CENTRE FOR INCLUSION AND CITIZENSHIP

"Living a Good Life" - Quality of Life and Home Share

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a place of mind

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“Living a Good Life” - Quality of Life and Home Share

Community Living British Columbia (CLBC) is committed to a vision of supporting people with intellectual disabilities to live “Good lives in Welcoming Communities” (CLBC, 2014). Home Sharing is a residential option that strives to support that vision. It is the fastest growing residential option in B.C., serving over 3,500 people with Intellectual Disabilities in the Province of B.C. (CLBC, 2014; Hole et al., in press; Stainton et al., 2008). Home share as a model has been in use for some time but research in the area is limited (Stainton et al., 2006). In BC, home sharing has rapidly become the most common residential service model growing by 350% in the past 15 years. It is the fastest growing residential option within the province and there are now approximately 2700 adults involved in home sharing (CLBC, 2015). This rapid increase can largely be attributed to cost saving efforts on the part of CLBC as home sharing is significantly less expensive than traditional residential support models such as group homes by as much as 70% (Stainton et al., 2008). Other factors contributing to the rapid rise has been the response of some non-profit agencies to self advocates who demanded increased independence (Key Informant, personal communication, spring 2012).

The significant cost savings involved in shifting to a Home share model raises concerns about the risk of over-riding or reducing individual choice in favour of economic efficiency. Indeed the findings reported here do indicate that a lack of choice was evident in some cases. The primary aim of this research is however to evaluate whether home share has resulted in improved quality of life for people served by CLBC through home share and to a lesser degree evaluate how quality of life has been impacted by the move to home dharing from traditional models such as group homes.

The focus on Quality of Life in this research is in line with another strategy for achieving the CLBC Vision of “Good lives in Welcoming Communities” through CLBC’s “Include Me Initiative.” This initiative is based on the internationally acclaimed Quality of Life (QoL) framework developed by Dr. Robert Schalock (CLBC, 2014). The “Include Me” initiative is an approach to measuring personal outcomes of individuals receiving CLBC services. The QoL framework informs the process for gathering information and engaging people with intellectual disabilities in a discussion about how programs and supports can be designed to improve and enhance their QoL (CLBC, 2010). Through this initiative, CLBC is gathering evidence-based knowledge to guide decision making at all levels of the community living service system and to inform continuous quality improvement (CLBC, 2010). It will help individuals and families make informed decisions about the type of services and supports that align best with their own

QoL priorities. It will help service providers identify service delivery areas for improvement. Finally, the data gathered will inform the direction of CLBC policy and practice (CLBC, 2010). The findings of this report are intended to support this ongoing initiative. The findings will also inform readers by reporting on the QoL experience of a group of people with intellectual disabilities who moved from group homes to home share.

Theoretical Background

The QoL framework used in this research is based on the *Schalock QoL model* (Schalock, 2004; Schalock et al., 2002; Schalock et al., 2005). This framework emerged from over twenty years of empirical research in the area of quality of life measurement (Schalock, 2004). An essential idea embedded within QoL is that people, places, and surroundings can promote and enhance a good life (Schalock, 2002). This framework is widely recognized within the critical disability field as a mechanism for evaluation and assessment of programs and services. It is statistically robust and it is a standardized instrument.

QoL is a *sensitizing notion* and a *unifying theme* that overtime has become a *social construction* (Schalock, 2004). The *sensitizing notion* provides a point of reference and guidance for programming based on an individual's needs, desires, and preferences. This framework focuses on the person-centred planning in the environment that will ultimately strengthen personal outcomes. QoL also provides the field with a *unifying theme* for conceptualizing, measuring, and applying the QoL construct. Finally, as a *social construct*, QoL becomes a predominant principle that not only guides individual well-being but acts as a shared point of reference that supports collaboration for programming in community and for societal change. Thus, a strength of the *Schalock* QoL framework is that it can guide transformative change because it addresses the micro, meso, and macro systems in which people with intellectual disabilities live, work, and play. As Verdugo et al. (2012) emphasize, the QoL framework has evolved over time from a “sensitising notion to a social construct that can guide program practices and provide a useful conceptual and measurement framework to assess personal outcomes guaranteed under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)” (p.1037). The *Schalock model* provides a mechanism to operationalize and measure the rights articulated in the Articles within the UNCRPD; information that can then be used to enrich a person’s life and protect their human rights (Verdugo et al., 2012). There are four organizing principles at the core of the QoL framework:

1. QoL is composed of the same factors and relationships for all people;

2. QoL is experienced when a person’s needs are met and when an individual has the opportunity to pursue life enrichments in a major life activity setting;
3. QoL has both subjective and objective components; and,
4. QoL is a multidimensional construct, influenced by individuals and environmental factors. (Verdugo et al., 2012, p. 1037)

As a multidimensional schema, the *Schalock model* is comprised of eight core quality of life domains: personal development, self-determination, interpersonal relationships, social inclusion, rights, emotional, physical, and material well-being. These eight domains are influenced by individual personal characteristics and environmental factors. While these domains are constant, they vary individually in relation to a person's values and priorities (Schalock, 2011, web interview). The eight domains and their three qualifying indicators were identified by Schalock and Verdugo through a rigorous review of 9749 abstracts and 2455 articles, and an in-depth analysis of 897 articles that met stringent inclusion criteria (Schalock, 2004). Underlying this structure is *a priori* knowledge that the eight domains are correlated. There is consistency between the domains which at times interact, intersect, and connect (Wang et al., 2010). These eight domains were arranged into three second-order factors based on the frequency with which research results clustered and correlated.

- Independence: self-determination and personal competence.
- Social Participation: interpersonal relationships, social inclusion and rights
- Personal well-being: emotional, physical and material well-being.
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The findings that follow are organized by the aforementioned second-order factors and the corresponding domains.

The subsequent sections describe the methods and findings of an exploratory qualitative research project that looked at the outcomes of twenty-five individuals with intellectual disabilities who moved from a group home to a home share living arrangement with a dual emphasis on the individual’s satisfaction in her/his current home share and understanding the individual’s current QoL as informed by the Schalock QoL framework. This will be followed by a discussion of the findings and recommendations based on this research. Ethics approval was granted by the University of British Columbia Behavioural Review Ethics Board.

METHODS

Descriptive qualitative methods (Sandelowski, 2010) were used to examine three research questions:

1. How do home share stakeholders (self advocates, home share providers, and family members) perceive the QoL of individuals who moved from group home to home share?
2. How did people experience the transition from the group home living arrangement to the home share living arrangement?
3. How have QoL outcomes changed for people who have moved into home sharing?

