human services, people with disabilities continue to live lives of clienthood, marginalisation, and exclusion and human services staff struggle to make social inclusion a priority. The purpose of this study was to explore the perspectives of human services staff about their experiences of an organisationally inspired initiative intended to change the focus of their everyday practices to better facilitate the social inclusion of persons with disabilities. A qualitative case study was used to gather observations, field and reflective notes, semi-structured interviews with staff ($n = 15$), and reflexive journaling. Thematic analysis of the data led to three themes: (a) challenges, old and new, (b) needing (careful) change, and (c) creating, learning and working together. These findings highlight the complexity of how to create change in the field of human services, but also demonstrate how innovative approaches have the potential to shift and reimagine how human services workers can better support people with disabilities in living meaningful lives.

KEYWORDS

Case study; change; citizenship; disability; innovation; services; social inclusion; support workers

Introduction

'That's my phone, sorry. Excuse me just a moment.' Sandra, a participant in our study, answers a phone call during the study interview. After she hangs up she says, 'Well, how long have I been sitting there? I have 3 more messages. It doesn't stop. It just doesn't.'

Sandra's interview quote reflects some of the everyday challenges and realities of working in the field of human services¹ in support of people with disabilities.² The demands of ensuring housing, medical and personal care needs are met are significant and at times, relentless. Meeting these needs alone does not equate to a meaningful life for people with disabilities. Yet because of their urgency, they may often become the focus of the supports provided and of the workers who provide them. What then becomes of supporting social inclusion, belonging and engagement in community? What becomes of supporting citizenship? Where and how do these needs fit into the everyday responsibilities of workers who support people with disabilities?

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There exists a tremendous history of mistreatment, abuse, marginalisation and oppression of people with disabilities around the world (Charlton, 1998; Shakespeare, 2006). Despite the adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006, many people with disabilities continue to face considerable inequalities, such as poor access to health care, education and employment; being subject to prejudice and disrespect; and being denied autonomy in decisions of everyday living (World Health Organization, 2011). For people with intellectual disabilities, and particularly those with more severe intellectual disabilities, these inequalities endure and are significant (Hall et al., 2005; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009).

In a systematic review of empirical research studies between 1996 and 2006, Verdonschot and colleagues (2009) examined community participation of persons with intellectual disabilities. The authors reported that overall, compared to persons without intellectual disabilities and members of other groups experiencing disability, participation in community life remained considerably lower for persons with intellectual disabilities. Specifically, they found that persons with intellectual disabilities were 3–4 times less likely to be employed; had smaller social networks; and their engagement in community, civic and social life primarily occurred within the company of a services worker. The general nature of these findings reflects other work in the area of social outcomes for people with intellectual disabilities (e.g. Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Gray et al., 2014; Hall et al., 2005) echoing the call for continued progress and change to improve their lives.

Currently, workers in the field of human services are considered essential in the lives of people with disabilities. Among the approximately 14.3% of people in Canada with a disability, over half require assistance with every day activities (Statistics Canada, 2006). While families are most often the main care providers, 13.4% of these individuals rely on the support of human services organisations to assist in their daily living (Statistics Canada). For people with an intellectual disability, in particular, these workers play a pivotal role in the quality of their lives, which includes helping to establish and maintain their social networks (Abbott & McConkey, 2006; Robertson et al., 2001). In a two-part study examining staff attitudes, Bigby and colleagues (2009) reported that although staff felt inclusion and choice were important for people with intellectual disabilities, these were viewed as unattainable in practice, particularly when supporting individuals with severe intellectual disabilities. Exploring the social networks of people with intellectual disabilities in residential settings, Roberston and colleagues (2001) reported that these networks were comprised of three or less people and that staff and family were the primary sources of practical, informational and emotional support. Finally, Abbott and McConkey (2006) explored social inclusion from the perspectives of people with intellectual disabilities using focus groups. Findings of their study highlighted four barriers to social inclusion. Among them was the role of support staff and services managers with regard to their lack of availability, the requisite of always having to report to them, the need for their support to attend activities and their role as caregivers. Participants articulated the importance of being listened to by support workers and being supported to make autonomous decisions among potential solutions to overcome these barriers (Abbott & McConkey).

There is broad recognition that social inclusion is a primary goal within the field of human services in the Western world (Bigby & Wiesel, 2015; Johnson, Douglas, Bigby, & Iacono, 2012). Although, the terms person-centred, self-determined and individualised are now used to represent a shift away from group-based services towards more autonomous alternatives

for people with disabilities (Kendrick, 2006), in many ways people with disabilities continue to live their lives at the margins of our society with identities of clienthood or service user and not of citizen (Shakespeare, 2006). Furthermore, the field of human services has been criticised for contributing to the dependency of people with disabilities (Abbott & McConkey, 2006), and their role in supporting social inclusion is still unclear (McConkey & Collins, 2010). Yet, 'the roles that support staff undertake or which they are equipped and encouraged to fulfil' may be a strong determinant of social inclusion for people with an intellectual disabilities (McConkey & Collins, p. 692). Given the pivotal nature of human services workers in the lives of people with intellectual disabilities, researchers have proposed various approaches to stimulating change to align their everyday practices with the values underlying inclusion. Recommendations have included such things as changing the nature of recruitment and training, creating safe meeting spaces for staff to share experiences and explore policy, as well as keeping staff accountable through the implementation of procedures to oversee their practices (Bigby, Clement, Mansell, & Beadle-Brown, 2009). Bigby and Wiesel highlighted the importance of creating strategies and recognising the staff skills required to support the engagement of persons with intellectual disabilities in community life in order for them to move from a position of mere presence in the community to being meaningful participants within it.

