Microboards™, Social Capital and Quality Of Life

Final Report of a Two Year Qualitative Inquiry

AUTHORS:
Tim Stainton, Rae Morris, Celeste Borja;
Canadian Institute for Inclusion and Citizenship

RESEARCH TEAM:
Tim Stainton, Rae Morris, Celeste Borja, Claudia Nei, Shelley Cook;
Canadian Institute for Inclusion and Citizenship

RESEARCH PARTNERS:
Linda Perry, *Vela Canada;* Zainum Bahadshah, *Community Living British Columbia*

THE UNIVERSITY OF BRITISH COLUMBIA
Canadian Institute for Inclusion and Citizenship

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MICROBOARD™

A small group of people who have agreed to collaborate with an individual with a disability to form a person-centered 'board'.

Persons with disabilities (PWD) may face multiple barriers to establishing relationships and becoming involved in their communities, which can limit opportunities for generating and maintaining social capital (Dimakos et al., 2016; Kampert & Goreczny, 2007; Mithen, et al., 2015). Social capital has received some attention in the intellectual and developmental disability (IDD) field (eg. Shpigelman, 2018; McClimens & Gordon, 2009; Mithen, et al., 2015; Widmer, et al., 2008) and provides a useful lens to measure the extent of relationships, understand the nature of relationships and, help to identify how we can develop and maintain these relationships. Quality of Life (QoL) has received significant attention in the IDD field (eg. Brown et al 2009; Beadle-Brown et al 2016; Reinders H. & Schalock 2014). While distinct concepts, the two have multiple intersections with social connections and relationships being a critical variable in QoL outcomes. One community-based initiative with the potential to address gaps in social capital among individuals with IDD and thereby improve QoL is Microboards™ (MB). MBs are small groups of people who have agreed to collaborate with an individual with a disability to form a person-centered 'board'. MBs have generated anecdotal evidence and some research support (The Women's Research Centre, 1994) for the positive impacts they can generate on the enhancement of social capital for persons with disabilities, but there is limited formal research to date on the impacts of MBs on individuals and communities. The research project reported on here sought to examine through qualitative interviews with MB members, how MBs may help to connect people to their communities and serve as a means to enhance and sustain social capital and QoL for people with IDD.

Background

MBs were first developed in British Columbia in 1990 to provide information to friends and family members of PWD who wished to move away from the traditional block funding model towards a network based individualized funding approach (Vela Canada, n.d.). Since its inception, Vela Canada, the nonprofit society dedicated to MB development and support, has helped to create over 1200 MB in the province. Vela Canada has also supported the development of MBs internationally with strong MB foundations in Northern Ireland and Australia. A MB is usually comprised of a small group of dedicated friends and family who "join together with the individual to create a non-profit society (board)" (Vela Canada, 2015). This non-profit society is solely dedicated to support the single individual. Vela Canada's mission is:

"To promote and secure innovative and individualized community options for people with disabilities."

Vela does this by providing:

• support and encouragement to think about what a good life means to you;

• person centred planning;

• networking opportunities;

• information and education;

• facilitated problem solving;

• service development;

• budget creation;

• negotiation support;

• sample employment documents; and

• assistance with paperwork

(Vela Canada, n.d.)

The purpose of a MB may include, but is not limited to, helping an individual "plan his/her life, brainstorm ideas and problem solve, advocate for what he/she needs, do fun things together, connect [an individual] to his/her wider community, and monitor services and ensure he/she is safe" (Vela Canada, 2015).

Social capital refers to the "connections among individuals—social networks and the norms of reciprocity and trustworthiness that arise from them" (Putnam, 1995). As Woolcock (1999) notes: "The basic idea of social capital is that a person's family, friends, and associates constitute an important asset, one that can be called on in a crisis, enjoyed for its own sake, and /or leveraged for material gain." Quality of life is generally understood as the extent to which we feel satisfaction and fulfilment in our personal and social experiences, but this term has many different definitions depending on the context (Phillips, 2006). In relation to social capital, quality of life is understood as existing within a 'collective context' which encompasses broader societal factors and the ways in which these factors can affect the well-being of individual people within a community (Phillips, 2006). MBs then, can be seen to represent an intentional means of building and sustaining social capital and QoL. The connection between MBs and social capital and QoL can be seen clearly in the expectations of MB members:

"All Microboards™ facilitated by Vela use the following principles and functions as their building blocks for development:

1. *Microboard members must establish and maintain a personal relationship with the person for whom the board is created.*

2. *All people are assumed to have the capacity for self-determination. This capacity will be acknowledged, respected, and demonstrated in all of the dealings of the Microboard.*

3. *All planning and decisions made by a Microboard will demonstrate regard for the person's safety, comfort, and dignity, with consistent respect for his/her needs, wishes, interests, and strengths.*

4. *Microboard members will act as sponsors to the community, ensuring the person participates in community activities with Microboard™ members (e.g. family functions, social events). This is done in ways that are natural for each of the people involved.*

5. *Ensure the person has the opportunity to both receive from and give to his/her community, as well as with other individuals in his/her network.*

6. *All Microboard members will conduct their board business in the spirit of mutual respect, cooperation, and collaboration." (Vela Canada, 2015)*