For the purposes of this research, home sharing is defined as a residential option where an adult with intellectual disability lives in a home with someone who is contracted to provide ongoing support (CLBC, 2010). Home sharing is a residential living arrangement in which one or more adults with intellectual disability share a home with an individual or family (not biological or adoptive parent or legal guardian) who is contracted to provide residential and, at times, additional support as needed; the caregiver is paid for her/his caring labour (Hole et al., in press; Stainton et al., 2006; 2008). The closeness of the relationship is dependent on the individual's desires and wishes. Some people live as roommates in a reciprocal relationship, while others live in the home as a family member and still others live quite independently from each other for example in a separate suite within the home. The individuals are not only sharing physical space, they are also sharing their lives. The goal is to provide flexible responsive supports in a way that balances the individual's needs with her/his desire for independence (Hole et al., in press; Stainton et al., 2008). This model aims to be person-centred. A key to achieving success is a very supportive interpersonal relationship between the individual with intellectual disability and the home share provider and others who may be living in the home (Hole et al., in press). For some people home sharing is a path to greater independence while for others home sharing is itself the goal (Stainton et al., 2008).

Sampling and recruitment

Participants in this research are comprised of self advocates (SA), home share providers (HSP), and family members (FM). Convenience and snowball sampling were used to recruit participants for the present study. Calls for participation were distributed via a number of channels including: newsletters from organizations serving disability communities throughout the province, email listservs, networking, and email distributions. Individuals with an intellectual disability (self advocates), home share providers, and family members involved in home sharing were invited to contact a member of the research team. Recruitment took place from the beginning of January 2012 to June 30, 2014. There were thirty-two participants in this project representing the experiences of twenty-five individuals with intellectual disabilities who at one time had lived in a group home and at the time of this research lived in a home share (see below for demographic information).

Procedures - data collection and analysis

Individuals were given a choice of participating in an individual interview via Skype, telephone or face-to-face. Interviews were conducted by graduate students supervised by the lead researcher. 29 interviews were conducted; in total 32 individuals participated (17 SAs, 7 HSPs, and 8 FMs). 3 interviews were conducted with couples. 4 interviews were conducted with SAs with a support worker present to assist with the interview process (e.g., communication). The remainder of the interviews were conducted one-on-one with SAs or HSPs. These interviews represented the experience of 25 SAs.

The individual interviews lasted between 20 to 70 minutes. SA participants' (n = 17) adaptive functioning and communication skills varied; consequently, 9 SA responded to the interview questions independently while 5 SA responded with minimal assistance. They asked for a question to be clarified or asked the support person to provide some detail that they could not remember. This assistance was provided by a HSP, a family member, a support worker, and/or a home share coordinator. The remaining 3 SAs required interpretive support which was provided by their HSP. All interviews took place in an accessible location either in the participants' local communities, via telephone, or by Skype.

A semi-structured interview guide informed by the Schalock QoL framework was used to ensure that all participants were asked similar questions. Examples of questions asked of self advocates included: How did you decide to change from living in a group home to living in a home share? (Beginnings) How did you get used to living in a new home and sharing with different people? (Transitions) What kind of activities do you do? Who decides? What would you like to do different? (Experience) How long have you lived in Home share? What changes have you seen or experienced? (Over time) Examples of questions asked of HSP and FMs included: How did you become involved or interested in Home Sharing? (Beginnings) What did the planning process look like? (Transition) What did you expect this experience would be like for you and for your family members? (Experience) How would you describe the relationship between you the HSP and SA and/or HSP and FM? (Relationships) What changes have you seen in the SA? (Overtime) All interviews were digitally recorded and transcribed verbatim.

A combined inductive/deductive analysis was used to compile the data into categories informed by the Schalock Quality of Life Framework:

A. INDEPENDANCE:
    1. Personal Development
    2. Self-determination
B. SOCIAL PARTICIPATION:
    3. Interpersonal Relationships
    4. Social Inclusion
    5. Rights
C. WELL-BEING
    6. Personal
    7. Emotional
    8. Physical and Material

Two research assistants and the lead researcher coded several interviews independently and then reviewed the interviews to ensure consistency. The remaining coding was completed by a graduate student (AR) under the supervision of the lead researcher (RH). Final analysis was undertaken by a graduate student under the supervision of the lead researcher. These findings were then discussed by the research team and further refined.

The reported findings are supported by participant quotes and the following acronyms will be used to indicate which participant is being cited: self advocates by (SA and participant #), family members by (FM and participant #), and HSP by (HSP and participant #). Each SA experience is numbered 1-25. When a HSP or FM is speaking, they are also numbered and then linked back to the SA they are representing: for example, this notation (HSP #7 {SA #24}) indicates that HSP #7 is speaking about SA #24.

RESULTS

Description of participants

In total, 32 people participated in 29 interviews. These interviews represented the experience of 25 SAs. 17 of the 25 (68%) SAs represented in the study participated directly in the interviews. In total 7 HSP participated in this research. 8 respondents were family members (FM) - 3 couples, 1 step-parent, and 1 sibling.

Participant Breakdown.

Participants	
# of SA	17
# of HSP	7
#of FM	8
Total Interviews	32

Age and Gender of SA represented.

Age		**Male**	**Female**
19 - 30 years	8	10	15
30 - 40 years	12		
41 - 50 years	5		
51 - 60 years	2		
61 - 70 years			
		Total of Self Advocates Represented	**25**

Geographic Breakdown.

Region	
Interior	8
Lower Mainland	22
Vancouver Is./Sunshine Coast	1
Northern BC	1
Total Interviews	32

Thematic Findings

In general, the findings of this exploratory study revealed that overwhelmingly self advocate, homes share provider, and family member participants agreed that the home sharing model was flexible, adaptive, and supported quality of life more effectively than group homes. Informed by the Schalock QoL framework, four prominent themes emerged from the analysis of the findings. These include: increased independence through a flexible and adaptive home sharing arrangement; the significance of the of the HSP/SA relationships and how this pivotal relationship enhanced QoL; the ability of home sharing to support social inclusion; and, an improved overall sense of emotional well-being of SAs who had moved from group homes to home share. In the subsequent section, we describe the findings in greater detail. These findings are grouped according to the three second order factors - independence, social participation, and personal well-being - and, subsequently, organized under the QoL eight domains: 1. Personal Development, 2. Self-determination 3. Interpersonal Relationships, 4. Social Inclusion, 5. Rights, 6. Personal Well-being, 7. Emotional Well-being, and, 8. Physical and Material Well-being.

Independence Factor

In this section, we describe the findings pertaining to domains one and two of the QoL framework under the first category of independence: personal development and self-determination. Personal development (domain one) considers educational achievements and educational status along with cognitive, social and practical competencies. Domain one also scrutinizes personal performance in terms of personal success, achievement, and productivity. Self-determination (domain two) focuses on autonomy and personal controls. It also considers goals and values in terms of personal desires and expectations; finally, self-determination examines choices from a broad perspective that explores an individual's opportunities, options, and preferences (Schalock et al., 2002). This section focuses on how participants understood the transition from group home to home share and how this change impacted the SAs in the domains of personal development and self-determination.

Domain One: Personal development.