Purpose

The purpose of this study was to explore the perspectives of human services staff about their engagement in an organisationally inspired initiative intended to change the focus of their everyday practices to better facilitate the social inclusion of persons with intellectual disabilities. The specific emphasis was how human services staff initially experienced the change initiative and its accompanying processes. The need for change in the field is evident given the continued marginalisation of people with intellectual disabilities (Hall et al., 2005; Verdonschot et al., 2009), the significant role of human services workers in their lives (McConkey & Collins, 2010) and the call for new strategies and approaches to creating change in the field (Bigby & Wiesel, 2015). Rethinking how disability policy goals such as choice, participation and inclusion can be translated into practice for people with intellectual disabilities and for those who support them is critical (Bigby et al., 2009). While the long-term goal of the organisational project is to improve the lives of people with intellectual disabilities, the focus of this study was how staff initially experienced their involvement in the project, a necessary step towards understanding and creating meaningful change. The project, which is referred to as Project Citizenship, uses the concept of citizenship as a lens to both frame and guide the initiative.

Citizenship

Citizenship has traditionally been associated with rights-based discourses concerning civil, political and social citizenship (Marshall, 1950). However, more broadly construed citizenship may be understood as the realisation of equal opportunities to take part in society (Nirje, 1992). Other terms commonly used to describe citizenship consist of social inclusion, community participation and autonomy (Brannelly, 2011). Essentially, citizenship is a developing concept that can be used as a way to explain relationships between people, groups and

society (Oliver, 1993). These relationships are well illustrated by Knox (2006), whose definition of the essence of citizenship we employed in the current study in keeping with its interpretation within Project Citizenship. According to Knox, citizenship is comprised of a number of components:

A person being integral to their community, a person who both is valued and respected, and feels valued and respected within their community; a person whose inherent dignity as a human being is upheld; and a person whose uniqueness is not only recognized but is also considered a valuable contribution to a rich and dynamic societal fabric. (p. 3)

While interpretations of citizenship are debated (Gilbert, Cochrane, & Greenwell, 2005), there is an agreement among scholars who study disability that people with disabilities have and continue to be systematically denied meaningful opportunities to participate in activities that facilitate a sense of citizenship (Oliver, 1993; Yeung, Passmore, & Packer, 2008).

Method

A qualitative case study was adopted for this study. This type of naturalistic inquiry takes place in real settings in order to better understand the perspectives of participants and to provide depth to the issues under exploration (Creswell, 2013; Stake, 1995). This approach supported the exploration of a bounded system or case (employees from a human services organisation) over a period of time, through the collection of detailed and relevant information through multiple sources (Creswell, 2013). Approval for this study was received from a University Research Ethics Board. Informed consent was provided by all participants and the Executive Director of the human services organisation where the staff were employed. Pseudonyms are used to protect individual confidentiality.

Context and Participants

This study emerged through collaboration on a University community service-learning partnership grant between the Executive Director and Senior Managers (hereafter referred to as senior leaders) at the Skills Society and the first author, who was an assistant professor at a Canadian University. The Skills Society is a not-for-profit human services organisation that 'provides support services to children and adults with developmental disabilities, survivors of acquired brain injury, and their families' (Skills Society, 2016a; About section). Their vision encompasses 'a community where all individuals are valued citizens deserving respect, dignity and rights' (Skills Society, 2016a; About section, Vision). As part of this vision, senior leaders at the Skills Society developed an initiative called Project Citizenship which was the basis for the partnership grant. Informed by social innovation strategies including 'new learning, technologies and methods blended with the best traditional approaches to social change' (Etmanski, 2015, p. 24; Weinlick, 2010), the project involves the creation and sharing of stories highlighting the contributions and talents of people with disabilities 'to inspire, shift attitudes, build empathy and move people to action' (Skills Society, 2016b; project Citizenship section, para. 2). Specifically, the Skills Society's employees have been engaged in identifying, creating and documenting stories of citizenship, of and with people with disabilities, through the use of various media (photography, film, art and narrative) in collaboration with the people they support, their families and allies, community members and university students through community service-learning courses. These 'citizenship' stories

and the processes involved in identifying, creating and documenting them are intended to contribute to social change (i.e. greater focus on the citizenship of people with disabilities) both within the everyday practices of the Skills Society and beyond. Storytelling was chosen by senior leaders because it 'is widely recognized as an important tool for enhancing quality of life' (Grove, 2015, p. 30). Visual stories were deliberately selected as the primary media to make them more accessible to people with intellectual disabilities as they experience many barriers to sharing their stories (Cameron, 2015; Grove, 2015) through other (non-visual) forms. One example is the story of a young man who initiated a school basketball league and the ways in which he positively contributes to the lives of the children and staff at an elementary school. Another story documents the entrepreneurial skills of a young woman who creates and sells crafts at a Farmers Market. The stories are diverse, yet connected in the ways in which they collectively attempt to share the hopes, talents and contributions of people with disabilities.