Research has shown that persons with disabilities (PWD), specifically those with intellectual disabilities, face difficulties establishing relationships and becoming involved in their communities (Dimakos et al., 2016; Emerson & McVilly, 2004;

Kampert & Goreczny, 2007; Lippold & Burns, 2009; Mithen, et al., 2015). This social isolation can cause serious challenges to attaining social rites of passage, such as employment, marriage or parenthood. (Dimakos et al., 2016; Duggan & Linehan, 2013). Ultimately, this results in a downward spiral of PWD experiencing even greater discrimination, marginalization and isolation, and precludes their full inclusion into society (Duggan & Linehan, 2013; Jahoda & Markova, 2004; Pretty, et al., 2002). In addition, PWD may not always receive the disability-related supports they need to reach their full potential, thus further hindering inclusion. Many self-advocates with IDD prioritize a desire for increased inclusion in their communities over and above a desire for positive change in other areas of life including socialization, vocation, personal possessions, and personal activities (Kampert & Goreczny, 2007).

One practical way of facilitating community inclusion for PWD is to increase social capital, which is characterized by the formation of positive relationships and support networks (Duggan & Linehan, 2013). It has been documented that when PWD have more individuals in their support network, they have "better communication skills, healthier emotional functioning, more positive coping strategies and a better grasp of life skills" (Dimakos et al., 2016;). By establishing positive relationships between PWD and other members of society, barriers to supports and resources can be eliminated, and individuals can work together to achieve common goals (Chenoweth & Stehlik, 2004; Kampert & Goreczny, 2007). Furthermore, when discrimination does not accompany social contact, PWD are given the opportunity to demonstrate their strengths, capabilities, and desires, thus allowing them to be valued and accepted by society (Devine & Parr, 2008). Therefore, increasing social capital strengthens communities, which can further help members of society to support PWD (Chenoweth & Stehlik, 2004).

When social capital is increased, not only are benefits seen for PWD, but all members of society can experience reciprocal gains. Greater social capital and larger social networks can significantly increase trust between individuals, and can facilitate greater happiness and life satisfaction (Koutsogeorgou et al., 2013). Thus, when individuals experience a higher QoL, health and well-being can also be improved (Allan, et al., 2009).

The idea of MBs increasing social networks for PWD is a relatively new concept and there is limited literature surrounding the impacts MB have on individuals and their respective communities. The current study was conducted to determine the outcomes and added values of MBs, both for PWD and other members of society. By inviting PWD who had a MB and MB members to participate in qualitative interviews, we sought to evaluate the effects of MBs on individuals' social capital, QoL, self-determination, and community inclusion. Ethics approval for the study was obtained through the University of British Columbia Behavioural Research Ethics Board.

Methods

RECRUITMENT

Prospective participants were identified via purposeful sampling based on their involvement in a MB in British Columbia supported by Vela Canada. Information about the purpose of the study, process of participation, and study team information was shared by Vela Canada with 212 individuals including persons with IDD, board members, and community members. Participants were invited to either reach out to the research team or to provide informed consent to be contacted by the research team to discuss further if interested. Potential participants were informed that agreement to be contacted does not equal agreement to participate. 31 individuals agreed to be contacted and were screened for inclusion criteria by the research team. 21 people were contacted by the research team to provide further information on the process and purpose of participation, including confidentiality and informed consent information.

SAMPLE

Potential participants were included if they were over the age of 18, were a resident of British Columbia and currently involved in a MB, and were capable to provide informed consent. Participants that did not meet these criteria were excluded from the study.

If otherwise eligible, individuals who did not wish to participate or who revoked their consent during or after participation were excluded from the study and their information and details were deleted.

PROCEDURES

Historically, research that includes participants with IDD has involved the use of quantitative data collection and analysis, which can capture important information but may miss some aspects of the stories and experiences of individuals in this population (Altman & Barnartt, 2000; Beail & Williams, 2014). The last several decades have seen a push to better incorporate the voices and lived experiences of individuals with IDD into research (Boxall & Ralph, 2011; Crook, et al., 2016; McDonald, 2012). The current study utilized a qualitative methodological approach as an initial form of data collection that allows for the emerging thematic content to be dictated by the participants more than by the researchers (Di Lorito, et al., 2017; Milton, 2014). Semi-structured interviews were conducted in person or by phone with a member of the research team and were audio-recorded and transcribed verbatim for thematic

analysis using NVivo12, a qualitative data management software program (QSR International, 2018). Informed consent was established at several points during the recruitment and interview process, and participants were informed that their decision to participate at any level would not be relayed back to the community organization and would have no impact on their relationship with the organization or future funding opportunities. An adapted informed consent form using accessible language was provided to participants with intellectual disabilities.

ANALYSIS

Analysis of emerging themes was conducted simultaneous to data collection. Data collection was continued until saturation of themes was reached (Guest, et al., 2006). Triangulation of emerging themes was conducted via team analysis and consensus as well as member-checking through conference presentation and discussion with subject matter experts and individuals with lived experience with a MB as per qualitative methodological rigour guidelines (Morse & Field, 1995).