Personal development was described in vastly different ways by each participant. Despite these individual differences an overarching theme emerging from the data indicated that home share, when done well, is an adaptive and flexible residential option that can foster and support an individual's personal development. For example, since moving from a group home to home share almost all (92%) of the participants reported that the self advocates' personal competencies had changed, and 80% stated that the self advocates' personal competencies had improved. One HSP explained that the self advocate who lived with her had limited communication skills. She noted improvement in this area since moving into the home share recounting how the SA had developed her ability to participate in *"three-way conversations... and she's on track of what we're talking about"* (HSP#2 {SA#4}). Five participants (FM#5 {SA#10}; HSP#2 {SA#4}; HSP#3 {SA#6}; HSP#4 {SA#20}; HSP#6 {SA#23}) described how the person with ID no longer required medications to manage their behaviours: *"He's on nothing anymore, nothing at all, and he just functions, really well"* (FM#5 {SA#10}). One HSP stated that the transition from group home to home share was difficult because in the group home *"staff was always with him, all the time, and sorta, doing everything for him"* (HSP#1 {SA#1}). Since moving into home share, the SA now helps set the table and empty the dishwasher. He also walks or takes the bus by himself when he attends activities (HSP#1 {SA#1}.

Personal competencies of self advocates represented in this study and as described by HSPs, FMs, and SAs varied widely and reflected individual preferences and the SAs' specific competencies. HSPs, FMs and SAs described areas of cognitive, social, and practical competencies that had improved from simple tasks of daily living such as *"getting dressed"* to more complex activities such as *"arranging a visit with a friend"* or *"organizing a schedule."* HSPs also identified goals or areas where SAs could continue to develop their personal competencies; for example, some HSPs described how SAs might be working to develop food preparation skills or learn about nutrition.

The importance of performance, one component of personal development, was highlighted by one SA who described a good day as, *"It's productive"* (SA#7). Participants also discussed employment status, another aspect of performance. Nine of the SAs represented in this project (participating directly or represented by their HSP or FM) had part-time jobs and one worked full-time. This was a source of pride for these SAs. Additionally, participants described aspects of performance and personal development when recounting the variety of recreation programs that SAs attended such as cooking classes, Special Olympics and other sports activities, and music classes. When discussing these activities, a number of participants described successes in the performance element of personal competencies by describing the SAs' ability to travel independently and/or to attend a program by oneself. For example, one HSP explained, *"He goes on his own and does it"* (HSP#3 {SA#6}). And, some SAs described how they arranged and managed their own travel plans: *"I take the Handydart, and as long as I get my haircut, I'm happy"* (SA#3). These SAs were more satisfied with an increased level of independence achieved through travel.

While 80% of the respondents indicated that the home share positively supported the SA to achieve improved personal competences. It is also worth noting that none of the FMs, HSPs, or SAs talked about educational achievements or education status, and only a few talked about performance, achievements, and productivity. It would be interesting to explore why these aspects of the personal development domain were not touched upon. Personal development (domain one) was critical for independence for many of the SAs represented by this research. Achievement in this domain often related to an increased level of social, cognitive, and practical competencies. This, however, did not diminish the participants' emphasis on the importance for self-determination (domain two).

Domain Two: Self-determination

There are several dimensions of self-determination: autonomy, personal control, and choice. Frequently, the value of self-determination was demonstrated in the research through participants' discussions of autonomy. Several of the SAs and FMs enthusiastically described increased autonomy in the home share model: e.g., *"I just make my own decisions"* (SA#2); *"Mostly I decide"* (SA#7); and, *"We go out and do stuff!"* (SA#13). Several HSP described how they worked to support independence by supporting the self advocate to do more things by themselves. For example, in one case a HSP described how he encouraged independence, *"[We] figure out the bus, have him take the bus to work from here and then going to certain programs that are close by on his own"* (HSP#1 {SA#1}). In another situation, the HSP illustrated how she was coaching the SA to order for herself in a restaurant *"then sorta standing back* *and watching"* (HSP#3 {SA#6}).

Several self advocates expressed increased flexibility in home sharing that lead to enhanced self-determination. At least two self advocates (SA#7; SA#14) stated that they liked home shares more than group homes because in the group home their needs were secondary to other residents. For example, one SA (#7) stated, *"I left the group home because it was difficult for me… there were two other individuals being served."* Another SA said, *"[The group home] was like more protocols… more rules and guidelines"* (SA#12); and, SA #13 stated, *"I don't like it! [group home], it's not for me."* Four HSPs and two FMs described how the SAs were able to exercise increased personal control in home shares. *"She's better than she used to be at initiating (calling a friend, arranging a coffee date) things like that. It's still not very often but it does come"* (FM#1 {SA#3}). A HSP stated, *"Oh much more independent… much more opinionated too!"* (HSP#2 {SA#4}). Finally, another parent described, *"They help him to be as independent as possible. They support inclusion"* (FM#6 {SA#12}).

Another aspect of self-determination that supports independence is a sense of personal control. One SA shared that since moving into a home share they have had more control about how they managed their environment: *"When you're not having a good day, you don't like people in your space. You like to be by yourself"* (SA#7).

The third element of self-determination is choice. The QoL framework recognizes that individuals need opportunities, options, and support to express preferences. An examination of the diversity of home share compositions underscored all three of these components of self-determination: the SAs' choice of living arrangement and the degree of independence and/or support that they wanted and/or needed was made explicit in part through the different home shares represented in the research. Some SAs had their own bedroom within the house; some SAs lived in a separate suite within the home; and, sometimes the SA received additional support workers and/or respite care. Each living situation was developed to support the SA and ensure the viability of the home share. For example, in one situation the SA was living with a dependent family member. She lived semi-independently in a separate unit next door to the HSP. The SA lived independently with some support from the HSP; she received budgeting support from the HSP and friendship. They ate dinner together several times a week, taking turns to prepare meals. Another situation involved a married SA couple. They lived together with a home share provider. The SAs were First Nations and the home share provider supported the SAs to connect with their home communities. In these examples, the unique living arrangements maximized the individuals' autonomy and opportunity for self-determination.

Of note, one finding related to independence concerns the importance of being responsive to the SAs changing preferences. For example, one HSP described how the agency required a separate suite for the SA, but after living in the home share for a year, the SA did not want to live in a separate suite; *"She threw an absolute fit… she wanted to live upstairs with the family. So we changed to accommodate her preference"* (HSP#2 {SA #4}). Another HSP described how the self-advocate liked his suite, and over time increasingly preferred to prepare and eat meals alone: *"He likes the idea of it… you know his own independence, his own space"* (HSP#3 {SA#6}). Finally, one family member recounted a story about her sibling's choice not to come home for thanksgiving the year after moving into a home share: *"...because he was busy now. He doesn't want to come home … he likes to be busy"* (FM#3 {SA#8}). These examples demonstrate how some home shares are able to adjust and accommodate personal preferences that change overtime, an important aspect of the Schalock QoL framework.