The purpose of this study was to examine how the Skills Society's employees experienced participation in Project Citizenship and its accompanying processes in its inaugural year. Purposeful sampling (Creswell, 2013) was used to recruit 15 mid-level management Skills Society's employees who were engaged in the project early on. In its first year, senior leaders at the Skills Society focused much of their attention on staff who provided mid-level management within the organisation in order to establish and further develop the project. At the time of the interviews, participants (12 women and 3 men; mean age = 40 years, 6 months) held the following positions: community support worker ($n = 2$), team leader ($n = 4$), manager of community supports ($n = 7$), senior leader ($n = 1$) and coordinator ($n = 1$). The general duties associated with these roles involved such things as: managing supports and developing individual support plans, supervising and training staff, working with and advocating for people with disabilities and their families, managing budgetary responsibilities, and monitoring best practices. On average, participants had been employed in these positions for approximately 5 years. All had previous experience working in the field of human services ranging from 4 months to 28 years, with an average of approximately 14.5 years. We have not provided a table cross-referencing these demographics with participant pseudonyms in order to protect their identities.

Data Collection

Observations and Field Notes

As the senior leaders moved forward with Project Citizenship, they facilitated biweekly 'think tank' meetings to share, explore and engage in creative problem solving processes with staff, based on social innovation and design thinking (Etmanski, 2015; Weinlick, 2010; see also Skills Society, 2016c for a video about the think tank process). The goal of the think tanks was to create an environment of reflective openness to encourage staff to use divergent and convergent thinking in order to challenge assumptions and to inspire new ways of supporting people with disabilities, in line with the goals of Project Citizenship. These new ways of supporting people were intended to facilitate citizenship in their lives and would be the focus of the documented stories. Although these meetings were primarily attended by the mid-level management, who were interviewed for this study, people with disabilities as well as family and community members were also welcome. The first or second author regularly attended these meetings as participant observers (Creswell, 2013; Stake, 2010) in

the first two years of Project Citizenship. The third author also attended on several occasions. During and following the meetings, we took field notes (Creswell; Stake), documenting our observations and interpretations of the processes, activities and outcomes. Importantly, the meetings also provided an opportunity to establish rapport and build relationships. We also engaged as participant observers in numerous other settings with the Skills Society. These included attendance at organisational and annual general meetings, special events showcasing Project Citizenship (e.g. art exhibits and community events), and at the Citizenship Action Hall where university students, Skills Society staff and people with disabilities gathered to explore citizenship. The first and second authors also collaborated on several presentations with senior leaders to share the project and to contribute research updates.

Semi-structured Interviews and Reflective Notes

Semi-structured interviews with participants were conducted by the third author. A semi-structured interview guide was used to probe participants' experiences of Project Citizenship with embedded flexibility to allow them to discuss what was most relevant to them. The guide was initially developed in collaboration with Skills Society's senior leaders and subsequently modified by the first and third authors based on how the interviews transpired. Examples of interview questions included:

- (1) What does citizenship mean to you? Is citizenship important for people with disabilities?
- (2) What has been your experience of Project Citizenship? How do you envision your role within it?
- (3) Has Project Citizenship changed your day-to-day job at all? If yes, in what ways? If not, why do you think this is the case?
- (4) What do you think the impact of Project Citizenship will be within the Skills Society and beyond?

The first interview was conducted five months following the introduction of Project Citizenship and the last interview took place at 11 months. The interviews were digitally recorded and transcribed, were held in a private location selected by participants, and lasted on average approximately 43 min. The third author took reflective notes documenting her experiences interviewing participants, noting interesting aspects of the individual interviews, and highlighting critical information (Patton, 2002).

Reflexive Journaling

Each member of the research team kept a reflexive journal during her involvement in the present study and in Project Citizenship. These notes contained descriptions of meetings, interviews, discussions and events. The notes also contained personal reflections about Project Citizenship itself. We explored the ways in which the project was unfolding, as well as questioned and considered the methodological rigour of the study, assumptions tied to disability and critiques of the intentions, processes, and outcomes of Project Citizenship. Importantly, this type of reflexivity added depth to our interpretation of the interview transcripts and provided a critical method by which to consider our own biases, assumptions and vulnerabilities (Creswell, 2013).