Results

DEMOGRAPHICS

The final sample included a total of 21 participants (3 with IDD, 15 board members, 2 staff, and 1 community member), representing 13 MBs spanning an average duration of 2.29 years (2-22 years). The majority of interviewees (57%) were mothers (and simultaneously board members) of the person with IDD receiving supports, and the age of the person with IDD receiving supports ranged from 20-55 years (mean = 33.72). Participants were located in various regions of the province, including Vancouver Island, Northern BC, Okanagan, Mainland Vancouver, and Interior BC; though most participants hailed from the Lower Mainland Vancouver area. See Table 1 for detailed demographic information.

Table 1: Demographic Results

Participant Demographics	Group	Total
Participant Category	Parent and Board Member	12
	Board Member only	3
	Self-Advocate	3
	Staff	2
	Community Member	1
Age Range of Person with IDD	20-30	2
	31-40	3
	41-50	3
	51-60	2
	Unknown/not shared	3
Geographical Region	Vancouver Mainland	7
	Vancouver Island	2
	Interior BC	2
	Okanagan	1
	Northern BC	1
Length of MB in Years	1-10	3
	11-20	6
	20+	3
	Unknown/not shared	1

57%
**OF INTERVIEWEES
WERE MOTHERS**
(and simultaneously
board members)

**AGE RANGE OF PERSONS
RECEIVING SUPPORT**
20–55
YEARS

QUALITATIVE RESULTS

Despite the expectation that participants would identify MBs as having a direct impact on social capital of individuals with IDD, this direct association was not reported by participants. What emerged instead was an overall finding that MBs serve as a "platform" or "vehicle" upon which several mediating characteristics more directly contribute to outcomes that include an increase in both social capital and QoL among persons with IDD. This is exemplified by the following participant quotes:

Our Microboard is the vehicle that we were able to actually have a program and have the funding to pay [our support] people.

The Microboard is in the background making sure she is happy enough and keep sending money.

We use our Microboard as our sounding board right now—asking for advice, asking for help if we needed...It's a safety net is what it is.

The outcomes of MB involvement grouped into two major themes: Quality of Life (QoL) and Social Capital; and the mediating characteristics of MBs that were identified were: Autonomous, Person-Centered, Empowering, and Interconnected (see Figure 1 below).

MBs serve as a "vehicle" upon which several mediating characteristics contribute to outcomes that include an increase in both social capital and quality of life.
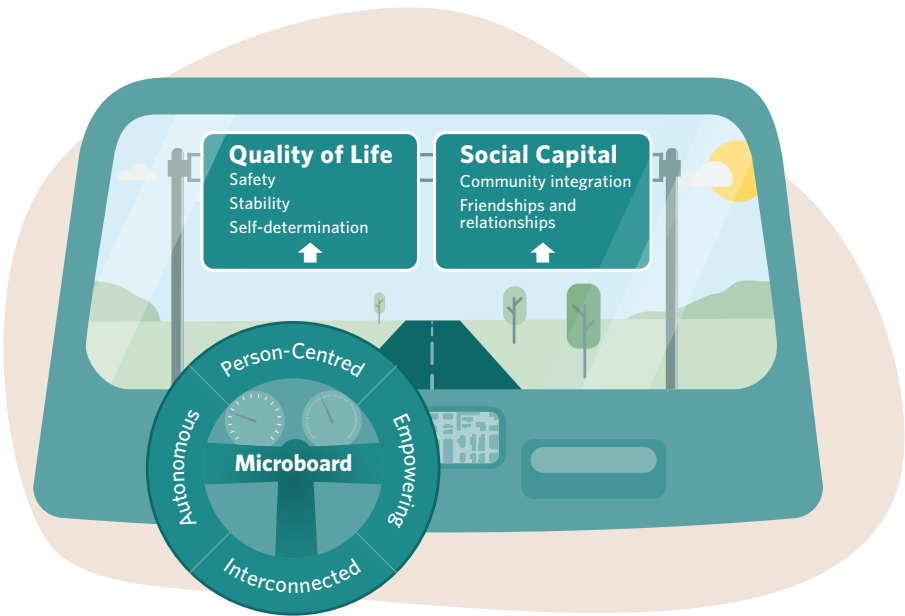
OUTCOMES OF MB INVOLVEMENT

THEME 1 — **QUALITY OF LIFE.** Although QoL was not directly asked about in the interviews, many participants spoke about increases in general well-being, health, safety, stability and self-determination of the individuals supported by the MB as a result of the outcomes of MB decisions including hiring of good quality employees for daily supports. Many participants noted that these areas of life felt less than ideal before having the MB in place.

I think the Microboard has been very good for us and for [him], otherwise [he] would not be where he is today. They have helped us to get him out of the group home and into his home....He has had a good 20 some years with us that he has been really able to enjoy life and be with the family.

Having the Microboard just makes it really flexible for somebody with such high complex needs to not just exist, but to truly live. And without the Microboard, [he] wouldn't have the unique, rich life that he does have.

I think since forming the Microboard there has been a big improvement in the overall awareness because when he was in the group home before, he was [...] almost like a zombie. [...] Since having the Microboard and having him at home, he has really come out a lot more. He is a lot more expressive about what he wants and the way that he wants things done. [And] I think it's because we are giving him a chance to express himself.