One negative issue relating to personal choice identified by several family members and two home share providers occurred during the process of transitioning from the group home to home share. Two FMs and two HSPs commented that home share was offered as the only option (FM#1 {SA#3]}; FM#2 {SA#5}; HSP#1{SA#1}; HSP#5 {SA#22}). There seemed to be a decreased sense of personal control in these situations. For example, one participant explained, *"We were notified at the beginning of August that the group home was closing down at the end of August"* (FM#2 {SA#5}). FM#1 {SA#3} also objected to the notice period of one month stating, *"There was only one month's notice that the group home was closing down."* In both situations a decision had to be made quickly, diminishing the opportunity for choice. A SA complained that it was *"frustrating… trying to find a (home share) that could accommodate a wheelchair"* (SA#3). While another FM shared that the SA was happy in the group home; she did not want to move and the family did not want her to move. Since then, the self advocate has lived in several unsuccessful home shares: *"She doesn't have a place that she can call home"* (FM#2 {SA#5}). Another family reported that the self-advocate clearly stated that *"she wanted to live in a group home,"* but they were told that this was not an option (FM#2 {SA#5}). One HSP stated that the family of the SA did not feel like they had any choice (HSP#5 {SA#22}). However, in all but one of these examples, after a less than ideal transition, the person with ID found themselves in a home share that they liked better than the group home and where they wanted to continue living.

Another way that choice was apparent in the findings related to the reasons why SAs moved from a group home to home share. There was diversity across participants. At least six of the self advocates interviewed initiated the move from a group home to home share themselves while others moved because of a change in policy either by a community living agency (e.g., an association for community living) or CLBC to close a group home (as described above). Others moved because of a personal issue: at least two SAs were kicked out of a group home. Others could not remember what motivated the move. Regardless of the circumstances that instigated the move, all of 17 SAs interviewed stated that they preferred home share to group homes. One SA explained, *"Home share has been very good because I was able to get employment"* (SA#7). Another SA stated, *"I don't live, live in a group home. I don't like it 'cuz it's not for me…"* (SA#13). Finally, another SA stated, *"I decided to live with my HSP because she was more suited to my care"* (SA#12).

The 17 SAs and most of the FMs and HSP described how moving into a home share had supported the SA to achieve their unique desires and personal goals. One parent expressed, *"Hopefully to just continue doing what he's doing because it's more than we ever expected!"* (FM#5 {SA#10}). One SA described how his health had improved since moving in the home share: *"I weighed 235 pounds, and now I'm down to 170"* (SA#12). Two other SAs expressed their goal for more independence (SA #13; SA#19): e.g., SA #19 stated, *"I eventually [want to] live on my own."*

It was very clear from the interviews that persons with ID were able to articulate their preferences and that within this residential option, they were able to exercise choices more. SAs with limited communication skills were observed to communicate their desires. A family member described how her adult daughter who loved animals was not able to have them in the group home but in the home share *"she was talking a little better… and she was happy, she was really happy, she loved animals … her HSP had cats, and dogs … she immediately decided the cat was hers: it was, 'My cat!'"* (FM#4 {SA#9}). Finally, another HSP summed it up this way: *"Whichever staff was with her [in the group home], [how they prepared her coffee] is how she had her coffee… They didn't know, like she doesn't really like coffee, she prefers tea"* (HSP#2 {SA#4}). Home share as a model seemed to provide more options for these SAs; consequently, SAs, as represented by the participants in this research, were able to assert choices, desires, and preferences.

Notably, another theme emerged around the intersections among personal development (domain one) and self-determination (domain two). For some, an important tension existed around who decides what type of personal development an individual should strive for and attain, and its relationship to self-determination? For example, one parent described how they designed their home to maximize their child's access to appliances so that she could *"cook at least some meals for themselves"* (FM #1 {SA#3}). The same parent remarked that it seemed like the person's *"life skills had declined since moving into home* *share."* However, from the perspective of the person living with ID, this was not an issue. When asked if she ever does any cooking, the SA stated, *"I have not for a while"* and then moved on to say, *"It's fantastic for me because I love home sharing… I don't like being by myself… I was kind of lonely there (in the group home)"* (SA#3). In this example, the individual exercised her right to self-determination by prioritizing the interpersonal relationship domain over the personal development domain.

While personal development (domain one) is critical for independence, for many of the SAs represented by this research, achievement in this domain often related to an increased level of social and practical competencies. That said, participants also repeatedly demonstrated the importance of self-determination as it relates to independence.

Social Participation Factor

The social participation factor is shaped by interpersonal relationships (domain three), social inclusion (domain four), and rights (domain five). Interpersonal relationships considers the individual's social network and social contacts, their relationships with family, friends, and peers, and it includes informal emotional, physical, and social supports. Finally, domain three also reviews recreation, how does a person spend her/his free time? This broadly includes sports, art, culture, relaxation, or other hobbies. Social Inclusion looks at community integration and SAs' participation in community activities. It also looks at the nature of community roles. In what ways do people contribute to community? For instance, do they volunteer? Domain four also considers formal social supports that a person might require including social networks and services. The final domain in the social participation cluster looks at Rights. It emphasizes: human rights (respect, dignity and equality) along with legal rights (citizenship, access and due process). In the next section we present these findings and look at how the home share model impacts outcomes for SA in these three QoL domains.

Domain Three: Interpersonal Relationships

Interpersonal relationships stood out in the findings as both significant and pivotal. Many of these relationships could be characterized as enduring, stable, and attached. Home sharing seemed to operate more successfully when the quality of the relationships were positive. The importance of the quality of these relationships is underscored when one considers the length of time that SAs lived with their HSP combined with any previous relationship history prior to entering the home share relationship. Over half 15 of the 25 SAs had lived in their home share for more than five years with 8 of the 15 SAs and HSPs having known each other for more than ten years. Four SAs were new to home share (less than 6 months).

Many HSPs and SAs had a pre-existing relationship prior to entering into home share. 5 of the 7 HSPs stated that they had worked with the SA as a support worker prior to living together. They had pre-established relationships with the SA. In at least four instances, the HSP, a previous group home employee, applied specifically to work with the SA because the group home was closing down and they were concerned about the SAs' future living arrangements and about the SAs' emotional well-being (HSP#2 {SA#4}; FM#4 {SA#9}; HSP#4 {SA#20}; HSP #5{SA#22}). In these situations, the HSP talked about long established friendships. One HSP said, *"...every time that a shift became available with that SA, I dropped one of the others and I took the shifts with her..., my favourite"* (HSP#2 {SA#4}). Another HSP described how worried she was about a particular SA. The SA was older and had behaviours that most workers found difficult to manage. The group home was slated to close within three weeks and there still was no placement for the SA; so, the HSP who previously had no interest in home sharing took a risk and contacted the family directly. When she realized the family did not have a plan for the SA when the group home closed, she decided to become the home share provider (HSP#5 {SA#22}.

These pre-existing relationships had implications for the quality of the home share experience. For many, the strength of the previous relationship, along with concern for the SAs' well-being, was the impetus for applying to become a HSP not only for these two aforementioned SAs but in at least six additional scenarios (FM#3 {SA#8}; FM#4 {SA#9}; SA#13; SA#18; HSP#4 {SA#20}; HSP#7 {SA#24}). This was not an unusual arrangement. In at least 9 of the 25 housing arrangements, the HSP knew the SA previously before becoming a HSP (HSP#2 {SA#4}; FM#3 {SA#8}; FM#4 {SA#9}; SA#11; SA #13; HSP#4 {SA#20}; HSP#5 {SA#22}; HSP#7 {SA#24}; SA#25). In addition, these prior relationships created a foundation where the HSPs were familiar with the SAs' personality, preferences, values, behaviours, mannerisms, and idiosyncrasies. In many situations, the HSP entered this residential option aware of SA's needs.