Analysis

The interview transcripts were the primary source of analysis. The observations, field and reflective notes, and reflexive journals offered a critical lens through which to question, challenge and support the analysis and interpretation of the interview data. We engaged in analysis using what Creswell (2013) describes as a process of 'analysis of themes'. We first performed 'within-case analys[e]s', examining each individual transcript in depth and developing tentative themes. We then performed a 'thematic analysis across the cases' to identify commonalities and differences (p. 101). The first two authors met on several occasions to contemplate and discuss the themes and the third author provided feedback on their relevance based on her in depth knowledge of the case and having performed the interviews.

Study Quality

In line with the study purpose and the approach we employed, we selected a number of validation strategies focused on process, as highlighted by Creswell (2013), in order to document and strengthen the quality of our work. Case study requires that researchers engage over a prolonged period of time in the field using persistent observation. As a research team, we maintained a close and consistent presence within the Skills Society that allowed us to develop trusting relationships with participants and to learn about Project Citizenship and its accompanying processes. Through our collection of multiple sources of data, we were able to triangulate and further corroborate our findings. Working as a research team afforded us the opportunity to debrief with each other and to add to our individual reflexive efforts. Finally, we have attempted to provide rich descriptions in our writing of both our process and findings so as to facilitate quality judgements for the reader (Creswell, 2013).

Results

The following three themes represent a collection of staff experiences of the initial involvement in Project Citizenship and draw attention to the multifaceted and complex nature of work in the field of human services. Although discussed separately, the themes are interconnected in keeping with the nature of this work and the ways in which staff described their experiences.

Challenges, Old and New

A prominent theme across the interviews, as evidenced in the opening quote of this paper, reflects the challenges staff experienced in their roles as human services workers. The complex, demanding and persistent nature of these roles was evident as staff described their day-to-day responsibilities. Many spoke about the substantial amount of work they needed to perform without the time and resources to do it and how 'every year we're being asked to do more and more with less and less [funding]' (Eve). Being 'busy all the time' (Becky), getting 'bogged down with the daily necessities, the challenges of budget' (Carla), and 'dealing with crisis ... and harsh realities' (Robert) were among the descriptors used by participants to articulate the incessant and intense nature of their work.

Participants were highly conscious of how these demanding components could lead to routine and narrow ways of providing support. Julie said, 'people get so stuck in their role of looking after those day-to-day things ... people's health and safety have to be assured, but I think there's more'. Julie went on to say, 'it's gotta be getting them into community and, we can't just have people surrounded by paid supports'. Similarly, Jay shared, 'it's a balancing act. Like, how much time do we focus on that stuff and making sure service agreements are signed every year and how much do we wanna focus on making sure that people are having good lives?' Staff recognised the importance of providing holistic support that addressed the immediate care needs of people and that 'focus[ed] on the humanity of the people we support' (Kelly). This was summarised by Lisa who expressed, 'we're so busy you know trying to figure out people's lives that we don't spend enough time letting them figure out more on their own and really get involved in the things that are meaningful to them'.

In addition to these issues, participants highlighted how, for frontline employees, there was an added layer of challenges. Robert noted that the Skills Society struggles with 'keeping and retaining and hiring good staff'. This was partly explained by Eve who said, 'one of the issues that we face is that we are not able to pay our staff enough so quite often our staff are working two or three jobs'. Kelly highlighted an irony of Project Citizenship. She stated, if we're supposed to be facilitating and focusing on the humanity of the people that we support [and] we don't extend that same respect to the person [front line staff] you're employing ... what kind of message is that ...?

Adding to this, Jay indicated that frontline workers 'can be quite isolated' in their roles. Working in the field of human services came with significant challenges, which were intensified by the types of services positions and life situations of staff.

The introduction of Project Citizenship added a new dimension and additional challenges to an already-demanding situation for employees. In the beginning, some staff felt Project Citizenship was 'a little overwhelming' (Lisa), with 'some confusion' (Joan), and were 'a bit skeptical on a long-term basis what they [world cafés and think tanks] accomplish' (Jay). The nature of how stories were to be captured (i.e. through different forms of media) also led to some anxiety on the part of staff. Fiona explained, 'what holds me back quite a bit is the technology'. Lisa summarised, 'I think people are afraid. You know ... not everybody can film, not everybody can work with art, not everybody can write ... it's intimidating to begin with'. Working with the university students, while viewed positively overall, came with challenges. Joan stated, 'we are not having as many students as we had hoped' and Becky shared that 'coordinat[ing] things with the students has been difficult'. Finding time was a common challenge across staff's day-to-day activities and was amplified through Project Citizenship. 'It's hard to set aside that time but you just need to do that' said Julie. Kelly shared, 'I'm not able to participate as much as I would like because I'm front line support'. Although participants identified front-line staff as critical to the success of Project Citizenship, how to involve them meaningfully given their unique constraints was viewed as important to address.

In discussing challenges to Project Citizenship, Robert explained:

A lot of the barriers [to the project] are basically set in place by some of the companies we work for, by the guardians, by parents, by the people, by our own sense of you know 'if that person gets hurt when I'm supposed to be taking care of them, 'how will I deal with that?'