> *Having the Microboard just makes it really flexible for somebody with such high complex needs to not just exist, but to truly live. And without the Microboard, [he] wouldn't have the unique, rich life that he does have.*

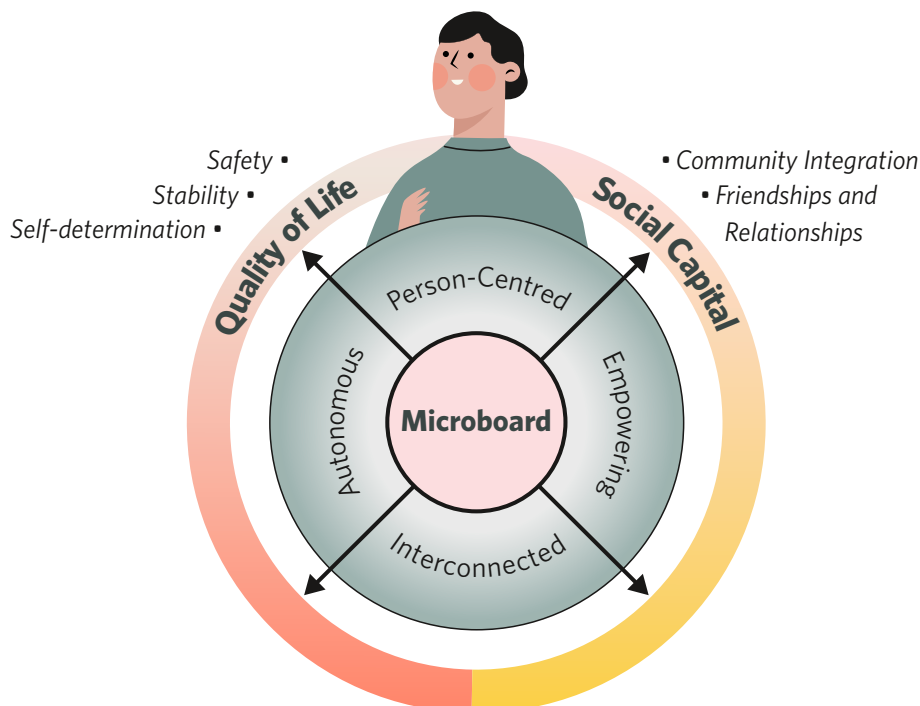
Safety •
Stability •
Self-determination •
Quality of Life
• Community Integration
• Friendships and Relationships
Social Capital
Person-Centred
Autonomous
Empowering
Interconnected
Microboard

FIGURE 1.
QUALITATIVE FINDINGS MAP

"

He knows his community, he knows his rec centre, he knows all of his neighbours, everybody at the shopping centre

"

THEME 2 — **SOCIAL CAPITAL.** Participants noted that they observed or experienced an increase in social capital of the person being supported, specifically community inclusion, friendships, and relationships (including personal and professional). One participant noted:

There's the benefit of a group of people that are not really part of that whole world but now we are part of it…we understand the needs and understand what real inclusion looks like much better than we did before we joined [the Microboard]. And all of those things wouldn't have happened if [he] was looked after by a major nonprofit organization that does it for a wage.

He knows his community, he knows his rec centre, he knows all of his neighbours, everybody at the shopping centre. [...] There's somebody else that knows where he's gone, he has all of those people's numbers and things on his phone that if he needed some help and he couldn't get a hold of his home share or a friend or whatever, he knows who he could talk to.

Many participants clarified that this increase was not directly a result of the MB itself, but instead was due to the front-line employees that were hired by the MB to support the person with IDD. Many participants noted that the ability to self-select, hire, and manage these employees created an opportunity to employ people who felt like the best fit to support the person with IDD in a positive way.

His worker is flexible so if there's a good play production going on, then she will take him to plays in the evening and adjust her work hours. [...] That really helps him to participate in the community.

Because of the inclusion funding that's available there, the workers that we've had have, for example, set up monthly Guitar Hero parties and invited lots of other folks from the community that have barriers as well and don't get included in much. And so she's created a social network of people that are often of the fringes of community.

We're so lucky that we have these people, but I think it partly is [her] personality, like they love [her]. They love being with her. [One of her workers] says, "I get so much out of working with her."

[She] lives with [home share provider] now. They've had this decades relationship. They love each other. When you call there and get their phone message [...] it's obvious from the message machine that [she] is a part of that family. It's great.

MEDIATING CHARACTERISTICS OF MBs

When asked to identify what aspects or characteristics of MB processes contributed to the outcomes identified, participants' responses clustered into four themes: Autonomous, Person-Centered, Empowering, and Interconnected.

THEME 1 — **AUTONOMOUS.** Participants noted that MBs are autonomous, meaning that they provide a sense of control and flexibility for individuals and their families over affairs such as budgeting and handling finances, creating their own programs and services, hiring staff, choice of environment/where to live and being able to take their funding and program wherever they go. Participants felt that this autonomy gave them the flexibility to make decisions related to funding, functioning, and resources, based on the context and individual circumstances of the person with IDD at the centre. This theme was captured by one participant who stated:

Even though it is work, you can look in the mirror at the end of the day or the morning and know and feel that you have some control over what happens. And I think for all parents, it's not that you want to control anything it's just that you want to be able to be part of maybe the decision-making.