The importance of the interpersonal relationships in the home share was also highlighted by how participants described the home share relationships. For instance one SA said this about her home share provider, *"She's been there for me when I've been hurting and had hard times and, she's been fun, she's been great!"* (SA#13). Another SA described her HSP this way *"...I can talk to her any time I want, need to"* (SA#14). Another SA said she hated her HSP when she first met her but over time they got to know each other and trust built: *"Yeah, I love her so much now she… she's my rock!"* (SA#15).

In fact, most of the SAs interviewed made positive comments about their HSP(s) and home share. For example, one SA had only been in a home share for five months but she was very enthusiastic about the model stating: *"All I can say is, home sharing is much better than group home living!"* (SA#7). 10 of the 25 SAs had lived in home share for just under four years but they spoke about their HSP with deep affection. One SA had never lived with a family. She liked helping out with the children and being part of the family. *"It's [home sharing] fantastic for me because [I] love home sharing"* (SA#2). Another SA had only lived with the HSP for three years but had known the HSP for over fifteen years. They had previously been *"housemates"* in their early twenties. They maintained the relationship in the intervening time. Three years ago, they decided to live together again. *"Home share is great! It's been an inspiration for me. It's the best thing I ever did. It's great to live with people who love you and share your lives"* (SA#25).

In three different situations family members talked about how the HSP had an interest in the SA that went above and beyond their expectations (FM#3 {SA#8}; FM#4 {SA#9}; FM#5 {SA#10}). One FM recounted how the HSP (a support worker at the time) had stayed in the hospital 24/7 with the SA during a medical procedure so that the SA would not be scared, much like a mother might for a child (FM#4 {SA#9}). Another family member stated, *"The HSP chose my brother"* (FM#3 {SA#8}). These situations also stood out because of the commitment, affection, respect, and compassion expressed by the HSP for the SA. In several situations, both the SA and HSP were very proud of the SAs' accomplishments. In one case the SA no longer interfaced with the judicial system (HSP #7 {SA#24}). In another case, an agency did not think a particular SA, who had a history of aggressive behaviours and had never lived in a family home, was a good candidate for home sharing, but due to a shift in CLBC policy, the agency was closing the group home. They asked the HSP who had a good relationship with the SA if he would consider home sharing. The SA fit right in with the HSP's family (HSP#4 {SA#20}). The HSP couple hoped that one of their two children will take over the SA's care when the couple are too old to do so; a sentiment often expressed by family members (HSP#4 {SA#20}).

These HSP and SA relationships were significant in facilitating connections. For example, one HSP was working with the SA to assist her to maintain a relationship with her mother and two sisters despite the fact that these visits often ended badly. After a recent family visit, the SA, distraught after being excluded from a family celebration, broke her glasses. The HSP talked about the familial situation with compassion and described the strategies used to support the SA to maintain these important relationships (HSP#6 {SA#23}). Another SA with First Nations status had not visited her home community in the north for more than ten years. The HSP had worked with the family and First Nations community in the North, and last summer the SA travelled home to visit her son and extended family (SA#13) for the first time in many years.

Another aspect of interpersonal relationships looks at the relationships SA have with family, friends and peers. Interestingly, in addition to forming a relationship with the SA and supporting the SA to have other relationships, the HSP often seemed to be the primary source of emotional, physical, and social supports. Only three SAs interviewed seemed to maintain a strong relationship with parents or a sibling (SA#3; FM#5 {SA#10}; SA#16). This ranged from dinner every Sunday night (FM#1 {SA#3}) to a sleepover bi-monthly (FM#5 {SA#10}). SA #16 described his sister as his *"best friend!"* Several other SAs visited with their families consistently but with less frequency or routine. While these visits were not always pre-scheduled, they sometimes included an overnight visit (SA#2; SA#11; SA#12; SA#18; SA#21; HSP#6 {SA#23}; SA#25). At least one SA saw his parents as infrequently as once a year (HSP#3 {SA#6}), while several other SAs saw their families during the year for holidays, vacations, birthdays, and/or other family celebrations (SA#1; FM #2 {SA#5}; FM #3 {SA#8}; SA#11; SA#16; SA#18). However, most of the SAs interviewed (over half) did not seem to have relationships with their biological families. In some instances, their parents had passed away and they had no contact with siblings or other extended family, or in several cases, the SA had never lived with their family of origin.

Seven SAs interviewed had a boyfriend/girlfriend or significant other relationship. One SA was married and lived with her husband in a home share (SA#13). The other SAs lived in separate homes from their significant other but visited frequently (SA#2; FM#2 {SA#5}; SA#6; SA#14; SA#16; SA#17). Several SAs expressed interest in having a partner (SA#11; SA#15); one of these SA had recently *"broken up"* (SA#11). One SA had recently determined that she was a lesbian. The HSP had assisted her to locate a group where she would meet other women (SA#15). Intimate relationships did not seem to be important to all SAs. None of the family members or HSP brought up the topic of intimate/partner relationships when discussing the SAs' interpersonal relationships. With respect to personal relationships, it is noteworthy that most SAs did not distinguish between friends, HSPs, or other agency support staff. Further, they did not seem concerned about the absence of friendships; they did not communicate concern in this area.

In the research findings, there were numerous examples of positive interpersonal relationships, including social networks and contacts, relationships with family, friends, and peers. There were also numerous examples of informal emotional, physical, and financial supports. These elements of social relationships distinguished domain three and, furthermore, are pivotal to the success of home sharing.

Domain Four: Social Inclusion

Social inclusion (domain four) considers community integration and participation, community roles, and formal social supports. SAs in this research benefited through increased access to social networks because of home sharing. The degree of community integration varied among the SAs. Some SAs were engaged independently in the community, while other SAs were unable to initiate or maintain relationships independently and gained access to "shared" social networks through the HSP. Some SAs had rich social networks that supported community integration and participation. At least four SAs attended church regularly and participated in the church community (SA#2; SA#3; HS#3 {SA#6}; SA#7). A number of SAs participated in Special Olympics, arts & crafts, cooking classes, and other organized activities in their area: e.g., *"We go to the movies and stuff, and yeah, swimming, cooking classes on Friday"* (SA#13). Some of these SAs also worked and/or volunteered (SA#1; SA#2; SA#3; FM#2 {SA#5}; SA#6; FM#3 {SA#8}; SA#10; SA#12; SA#13, SA#14; SA#15; SA#19; HSP#24 {SA#24}; SA#25). Importantly, and related to the domain self-determination, some SAs preferred a less active social schedule and chose to spend their days at home, going for coffee, or just hanging out with the HSP and/or a support worker (HSP#2{SA#4}; FM#4 {SA#9}; SA#14; SA#13; SA#16; SA#17; SA#18; HSP#4 {SA#20}; SA#21; SA#22; HSP#6 {SA#23}).