Barriers to Project Citizenship and facilitating citizenship were complex, multi-layered and further complicated by assumptions about people with disabilities. This was captured in the following quote from Robert:

We just thought we needed to be with him 24 h. That's what his public guardian wanted and as the years went by we just noticed he's miserable when we're around. But if he can sneak off somewhere, I've noticed that he's like talking to people and they seem to be interacting with him just like he's anybody else. So we went to the guardian and kinda talked to her ... we actually worked with some of our staff and came up with some things ... and then, it happened so quickly. So by the time we finally gave him his freedom, he's been planning it his whole life. Right?

Although a range of barriers were discussed related to Project Citizenship specifically, overwhelmingly staff expressed the project was important and there was a need for it.

Needing (Careful) Change

The second theme is characterised by the need to support people with disabilities in attaining meaningful lives and the careful consideration of the processes involved in doing so. The importance of 'carv[ing] out some time and be[ing] very purposeful' (Carla) and placing emphasis on enhancing the citizenship of people with disabilities was reinforced by all participants when they discussed the continued marginalisation of the people they support. As Sandra stated, 'we've come a long way since I started 28 years ago ... but society is still very naive in terms of acceptance'. Likewise, Jenny said 'it's taken a long time to get where we've come but there's a lot of work yet to do'. Staff shared numerous specific examples of how people with disabilities were persistently marginalised. Descriptions included 'the forgotten aunt or uncle who are in an institution', (Nicki), 'the perpetuation of too many small pockets of special little programs for people with disabilities' (Jenny), 'people [who] are labelled and ... put into positions of being lesser' (Andrea), '[people] being denied services' (Jim), and 'lots of barriers ... [to being] valued members of the community' (Eve). Participants were unanimous about their desire to provide better support. This was captured by Jenny who said, 'we want people to be more connected, we want them to feel that sense of citizenship in their community, to be true community members, to have fulfilling lives where they feel that they belong'.

Staff recognised the need to change their daily work and that this needed to be done carefully. In particular, staff shared that the processes involved in creating a story of citizenship needed to also reflect citizenship. This was often articulated using the word 'choice' and in discussions that focused on what people with disabilities want for their own lives. For example, Jay said 'we're leaving it up to this individual ... to let them decide how, how they wanna tell the story ... it's their story'. This was echoed by Andrea who shared, 'I think almost fundamental in this kind of project ... [is] how are they involved in their own story telling and story making and what story do they wanna tell?' In this regard, a participant also talked about ensuring individuals supported by the Skills Society did not have to participate in Project Citizenship (i.e. have their story documented). He said, 'it's essential [saying no], it's as important as the ability to say yes' (Jim). Staff shared an understanding of citizenship in line with the one promoted through the project, however, there was also recognition that what citizenship looked like in practice 'can be very diverse and very different for each person' (Julie) but that the stories could also demonstrate possibilities that people with disabilities, themselves, had not considered.

When asked about the potential impact of Project Citizenship, staff expressed their optimism for change within the everyday practices of the Skills Society and the field of human services. Lisa shared, 'we talk a lot about person centeredness ... this is the first time that

I've actually seen us sit down and do something, and especially on such a scale. It's more than a thought, or an idea or a conversation'. Carla shared that 'Project Citizenship comes with an energy and a newness. It's just shaped a little bit different'. The personal impact of engaging in creating stories at times surprised staff and provided an opportunity to view their work and the people they support differently. One staff said of a co-worker, 'the impact that [creating the story] had on her because she saw a different side of [him] ... she said that it was so cool to see him in a different light' (Julie). Nicki shared how the project was changing her approach. She said, 'it's already making me think about things from a different point of view and that is like being open to possibilities, not seeing what's presented in front of me but looking at what could be'.

For some, involvement in Project Citizenship did not change their thinking about their roles but provided clarity. Kelly explained, 'it hasn't changed my perspective on things ... but ... I'm sharper ... I'm clearer on it now'. Similarly, several staff articulated that many of them were already doing this type of meaningful work but that Project Citizenship brought greater focus and further reinforced its importance. As Jay shared, 'a lot of them [staff] have been connecting people to their communities for quite a while ... they come to realize that not only have they been doing it but it's, it is part of their job'. Likewise, Jay felt that Project Citizenship was 'helping our own employees understand the deeper potentials of the work they could be doing'. Staff members were proud to share stories that had quality of life impact for people. As Sandra said, 'we've had some exceedingly successful folks that have been hooked up to their community with unpaid supports, which in that particular individual's life has made a huge impact, a huge difference'.

Beyond seeking change within the lives of the people they support and the field of human services, participants also shared their hopes that the project would contribute towards a shifting of attitudes about people with disabilities at a societal level. At the end of the first year, the Skills Society held a gala at an art gallery to share the stories of citizenship with the public. Looking towards the gala Lisa said, 'I'm hoping that we've made a little bit of a you know entrance into the community and getting them thinking about it ... hopefully we're not just working within our own doors kind of a thing'. Carla expressed:

I would hope that the gala is really to honour the individuals and to have their guardians or their friends and special people in their lives see the importance of community, of relationships, of having choice, and just being engaged, trying different things, and knowing that this isn't a start and finish, that it's ongoing.