Another participant stated:

There are just so many people who don't know what a Microboard is and every time I tell them, especially if they know the things that [he] has been involved in, I just say you know the stuff he is doing, I couldn't do that if I didn't have the Microboard. [...] I am so grateful for that kind of autonomy and the advocacy of being there on those really essential things to make it so that we could do that, as opposed to institutionalizing. That has just been invaluable. As I eluded to before, it really has gone into all the realms, social, the physical and relationships, in order to being able to hire a support person the way that we want to, it has maximized his potential as a person.

THEME 2 — **PERSON-CENTERED.** Participants spoke about MBs as being person-centered in that decisions and resource allocations are decided and adapted to meet the needs or goals of the individual with IDD for whom the MB was created. Across all participant stories, the person receiving supports was invited to collaborate with the board in discussions and decision making processes, including place of residence, activities, and opportunities to be included in the community. One participant noted:

Having the Microboard just makes it really flexible for somebody with such high complex needs to not just exist, but to truly live. And without the Microboard, [he] wouldn't have the unique, rich life that he does have. He wouldn't have the physical care where he can get in specialized equipment to keep his physical body okay, to keep him cooking, to enjoy some

> *You can look in the mirror at the end of the day or the morning and know and feel that you have some control over what happens*

> *...the function of the Microboard is to surround an individual, to support them, to connect them, to make sure that they have a voice.*

**MEDIATING
CHARACTERISTICS
OF MBs**

AUTONOMOUS

PERSON-CENTERED

EMPOWERING

INTERCONNECTED

" *He tells us what he likes and what he doesn't like.* "

of these activities that he enjoys. He would not have the life that he has if it was not such a unique—without the Microboard. It's just so person-centered.

Another participant stated:

I think what the function of the Microboard is to surround an individual, to support them, to connect them, to make sure that they have a voice, that not only their needs are being met but that what they want to accomplish in life. We support them in accomplishing those things, whatever goals they have again we support them in accomplishing them to the best of their ability.

THEME 3 — **EMPOWERING.** Participants reported that the MB served to promote empowerment of the individual receiving supports, as a result of the members of the board being invested at a personal level in the visions and goals of the individual. Participants noted that board members took on the role of supporting individuals in overcoming obstacles to get closer to their visions and goals. Additionally, board members take on the challenge of seeking out opportunities for individuals so they can flourish in their communities (i.e., finding/creating relationships and friendships, finding employment, advocating for community inclusion, developing life skills) and developing a sense of pride in their own achievements. The MB helped to facilitate avenues and opportunities to promote self-awareness and self-determination, and to maximize an individual's potential for independence. One participant noted:

At the beginning [she] would just not talk, she was so mad and upset and traumatized [...] But finally we got it so that these big sheets of paper and all colored markers and it was like, what are [her] dreams? What are her hopes? What does she see in one year? What kind of people does she want?... What kind of jobs does she want to do? It was just a vision, [her] vision and we really supported her. [...] It was [her] dream and they wrote it all up afterwards and it was so empowering for [her].

Another stated:

I think we gave him a lot of opportunities to come out and enjoy things and he did, yeah. He tells us what he likes and what he doesn't like. We therefore incorporated all the things that we thought he would like for him and he really came alive with all the things.

THEME 4 — **INTERCONNECTED.** Participants noted that having multiple board members allowed for a variety of values, connections, experiences, expertise, and perspectives to influence the decision-making process. Additionally, board members often acted as a source of support, including both direct support and indirect support such as leveraging their networks to connect the individual to the broader community in various ways. One participant stated:

The Microboard contributes to [the person-centered planning sessions] along with the staff, by generating ideas and other ideas for connections to community and certainly the people who are local have brought their networks to [the individual's] life and their circles as well. So their involvement is both direct and oversight.

Another said:

Having the Microboard step in around some of these difficult decisions was so invaluable to me because it was now shared decision making with a network of people bringing a variety of perspectives. I felt really well supported and I kind of feel like [my husband] and I could die because we've got these very committed people overseeing [our daughter's] life and services and supports. You know, it's so comforting to us to share this with people who have made such commitments to [her] life and that's huge for me.

One participant provided specific examples of board members using their networks to connect and include the supported individual into community events or projects:

We have one of our board members that sits on the arts council. And when the arts council was doing a Christmas craft fair, [he/individual] was invited to make some crafts and sell them and display them at the craft fair as well. And so that was like through the Microboard and those connections he got to be involved in that—in the arts council when they were doing different things in the community.

A prior board member is a teacher and so she connected with another teacher in town. So [he/individual] is now invited and participates in an elementary classroom where the students read to him once a week. And so out of that he was able then to go skating with that classroom and also when they went downhill skiing, went on a ski trip, he was able to participate.

> "
> *Having the Microboard step in around some of these difficult decisions was so invaluable to me because it was now shared decision making with a network of people bringing a variety of perspectives. I felt really well supported...*
> "

... Over 17 years we've run into things that's been new for us and just to know that they're out there for us to help us through difficult times, to inspire and motivate us through the sharing of other Microboard people, I don't think we could do this without their expertise and support in the background.