The interviews demonstrated a sensitivity and recognition from the HSP and the agencies that not all SAs want to be involved in the same level or quantity of activities. An individual's schedule needed to reflect the SA's preferences and desires. In fact one SA's anxiety became more manageable when his schedule was reduced to include fewer activities. He experienced a busy schedule as hectic and anxiety provoking (SA#17). At least two SAs stated that they liked to be home in the evenings (SA#3; SA#7). Several SAs were very busy during the day but their HSPs were clear that these same individuals wanted to be in bed early and desired to be home at night (SA#2; HSP#3 {SA#6}; HSP#7 {SA#24}). Another SA talked about watching movies in the evening with her roommate as preferable to going out in the evenings (SA#3).

For at least six of the SAs, their social network revolved around the HSPs' social network (SA#2; FM#3 {SA#8}; SA#16; HSP#4 {SA#20}; HSP#5 {SA#22}, HSP#6 {SA#23}; SA#25). For example, for some SAs the extended family of the HSP also interacted with the SA. One HSP said that the extended family knew that the SA collected pamphlets, *"When my family goes somewhere, they'll bring her home a pamphlet… They just sort of included her. She just became part of the family"* (HSP #2 {SA#4}). Several HSPs talked about how their family and friends all embraced the SA, making a point to include the SA in social activities, such as attending sporting events or going to movies (HSP#5 {SA#22}; HSP#6 {SA#23}). At least two SAs traveled extensively with their HSPs (FM#3 {SA#8}; SA#11).

Another area that improved social inclusion was the relationship between the HSPs and the FMs. There was recognition that when the FM and the HSP worked together, outcomes improved for the SA (FM #1 {SA#3}; FM#3 {SA#8}; FM#5 {SA#9}; FM#6 {SA10}). A good relationship between the FM and HSP improved the quality and quantity of home visits. One family member explained how they were better able to support their sibling during a family visit because of tips provided by the HSP about how to respond to a particular behaviour (FM#3 {SA#8}). Another family member became very emotional and choked up when they talked about the HSP: *"They treat him like a son. They are just like family to us. They are just wonderful"* (FM#5 {SA#10}). This FM provided informal respite to the HSP by encouraging overnight visits at least twice a month.

Many of the SAs interviewed participated in social activities through the community based agencies and/or recreation centres. These activities formed a mechanism for improving interpersonal relationships and increasing social inclusion. One sibling stated, *"This group, they meet I think once a month. They are always planning to do things including trips to Las Vegas, and a trip to Hawaii, and whatever a cruise"* (FM#3 {SA#8}). While it appeared that many SAs' interpersonal relationships revolved around paid support staff and HSP, these relationships seemed genuine and based on mutual respect and caring.

Some SAs had lived in more than one home share (SA#7; SA#12; SA#13; SA#15; SA#14; SA#17; SA#24). These home shares had failed overtime but this was usually due to a change in the family circumstances and/or health issues. In one instance the HSP passed away, while in several others the family situation changed and the HSP could no longer remain in a supportive role with the SA. This seemed to underline the fact that personal circumstances and environmental factors impact QoL and that over time change will occur.

The findings suggested that home sharing effectively supported social inclusion with 24 of the 25 SAs represented in this research indicating that they were satisfied by their level of community engagement and formal supports.

Domain Five: Rights

Rights includes both human and legal rights. Human rights encompass respect and dignity of the person and equality while legal rights include citizenship, access, and due process. In this research, the findings pertaining to rights were distinguished primarily by a lack of discussion about the topic. In fact, the participants did not discuss rights overtly, but human rights and legal rights seemed to be reflected in the satisfaction most all SAs expressed about living in home shares as discussed above. When asked do you like where you live now, one SA stated, *"Yes, it's more flexible"* (SA#3).

With respect to legal rights, there were three cases where the SA had prior involvement with the criminal justice system. The three SAs talked about how the HSP and the agency worked with them so that they no longer interfaced with the legal system: e.g., *"He has not been on probation for three years"* (HSP#7 {SA#24}). Another SA stated, *"When the cops were called a couple of times, it kind of scared me half to death… so that might have changed my attitude"* (SA#12). The third SA had lived on the streets, and then in a group home, and finally in a home share; *"I like it. We did more like family oriented stuff, like we went camping"* (SA#19). These situations reflected a respect for the dignity of the person and a willingness to support them to overcome their challenges.

And while there was a lack of explicit discussion about rights, in three interviews the issue of human rights was raised indirectly, twice by family members and once by a HSP. The HSP described the pressure felt by herself and the family when the group home was closing in less than a month and no placement had been found. The two families also felt disrespected when they had to find a home share for their SA in less than a month (FM #1 {SA#3}; FM #2 {SA#5}; HSP#5 {SA#22}). One family raised serious concerns because medical issues were not managed adequately during the transition. In fact, they themselves had to go and care for the SA for the first couple of weeks until a home care nurse was put in place. The other family expressed that the CLBC GSA rating was inaccurate and led to inappropriate placements where the previously happy SA developed anxiety. Formal supports were not provided and the parents paid for the SA to attend counselling. They referred to the experience as *"the trauma of it all"* (FM#2 {SA#5}). The families did seem to feel that their right to due process had been trampled on, along with their legal right to access adequate services. Furthermore, they communicated that the dignity of the SA had not been considered. It was evident that the transition period had left these participants dissatisfied. However, in two of these three cases, despite the challenges in transition, the ensuing home share was successful.

Again, overall participants were satisfied with their home sharing arrangement; consequently, it seemed that their human rights were adequately protected.

Personal Well-being Factor

The third and final cluster of domains in the Schalock QoL framework fall under the personal well-being factor and includes emotional well-being (domain six), physical well-being (domain seven), and material well-being (domain eight). In this final section, we discuss how the transition from group homes to home share impacted emotional, physical, and material well-being.

Domain Six: Emotional Well-being

Emotional well-being encompasses three areas: contentment, self-concept and lack of stress. Contentment includes an individual's sense of satisfaction, his/her mood, and enjoyment; self-concept involves identity, self-worth, and self-esteem; and, finally, lack of stress embraces the importance of the predictability of an individual's circumstances along with his/her sense of control within that environment.

SAs and FMs talked about how they felt about the move from group home to home share. Their thoughts provided insight into how the move impacted their sense of emotional well-being. One SA was nervous when she first moved into the home share but over time she allowed herself to appreciate the experience: *"[I] started calming down. I started thinking that I'm going to enjoy this"* (SA#2). When asked about how the group home and home share compared, she said, *"[Home sharing is] way better than the [group home], must admit. We're always laughing"* (SA#2). When asked if they would change anything, one SA stated emphatically, *"Can't think of anything"* (SA #3). While another SA with limited communication described his home share as, *"Good!"* accompanied by a thumbs up (SA #6). Another SA stated that *"[living in a group home] ... start[ed] to get draining, like in terms of you're, um, momentum, or you're um, ability I guess to thrive and stuff... I can't say that I miss anything [about the group home]"* (SA #7).