Lastly, Nicki articulated:

I want it to be something that is really person focused, that it comes from them, it comes from them telling us their story, not the story that we think should be told but a story that they feel is important to be told, something that is unique about them and I would hope that in the end it's presented to the community and a bigger population in such a way that is dignified and inspiring and just educational.

Creating, Learning and Working Together

The final theme captures participants' experiences of the specific processes that were designed by senior leaders at the Skills Society to guide staff engagement in Project Citizenship and contribute to organisational transformation with regard to their everyday practices in supporting people in living meaningful lives. Primarily staff highlighted their

engagement in the think tanks and how these provided motivation, encouraged creative thinking and generated a sense of community. As Becky stated, 'it has made me get excited about my job again ... it's not just about the stories, it's about who we support, it's about what our jobs are ... [we] came into this field for a reason'. Likewise, Robert shared 'it [the think tank] definitely helps remind me of what we're supposed to be doing ... and it's fun! You know we have fun in those meetings!'

Staff shared how the supportive environment created in the think tanks 'encouraged people to maybe take some of those risks ... to think a little bit differently' (Julie). Lisa shared, to sit around as a group and start throwing out ideas, it is intimidating to begin with. But once you start and everybody's doing it ... you start to see a little bit of excitement. It's supported all the way through.

Similarly Jenny expressed, 'there's always room for really cool ideas, there's free thinking. It's really quite a nurturing environment where anything goes ... people feel safe, I think it's a really safe environment for some really innovative thinking'. Creativity was a central focus of Project Citizenship and this was evident to staff and described in the following ways: '[it's] not just doing the straight and narrow' (Andrea), 'it's letting loose to new ideas and a different way of doing stuff and seeing people as people' (Jenny) and '[to] experiment and go head first without really knowing where we're going but we're going' (Eve).

The importance of the think tank environment and the ways in which these meetings were structured was described by Joan who said, 'when you go to the think tank everybody has to check-in and you just tell ... how you're feeling for the day ... that helps people trust more'. The check-in process was part of the start of every think tank and also served the critical function of providing a venue to share personal and professional struggles. This was articulated by Julie who said, '[think tanks] just kinda give you permission to just let that other stuff go'. She went on to share 'normally you don't have that time and to hear other people's ideas or to help support other people that are maybe struggling'. Finally, Andrea described how the think tanks had made 'my workplace better ... it's hard to get everybody to buy in' but because the processes involved in Project Citizenship (e.g. think tanks, world cafés and special events) were 'welcoming and open ... it gives me a lot of inspiration to go to work'.

The collaborative nature of the think tanks and other activities and how this impacted learning was often talked about in the interviews. Jay shared that these types of activities were 'educational for our employees' and that he 'always learn[s] something from sitting in the think tanks'. Jenny discussed how 'bringing a whole collective of people together to come up with new ideas and new outlets and new opportunities' helped in being 'really innovative' which was necessary 'because there's so many barriers out there'. According to Lisa, 'the gathering of people and the gathering of ideas ... it's an opportunity for people to kinda sit back and listen and work together'. The collective approach used in Project Citizenship also assisted people who had a perceived lack of skills in creating stories. Andrea said, 'I'm not very artistic so that's where other people have to help me out'. Participation led to opportunities to enhance personal skills as Kelly explained, 'my communication skills have increased'. Learning from special invitees to Project Citizenship events was also viewed favourably. 'We always have guests', said Joan, 'it's always good 'cause then we can share with them and they share with us'. The value of having new perspectives was further highlighted by Kelly who stated, 'I think they need to bring outside people in more often'. Finally, the relevance and impact of engagement in think tanks were summarised by Robert who said,

how it made him 'really realize ... how great it would have been if we shared a long time ago ... it has been very instrumental to me'

Discussion

It has been well documented that persons with intellectual disabilities continue to experience exclusion from many aspects of community participation (Dusseljee et al., 2011; Gray et al., 2014; Hall et al., 2005; Verdonschot et al., 2009). The findings of our study offer further confirmation of this as participants spoke about the continued marginalisation and exclusion of the people they support. Our findings also resonate strongly with the need for the field of human services to place greater emphasis on the social inclusion of people with intellectual disabilities (Bigby et al., 2009; Craig & Bigby, 2015). There was recognition among staff that contributing to social inclusion was an important part of their jobs but this was consistently challenged by the highly demanding nature of their work. Taking part in Project Citizenship added another dimension to an already-difficult workload. Making time for the project, feeling uncertain about one's role and dealing with push-back from, for example, public guardians were among the challenges discussed by participants. However, overwhelmingly staff shared how the project had helped them to refocus and reimagine the possibilities of their work and increased their personal well-being.