ADDITIONAL THEMES

A number of additional themes emerged from the data that were less prominent than the key themes but were mentioned by more than two participants. Some participants spoke to the benefit of working with a facilitating organization who supported the setup of their MB and who engaged in broader advocacy efforts for MBs and for persons with IDD. Additionally, few notable challenges were mentioned including limited availability of resources, workload being shouldered by one person, administrative barriers, and concerns about sustainability of the MB system over time.

Benefit of Facilitation. Some participants expressed appreciation for having the support of an organization who facilitated the initial setup of their MB, and whose support they continued to feel on both an individual MB and broader advocacy level. One participant stated:

I feel like I'm really thankful that we have the Microboard but we also have the support of [facilitating organization] behind us...someone is always available. Maybe I won't have my regular facilitator, but I know that I can get in touch with head office and there's several people that I can talk to there. And of course, they can have all sorts of other ideas right, because we're newbies, we're still trying to figure things out.

Another stated:

We could not do this without [facilitating organization]. I think that's critical to mention. I had no idea how to form a non-profit society or put a budget together for funding. I had a vision, a dream of what a good life would look like for [person with IDD], and I could not have done this without [facilitating organization]'s staff walking beside us every step of the way in the early stages. And also, over 17 years we've run into things that's been new for us and just to know that they're out there for us to help us through difficult times, to inspire and motivate us through the sharing of other Microboard people, I don't think we could do this without their expertise and support in the background.

Limited Availability of Resources. Of all the challenges mentioned, the most common across participants was discussion of limited availability of resources, particularly limited funding, programming, and available employees. Participants spoke about how difficult it was to find and retain good quality employees when the funding provided was not sufficient to compete with the wages and benefits offered by unionized organizations. Participants noted that limited opportunities for affordable programming and high turnover rates of employees lost to higher paying roles at times was limiting to opportunities for participation and inclusion. One participant noted:

The lack of adult programming in the community after hours [...]—there's really nothing after 3 o'clock for sort of that adult type persons with disabilities can engage in and go out and meet new people, is challenging.

Another stated:

The number one issue is always staffing and everything flows out of that. If we had enough money that would be competitive with what other support people are making, then I would be able to hire people that are more steady and there wouldn't be the turnover and there would be more availability. [...] The turnover rate is pretty high, even when I do a lot of things to try and attract and make it as good as possible, it is a huge issue. That one thing alone, it pervades everything.

Workload on one Person. Some participants noted a lack of equality among board members taking on responsibilities associated with organizing and maintaining the MB. This theme was notably mentioned by participants who were mothers or primary caregivers of the person being supported. For example, one mother stated:

Basically I do all the work. I do all the work. [...] I have been the president since it started. Nobody seems to want to do the job, so that is the way it stayed.

A few of the mothers noted that taking on the majority of the workload of the MB was part of their responsibility as a parent of the person being supported. One mother captured this by stating "Basically, I do all of the administration of the Microboard and what has happened through it.[...] it is just something that I do because I'm a mom and it's a holistic thing that way." The workload being on one person was noted as exacerbated by challenges recruiting and maintaining employees, which one participant captured when stating "At the moment, I always have to pitch in because we can't find anybody. It is very difficult to find staff. We find it really hard to find and retain staff."

Administrative Barriers. Some participants noted that certain administrative requirements associated with MB processes can be limiting, particularly when

**CHALLENGES
FACED**

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**LIMITED AVAILABILITY
OF RESOURCES**

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**WORKLOAD ON
ONE PERSON**

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**ADMINISTRATIVE
BARRIERS**

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**LONGTERM
SUSTAINABILITY**

these were not able to be adapted for context or individual need. One participant stated:

Ones that are closer to him typically are ones that are actually being paid by the Microboard and they are not allowed to be on the Board. A lot of people that really are vested in his life are not able to be Directors on there, so I can't pass it on. A lot of the ones that worked with him are a younger generation, like a full generation younger, or his peers and age even, which is great, but I can't draw them in that way.

Another noted with regards to a community organization they used:

We tried to bring our own person in [to the program]. [Our worker] was willing to go in the mornings and help teach [him] but [the organization] wouldn't allow it because it's a unionized outfit and he cannot come in and work with [him], even if he wouldn't get paid, he could not work there. That was the unusual thing for us, we were offering and they wouldn't allow it.

Sustainability of MBs. Some participants expressed concern about the sustainability of the MB over time as board members stepped down due to retirement, life transitions, or other personal life circumstances. Participants noted that it was challenging to recruit younger members into board positions, and therefore many board members were of the same age group and likely to retire from their positions around the same time. Parents and caregivers expressed anticipatory anxiety about the sustainability of the MB as they aged into their elder years. One participant noted

As my husband and I age, [...] we are kind of progressing in years and that is a huge concern, just realizing with health issues and things like that, that we are unable to support the way that we would like to.

Another noted

Right now at this point the Microboard is pretty fragile. Because I know one of the people that are on it won't be on it next year. And he's just in a situation where he just doesn't have time. [...] We have to find somebody else to fill that fifth place. So I feel in a lot of ways some of the people that are on the Microboard are just there on paper to keep that number official.