Family members also described changes that they noticed in the SAs' emotional well-being. For example, one family member stated, *"He's not in conflict with other people like he was in the group home"* (FM#3 {SA#8}). Several family members remarked about the SA's state of mind: *"She was very happy there and she blossomed"* (FM#4 {SA #9}); *"We told [him that the home share would proceed], big relief, big smile, he was happy. We knew it was a good match!"* (FM#5; SA#10).

With respect to mood, fourteen SAs were reported to have improved mental health (SA#2; HSP#3 {SA#6}; FM#4 {SA#9}; SA#12; SA#13; SA#14; SA#15; SA#16; SA#17; SA#18; SA#19; HSP#4 {SA#20}; SA#21; HSP#6 {SA#23}). Some SAs were reported to have significant reduction in aggressive behaviours such as fewer angry outbursts towards others, or themselves after moving from a group home to a home share. In one instance, the SA no longer required 24/7 care (SA#18). Another SA who previously lived in two BC institutions and was not considered a good candidate for home sharing, stopped throwing feces, raising his voice, and acting out (HSP#4 {SA #20}). Some SAs were reported to have reduced use of medications and, in at least one instance, the SA no longer required medication to manage her behaviours (SA#19) suggesting that her previous mental health issues were linked to environmental factors. One HSP described how other people remarked, *"She's so much smarter."* The HSP exclaimed, *"She not smarter at all. She's just not drugged"* (HSP#2 {SA#4}).

Participants also spoke to an improved sense of enjoyment and satisfaction. One SA stated that she was happy and liked living in the home share: *"Now I'm included in everything"* (SA#2). Another SA said it took a while to adjust to the new residence but described the home share as follows: *"Lot of laughing with people, I remember, right from the start"* (SA#3). Her FM stated, *"She's extremely social and loves to be around you know, the bigger the group of people, the better"* (FM#1 {SA#3}). Home share seemed better able to meet the SA's needs for socialization, a component of self-concept. Another SA had a habit of taking off from the group home and get into trouble. Now he works five days a week and he said, *"[I] love home sharing and [I] would recommend it to anyone"* (SA#16).

In this research, home sharing also seemed to support an increase in self-concept another component of emotional well-being. One SA had been hospitalized for mental health concerns while living in a group home. Since moving into a home share, there had been a significant change in how she felt about life (SA#14). At the time of the interview, she was involved in organized activities such as cooking classes, Special Olympics, and arts and crafts. She worked two days a week and volunteered, and she had a boyfriend (SA#14). Another HSP described how the SA needed fewer medications; she attributed this change to *"knowing the person and understanding them and letting them be, and encouraging her [to make choices]"* (HSP#2 {SA#4}). The facets of emotional well-being – contentment, self-concept and predictability – seemed to be connected to the strength of the SAs relationship with the HSP.

Several SAs described the period when they moved from foster homes and transitioned into group homes as volatile (SA#12; SA#15; SA#21). This was a rebellious period in their lives where they ended up interfacing with the legal system and/or being hospitalized (SA#12; SA#14; SA#19; SA#21; SA#24).

Each of these SAs expressed in their own way, how much better they liked living in a home share than in the group home. The supportive and predictable environment along with the consistency of care provided by the HSP assisted these individuals to experience improved mental health. One SA stated that she really doesn't like to talk about the group home; it upsets her and she begins to feel anxious (SA#25). But, when describing the home share, she stated that it's great living in a place where *"they can't stop loving me!"* (SA#25).

The findings seem to indicate that when a good match is made, home sharing is not only flexible and adaptive, it is able to provide SAs with a predictable, stress-free environment. HSPs and SAs described how they supported predictability in the home share environment. For example, HSP #1 described how he supported the transition from group home to home share: when the SA first moved in *"I didn't change anything that he was used to… you know his schedule or routine…"* (HSP#1 {SA#1}). HSP#2, who previously worked in the group home where the SA lived, stated, *"There [was] a lot of conflict [in the group home]. [Here] she's not as stressed; not as confused either. Here she knows exactly where she stands"* (HSP 2 {SA#4}). Finally, SA #7 clearly articulated, *"Why I left, um, the group home was because it was so, it was, um, difficult to interact of all the different employees that were coming in and out, from one day to the next. I had to leave"* (SA#7).

Based on the level of contentment among 24 of 25 SAs, home sharing was able support emotional well-being for these participants. There is of course a link between physical well-being and emotional well-being which is seen in the findings and explored in the next section.

Domain Seven: Physical Well-being

Physical well-being is concerned with overall health including fitness and nutrition; it also includes activities of daily living such as self-care and mobility; and, finally, it involves physical activities and recreation. Many SAs expressed concerns about their physical well-being. These concerns seemed to centre around fitness, nutrition, and medications. Issues of physical well-being also centred around activities of daily living (self-care and mobility) although there was less emphasis on this particular aspect of physical health. That said, there was diversity across SAs participation in activities of daily living.

For the most part, SAs (84%) managed their own self-care with prompting including personal hygiene, but for others more accommodations and supports were needed; e.g., some SAs were unable to participate independently with meal preparation because he/she ate compulsively, and one SA used a wheelchair and needed assistance with personal care (FM#1{SA#3}]. In at least four cases, the SAs ate compulsively or snuck food. One strategy to prevent this behaviour had been to keep the SA out of the kitchen (HSP#1{SA#1}; SA#13; SA#21; HSP#6 {SA#23}). These SAs were not involved in food preparation because of the health risks associated with overeating but they helped with other chores such as setting the table or unloading the dishwasher.

In this research, participants described home sharing as being more effective in meeting the support requirements of SAs than group homes. Often participants described that in group homes SAs' needs were sacrificed because staff were pulled in other directions whereas in a home share the support was individualized. For example, three SAs reported that when they lived in group homes, their needs were not met (SA#7; SA#14; SA#16). For instance, one SA said that the other SA living in the group home took up the staffs' time (SA#7). Another SA stated, *"The attention had to go to the other people"* (SA#16). Another HSP described SA #6's group home, *"It was very difficult for him because he was sharing staff and, ah, you know, he's like very possessive to his main caregiver in a way that you know if he's feeling left out at all he'll act out… here it's just the two of us"* (HSP#3 {SA#6}).

Beyond activities of daily living, a more prominent finding arose around weight. Many of the SAs and the HSPs interviewed were concerned about the SAs' weight and the impact it had on overall health. Many SAs were overweight and wanted to lose weight. They were involved in exercise programs such as walking or swimming as a strategy for addressing fitness. Other SAs were involved in Special Olympics and other physical activities as a form of recreation and a means of experiencing social inclusion. In fact, several SAs expressed a goal of either losing weight or increasing their exercise. SA #2 stated, *"I'm losing weight. My physical health, it's really good. I'm better now than I was then [living in the group home]."* Another SA said that her goal was to increase her walking: *"Like do two laps around every day instead of one"* (SA#14). Finally, another home share provider said the goal was *"to get [the SA] out and to be physically active"* (HSP#5 {SA#22}).