The think tanks, in particular, provided a critical forum for staff to consider their work differently. Although the concepts underpinning citizenship were not new, the lens it provided and the energy that came along with the project, created a sense of newness and excitement. It helped to refocus what staff already knew they should be doing and importantly provided time and safe spaces to devote greater attention to it. The processes involved in Project Citizenship in many ways respond to the call for service leaders to 'give more emphasis to social inclusion tasks and provide the leadership, training and resources to facilitate support staff to re-assess their priorities' (McConkey & Collins, 2010, p. 691). Senior leaders at the Skills Society used social innovation strategies (Etmanski, 2015; Weinlick, 2010) and dedicated time and space to actively engage staff in re-envisioning how they provide support. Ensuring staff members have a safe space to share, debate and rethink providing support align with recommendations of Bigby and colleagues (2009) about how to foster positive attitudes and practices around social inclusion. It has been reported that human services staff struggle to promote choice-making and inclusion among the people they support and particularly for individuals with more severe intellectual disabilities (Balcazar, MacKay-Murphy, Keys, Henry, & Bryant, 1998; Bigby et al., 2009).

The reflective processes occurring within the think tanks led staff to examine the ways in which they were providing support. Although at times uncomfortable, in doing so, the think tanks necessarily disrupted staff's everyday thinking around work practices and the people they support. The experiential nature of challenging and changing thinking through sharing with others, questioning personal assumptions, and story creation also brought staffs' attention to 'a shared humanity regardless' of the differences attributed to disability (Matthews, Ellem, & Chenoweth, 2013, p. 237). In this way, workers were caused to consider and value citizenship within their own practice and personal lives and to wonder about their own stories.

In the creation and telling of stories, ensuring people were represented in respectful ways was an ongoing source of reflection and discussion among staff and senior leaders. According

to Smith-Chandler and Swart (2014), the primary assumption of narrative inquiry in research 'is that via storytelling, alternative voices of disability can be heard from the unique perspectives of the individuals themselves' (p. 425). That people supported by the Skills Society needed to be integral to the telling of their own stories was an often discussed issue within Project Citizenship. At the same time, caution and care were needed to ensure the stories did not reinforce harmful conceptualisations (e.g. defective, heroic, inferior) often attributed to people with disabilities (Smith-Chandler & Swart, 2014) but rather acted as counter stories to these damaging representations (Connor, 2009).

Social innovation provided the foundation and processes (Etmanski, 2015; Weinlick, 2010) upon which Senior Leaders developed and continue to move forward with Project Citizenship. Citizenship provided the lens and narrative and storytelling provided the change agent in efforts to challenge stereotypes, shift attitudes and move people to action. The potential of this approach to change the everyday practices of the Skills Society's employees is evidenced through the documented stories which emerged in part from the creative and collaborative problem solving staff engaged in with each other, the people they support and their families and allies, and university students. In addition to seeking new ways to enhance citizenship, staff found themselves learning and thinking differently about the people they support. Staff also had hopes that sharing Project Citizenship with families, community members, stakeholders and policy-makers would contribute to changing societal perceptions.

Finally, the well-being of workers in the field of human services has been considered in research that, for example, explores job satisfaction, stress and burnout. Although our purpose was not to explore these issues, through our interviews and in the literature there is recognition of the need to better understand and respond to these challenges (Balcazar et al., 1998; Devereux, Hastings, & Noone, 2009). An interesting future direction is the application of relevant theory to examine the processes of how change initiatives, such as Project Citizenship, might impact quality of work life for staff themselves. Importantly, the call for change in the field of human services in support of people with disabilities, must also consider the needs of human service workers to experience joy in their work, to feel supported and connected, to be motivated and inspired to do things differently (Etmanski, 2015; Weinlick, 2010). As one staff member noted, in order to improve things for people with disabilities, the people who support them must also experience a sense of meaningfulness and value in the work they do. In essence, human service workers need to also experience citizenship. The experiences of staff captured in this paper highlight how their engagement in Project Citizenship brought a renewed sense of excitement and purpose to their work that helped them to refocus and re-engage in seeking ways to facilitate the citizenship of the people they support. Finding ways to achieve transformation in work practices that are in so many ways ingrained responses to unyielding demands is a complex and arduous endeavour, yet imperative in order to address the marginalisation of people with disabilities, and particularly people with intellectual disabilities. Human services workers are pivotal in the lives of people with disabilities. Finding ways to provide more holistic support requires collective, deliberate and sustained reimagining of the ways in which the field of human services can be transformed.

Notes

1. The term human services may be used synonymously with disability services.

2. We use person-first language in this paper consistent with the language of the Skills Society, our community partner for this research.