Discussion

While our research question had been intended to explore how MBs support social capital of persons with IDD, our findings suggest that this relationship is not direct and is mediated by several characteristics of MB structures and processes including person-centeredness, autonomy, empowerment, and interconnectedness. What emerged was less a linear association between MBs and social capital—i.e. MB members are the social capital that is leveraged to improve the nature and extent of relationships and community connections, but a more complex and nuanced relationship. While there were certainly examples of this linear association, more commonly it was the basic values of MBs: person-centeredness, reciprocal relationships, self-determination, control over resources and decision making, and a commitment to enhancing community connections, that intersect in mutually reinforcing ways to allow MBs to act as a platform for, or a catalyst to, the development and reinforcement of social capital. For example the control over hiring and flexibility of resource utilization guided by the person's needs and wishes creates a context which seems to be far more conducive to enhancing social capital and QoL than more traditional, rigid models of support. The example above regarding the unionized environment where the person's worker was not allowed to support him is a good illustration of how more traditional systems may unintentionally allow the system or services needs to compromise the person's self-determination and reduce the flexibility that allows for more natural connections and participation.

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MBs seek to use social capital to create the conditions to further build and extend the person's social capital and quality of life.

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The multiple roles of MBs (planning support, funding administration, human resource management, decision making support, active participation and relationships, support coordination) also creates a unique blend of roles which in a more traditional approach would be filled by multiple persons and agencies, if at all. This seems to enhance the coordination of these roles in a way which retains a very person-centered focus more organically than when multiple actors are involved. The set of roles MBs perform corresponds well with core elements identified with empowerment, self-determination and a more rights-based approach (Stainton, 2005). By encompassing them all within the single entity of a MB there seems to be a more sustainable and consistent set of these key elements than situations where you have multiple actors and agencies fulling these roles in relative isolation from one another.

While these multiple roles do generate many positives they can also create significant burden if MBs do not share key roles amongst the members. As noted when everything or the bulk of the work falls on a single person, usually the mother, this can create both significant strain but also make the system vulnerable should that key person no longer be able to fulfill these roles.

The results also shed some light on the relationship between social capital and QoL. While initially the study focused on social capital it quickly became clear that this was so bound up with QoL outcomes and ultimately, social capital's impact is assessed less through the numbers and nature of connections than how those connections translate into enhanced QoL. This is not surprising when one looks at QoL indicators and the multiple intersections with social capital. Virtually every major set of QoL indicators include some version of social capital as an outcome indicator (see for example Brown et al., 2013). What the current study elucidates is how social capital is not just, or even most importantly, an outcome, but a catalyst for other QoL outcomes such as self-determination, empowerment, intimacy, personal fulfillment etc.

MBs, by intentionally building and leveraging social capital, do seem to provide a platform for a broad range of QoL outcomes. In a more traditional approach 'outcomes' such as employment or community connections are typically developed through a professional intervention and social capital may or may not ensue from such interventions. One of the unique aspects of MBs is using social capital as both and input and an outcome. In other words, MBs seek to use social capital to create the conditions to further build and extend the person's social capital and QoL rather than improvements in social capital and QoL being an outcome only of professional intervention.

From a structural perspective, it is clear that MBs provide a significant contribution to the administration and management of supports which otherwise would require paid intervention. While the current study is not able to determine in quantitative terms what this contribution amounts to, there is clearly an economic benefit to Community Living British Columbia (CLBC) in not having to fund additional administrative and management supports. On another level, the leveraging of the MB members' social capital potentially replaces paid intervention in ways which are more natural and potentially more inclusive than would through paid providers. Ultimately, where MBs are effective, long term savings may be realized through growth and improved QoL and social connections potentially reducing the need for paid interventions as well as minimizing crises and the subsequent need for intervention.

The majority of participants in this study were mothers or primary caregivers of the person with IDD receiving services, which generates curiosity about whether these themes would generalize to MBs that do not include someone in a 'mother' role. For example, there is a potential that the challenge identified as 'workload on one person' may be influenced by the fact that many of the participants being interviewed had a vested interest in the person receiving supports that may be beyond that of other board or community members who are not primary caregivers. Research suggests that parenting a child with IDD within a context where resources and supports are unavailable or difficult to access can contribute to heightened stress and feelings of lack of control and helplessness (Fairthorne, et al., 2016; Knox, et al., 2000). A sense of control and identity as a valued collaborator in care has been noted by parents of children with IDD as being highly desired (Knox, et al., 2000). It is possible that this sense of control may be a means of adapting to and coping with the stress of parenting an adult child for whom the service system does not provide enough support. A history of these experiences may contribute to primary caregivers feeling resistant to dispersing the workload among other members of the MB. Further exploration of this theme is needed before any conclusions as to the underlying contributors can be made.

Limitations

This project was conducted in partnership with community stakeholders, including members of the organization which oversees MB structures in British Columbia. In order to reduce the impact of this partnership on our analysis, the data collection and analysis portion of this project was conducted and reviewed solely by the University research team members. The community stakeholders were brought back in to member-check the initial emerging themes, after which further analysis was conducted independently of community stakeholders.