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References

- Abbott, S., & Mcconkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*, 275–287. doi:10.1177/1744629506067618
- Balcazar, F., MacKay-Murphy, M., Keys, C., Henry, D., & Bryant, F. (1998). Assessing perceived agency adherence to the values of community inclusion: Implications for staff satisfaction. *American Journal on Mental Retardation, 102*, 451–463.
- Bigby, C., & Wiesel, I. (2015). Mediating community participation: practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 28*, 307–318. doi:10.1111/jar.12140
- Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research, 53*, 363–376. doi:10.1111/j.1365-2788.2009.01154.x
- Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics, 18*, 662–671. doi:10.1177/0969733011408049
- Cameron, L. (2015). The thing is, we all have stories don't we? *Tizard Learning Disability Review, 20*, 37–40. doi:10.1108/TLDR-09-2014-0031
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- Connor, D. J. (2009). Breeding containment – The power of narrative knowing: Countering silences within traditional special education. *International Journal of Inclusive Education, 13*, 449–470. doi:10.1080/13603110701789126
- Craig, D., & Bigby, C. (2015). "She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disabilities in community groups. *Journal of Intellectual and Developmental Disability, 40*, 12–25. doi:10.3109/13668250.2014.977235
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE.
- Devereux, J., Hastings, R., & Noone, S. (2009). Staff Stress and burnout in intellectual disability services: Work stress theory and its application. *Journal of Applied Research in Intellectual Disabilities, 22*, 561–573. doi:10.1111/j.1468-3148.2009.00509.x
- Dusseljee, J. C. E., Rijken, P. M., Cardol, M., Curfs, L. M. G., & Groenewegen, P. P. (2011). Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research, 55*, 4–18. doi:10.1111/j.1365-2788.2010.01342.x
- Etmanski, A. (2015). *Impact: Six patterns to spread your social innovation*. Canada: Orwell Cove.

- Gilbert, T., Cochrane, A., & Greenwell, S. (2005). Citizenship: Locating people with learning disabilities. *International Journal of Social Welfare*, 14, 287–296. doi:10.1111/j.1369-6866.2005.00371.x
- Gray, K. M., Piccinin, A., Keating, C. M., Taffe, J., Parmenter, T. R., Hofer, S., ... Tonge, B. J. (2014). Outcomes in young adulthood: Are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*, 58, 734–745. doi:10.1111/jir.12069
- Grove, N. (2015). Finding the sparkle: Storytelling in the lives of people with learning disabilities. *Tizard Learning Disability Review*, 20, 29–36. doi:10.1108/TLDR-05-2014-0015
- Hall, I., Strydom, A., Richards, M., Hardy, R., Bernal, J., & Wadsworth, M. (2005). Social outcomes in adulthood of children with intellectual impairment: Evidence from a birth cohort. *Journal of Intellectual Disability Research*, 49, 171–182. doi:10.1111/j.1365-2788.2005.00636.x
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). Social interaction with adults with severe intellectual disabilities: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities*, 25, 329–341. doi:10.1111/j.1468-3148.2011.00669.x
- Kendrick, M. J. (2006). *The challenges of authentically getting what people actually need on a person-by-person basis*. Paper presented at the “One Person at a Time Conference”, Melbourne, Australia. Retrieved from <https://www.socialrolevalorization.com/articles/kendrick/challenges-of-authentically-getting-what-people-actually-need.pdf>
- Knox, M. (2006). He’s more than just a service user, you know. *Crucial Times*, 36, 3–4. Retrieved from <https://www.cru.org.au/crutimes/CT36/ct36.pdf>
- Marshall, T. H. (1950). *Citizenship and social class, and other essays*. Cambridge: Cambridge University Press.
- Matthews, N., Ellem, K., & Chenoweth, L. (2013). Crafting and retelling everyday lives—: Disabled people’s contribution to bioethical concerns. *Narrative Inquiry in Bioethics*, 3, 235–240.
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54, 691–700. doi:10.1111/j.1365-2788.2010.01295.x
- Nirje, B. (1992). *The normalization principle papers*. Uppsala: Centre for Handicap Research, Uppsala University.
- Oliver, M. J. (1993). *Disability, citizenship and empowerment: The disabling society*. Milton Keynes: Open University Press.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39, 201–214.
- Shakespeare, T. (2006). *Disability rights and wrongs*. London, UK: Routledge.
- Skills Society. (2016a). Retrieved from <https://www.skillsociety.ca/about/>
- Skills Society. (2016b). Retrieved from <https://www.skillsociety.ca/projects/project-citizenship/>
- Skills Society. (Producer). (2016c). *Project citizenship creative think tank process*. Retrieved from <https://projectcitizenship.com/tool/>
- Smith-Chandler, N., & Swart, E. (2014). In their own voices: Methodological considerations in narrative disability research. *Qualitative Health Research*, 24, 420–430. doi:10.1177/1049732314523841
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.
- Stake, R. E. (2010). *Qualitative research: Studying how things work*. New York, NY: The Guilford Press.
- Statistics Canada. (2006). *The 2006 participation and activity limitation survey: Disability in Canada*. Retrieved from <https://www.statcan.gc.ca>
- Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303–318.
- Weinlick, B. (2010). *Humour and serious play enhancing creative thinking in community disability service design* (Unpublished master’s thesis). Royal Roads University, Victoria, Canada.
- World Health Organization. (2011). *World Report on Disability*. Retrieved from https://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf
- Yeung, P. H. Y., Passmore, A. E., & Packer, T. L. (2008). Active citizens or passive recipients: How Australian young adults with cerebral palsy define citizenship. *Journal of Intellectual & Developmental Disability*, 33, 65–75. doi:10.1080/13668250701875129