Despite attempts to recruit a heterogenous group of participants, there were a few domains that were more significantly represented than others. For example, most of the participants resided in the greater Vancouver area of British Columbia which may bias the results to better represent the experiences of MB involvement in urban areas. Additionally, the majority of participants in this study were mothers and primary caregivers of the person with IDD being supported. As a result, the findings may be skewed to better represent the experiences of mothers more than the experiences of other MB members and/or the person with IDD being supported.

All of the interviews were conducted by research team members who were social workers or social workers in training, with both training and experience in counselling roles. This was a strength of the current study, in that the interviewers were all skilled in recognizing and discerning their own assumptions and biases from the participant responses, reducing the potential for researcher bias to influence the data collection and analysis. At the same time, clinical interviews and research interviews are vastly different in process and function, meaning it was important for the interviewers to regularly check in with themselves to ensure they weren't falling into a clinical role when discussing potentially difficult topics with participants. This experience of role conflict is not uncommon among social work researchers (Mendenhall, 2007). It has been argued that this dual-role tension may arise in both quantitative and qualitative research, but that qualitative researchers may be particularly aware of this dual role due to an emphasis on reflexivity in qualitative research. The dual-role phenomenon provides both challenges and benefits in research, and in order to reduce the potential for it to impact the outcomes of a study in a negative way, it has been recommended that researchers who balance the clinician-researcher role be attentive to when the dual-role feeling may arise (Hay-Smith, et al., 2016). In the current study, the interviewers were encouraged to be cognizant of their experiences of dual-role balancing and engage in internal reflection and peer and supervisor debriefing in order to navigate this ethically and professionally.

Recommendations

The results of this project highlight several areas where changes to existing processes and practices may contribute to positive outcomes for persons with IDD. A number of recommendations are presented for MBs, for community organizations that provide funding or management of MBs at an administrative level, and for future research in this area.

For MBs

- Be intentional in selecting members who are able to use their own social capital to build the social capital of the person at the centre of the MB in ways which further their personal goals and dreams through enhancing their social capital and their QoL.

- Be intentional in discussing how each member can contribute and leverage their own social capital to enhance that of the person at the centre of the MB.

- Undertake regular reviews of how MBs are, or could use, their social capital to further the goals and dreams of the person at the centre of the MB.

- Ensure a balanced set of responsibilities and roles with particular attention to ensuring that a single person does not become overburdened with responsibilities and the MB is simply there to support them rather than taking an active role in supporting the person at the centre.

- Be intentional about MB sustainability, renewal and stability.

For Facilitating Organizations (i.e., Vela Canada)

- Provide advice, training and direction to new and existing MBs on the importance of social capital and on how they can build, enhance and use their own social capital to further the goals of the MB.

- Support MB renewal and sustainability through advice and training with a particular focus on the importance of sharing roles and responsibilities amongst members.

- Identify MBs that have become heavily dependent on a single member and devise interventions to support broader buy-in across the MB members or through supporting recruitment of new members.

- Advise and support MB on the importance of MB succession planning.

For Funding Organizations (i.e., CLBC)

- Explore how the leveraging of social capital by MBs can provide transferable lessons for other models of support.

- Invest through training and funding efforts to enhance social capital, ideally in sustainable, integrated models of support.

- Undertake long term cost benefit analysis of investing in social capital development and enhancement.

- Review policies to identify policy barriers to leveraging social capital.

For Further Research

- Consider exploring the intersecting role of mother and board member in more detail, as well as conducting more in-depth analysis of MB structures that do not have mothers on the board to see if there is any difference in thematic outcomes.

- A subsequent quantitative study may be of benefit to build upon the current findings and attempt to broaden the diversity of participants as well as generalize the outcomes to a wider population of individuals involved in MB systems.

- Explore social capital inputs and outcomes across the service sector to identify models which are more or less conducive to enhancing social capital.

Conclusion

This small scale study sought to explore how MBs use and build social capital to increase the QoL of persons with IDD. While no absolute conclusions can be drawn from the study, it is clear that MBs have significant potential for contributing to improved QoL. Their use of social capital as a tool and the integration of multiple support roles within the MB suggest that MBs offer an alternative to more traditional models of support and are better able to leverage social capital than service structures that rely primarily on paid professional interventions. While MBs are as diverse as their members, the shared values, principles and approach enhances the likelihood that the outcomes identified in this study can be realized. The core mediating characteristics identified in this study—autonomous, person-centered, empowering, and interconnected—contribute directly to both social capital outcomes of friendships and relations and community inclusion as well as the QoL outcomes of safety, stability and self-determination. As noted in the discussion, these variables are not self-contained, but interact in a variety of ways creating a synergistic effect.

While MBs do face challenges of sustainability and potential to overburden a single individual (usually the mother), it is not clear that this is unique to MBs. The key issues with MBs are generally instrumental rather than structural. In other words, they are to do with how a given MB is implemented and managed over time rather than any problem inherent in the model itself.

Key questions remain regarding social capital and there is a need for more comparative study with other forms of support. In addition, a larger more detailed study would help us to understand how different variables such as age, location (rural/urban), gender, complexity of disability, indigeneity, and race influence the impact of MBs.

Microboards™ offer an alternative to more traditional models of supports and are better able to leverage social capital than service structures that rely primarily on paid professional interventions

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