Many SAs were on medications for a variety of issues ranging from seizures to mental health concerns. Many of the HSP were actively involved in managing and administering medications. The HSP interviewed were conscientious about ensuring that the SAs were on the right type and dose of medication: *"I'm actually quite proud of this… I took her to the doctor, who said she was on too many drugs… the SA is now on half the medication [seven months after leaving the group home]"* (HSP#2 {SA#4}). Another HSP talked about how the SA's anxiety was so high that it led to delusional thoughts. Since moving into the home share, the home share provider working with the psychiatrist had been able to get her onto medication that prevented her anxiety from escalating. Additionally a structured, predictable living environment had decreased the need for medication (HSP#7 {SA#24}).

In at least two cases, family members of SAs were frustrated and stressed out by the transition from group home to home share because there was no planning and a lack of clarity around who would provide needed medical care during the transition. In one case, the family had to step in and provide medical care because it was not provided during the transition period (FM#1 {SA#3}). While in another case, the family was frustrated that the HSPs were not assisting the SA by monitoring and administering medications. The SA was not able to manage prescribed medications (FM#2 {SA#5}).

With respect to recreation, many SAs spoke about recreational activities but not so much in the context of physical well-being; rather, it was discussed more in the context of social inclusion and in connection with social participation. For instance, many SA participated in Special Olympics or enjoyed swimming. In this sense, exercise was discussed more as a by-product of an active lifestyle and social inclusion than as a goal that contributes to physical well-being.

SAs who participated in this research were able to address fitness and nutrition issues more effectively than within a group home. Several SAs reported improved physical health in the home share.

Domain Eight: Material Well-being

The final domain of personal well-being is material well-being. Material well-being includes income and benefits, employment, and housing. Some SAs talked about lack of funding as a challenge (e.g., SA#2). At least two families felt that they needed to supplement the SA's funding allocation (FM#3 {SA#8}; FM#5 {SA#10}). Both of these families purchased new beds for their SA. One family decided to provide a monthly stipend to the SA because his allowance was inadequate (FM#3 {SA#8}). The stipend was used to pay for essential items such as new clothing. Another family was frustrated because the SA kept overspending on her cell phone. The family felt that the SA needed support to budget (FM#2 {SA#5}).

Employment is another aspect of the material well-being domain. As stated previously, nine of the SAs interviewed had part time jobs and one SA had a full-time job; however, the remaining fifteen SA were not employed. In one case the SA's anxiety prevented her from having a formal employment arrangement but the HSP found a way to incorporate the goals of employment into her schedule. The SA who loved gardening worked in the family garden (HSP#6 {SA#23}). Another SA helped out with chores on a small family farm (HSP#4 {SA#20}). There were a variety of reasons given by participants as to why employment was not attainable for some SAs such as challenges due to mental health or low adaptive functioning. For these SAs, it was an achievement to get out and participate in organized activities.

The final aspect of material well-being related to housing and the type of residential arrangements. All but one of the twenty-five SA represented by this research lived in home share. One SA had moved into cluster living with the hope that this type of housing would balance independence and supports more adequately for this SA (FM#2 {SA#5}). None of the SAs who participated in this research reported owning their own homes.

SAs, FMs and HSP reported improvements in the emotional, physical and material well-being domains since moving from a group home to home sharing. Consequently, based on this study, it seems that home share is an effective model that can support improved QoL for SAs.

DISCUSSION/CONCLUSION

The findings described in this report were informed by the Schalock QoL framework and focused on what can be learned about the QoL of individuals served by CLBC who moved from a group home and at the time of this research lived in a home share. We also explored how the experience of living in a home share affects/impacts QoL. These findings are based on the perspectives of home share providers, family members, and self advocates who were a part of the transitions from group home to home sharing with priority placed on the SAs' firsthand experiences when possible. Their perspectives add an invaluable perspective on the home share model and QoL.

QoL is intended to be emancipatory, accepting individual choice, and recognizing personal values (Schalock et al., 2002). Home share is an example of a community living arrangements that strives to facilitate social inclusion and accommodate the variable and distinct needs and wishes of people with ID (Stainton et al., 2006). This research revealed that 24 of the 25 SAs (96%) preferred living in home share over living in a group home. In fact, the 17 SAs that were interviewed emphatically stated that they were much more satisfied with the home share than their previous group home experience. Additionally, even family members who were at first hesitant or opposed home sharing indicated that despite challenges in the transition process they now preferred home share to group home. Home share, as a residential option, did not meet the needs of one SA; this SA was not interviewed directly rather she was represented in this study by a family member.

At a broad level, the findings of this research demonstrated that home share when working well provides flexibility that enhances QoL especially when the model is individualized around the SA’s abilities, desires, and needs. This is in line with previous research (e.g., Crawford, 2008) suggesting that there needs to be a move away from “one size fits all” approaches to supports (e.g., group homes) and, instead, there needs to be a move to supports and residential options that are designed around the individual's unique needs and preferences (e.g., Crawford 2008; Hole et al., in press; McConkey et al., 2004). Such a call foregrounds the importance of person-centred planning and raises questions regarding home sharing’s ability to complement and support goals of personalization and the implications for QoL. This questioning will be discussed in more detail later in this discussion; however, prior to this, we focus on a discussion of the findings of home sharing and QoL.

With respect to home share and the QoL framework, home sharing appeared to increase independence, social inclusion, and emotional well-being while accommodating the diverse and unique needs and desires of 24 of the 25 SAs represented in this research. In addition, there was increased independence, social participation, and enhanced emotional well-being among the majority of the SAs represented in this research. Importantly, a key finding of this research was the importance of the relationship between the HSP and SA (HSP/SA relationship). In fact, the HSP/SA relationship(s) seemed to be critical to the success of the home share model and, more specifically, to the QoL of the SAs. Such findings echo our previous work on home sharing (Hole et al., in press) where we found that the quality of the home share relationship(s) and the “match” was a key factor to home share successes.

In this next section, we first examine what the findings suggest in terms of the HSP and SA relationship and QoL. This will be followed by a discussion of how home share may contribute to positive QoL outcomes. This discussion will be based on the following key points supported by this research:

1. Home share was described as a flexible and adaptive residential option that increased independence;
2. Home sharing can support social inclusion; and,
3. Home share supports improved emotional well-being.

First, the present study demonstrates that the quality of the home share relationship(s) had a direct impact on the SAs' QoL. That said, we note that there was variation in the nature of the HSP/SAs' relationships; some relationships were intimate while others were characterized as more independent but still supportive and attentive to the SAs' desires and needs. Similar to researchers Amado et al., (2013), we found that a sense of belonging, commitment, and trust are key to facilitating positive QoL outcomes. As one SA clearly stated, *"It's great to live with people who love you and share your life"* (SA#25). In fact, Amado et al. (2013) found that these relationship qualities are key to promoting social inclusion.

Interestingly, and similar to Hole et al. (in press), the findings of the current study suggest that the quality of the home share relationships can be enhanced by HSPs and SAs having a pre-existing relationship. In the present study, HSPs were familiar with the SA preference, values, behaviours, and mannerisms but, more importantly, the HSPs were concerned about the welfare of the SA. These were stable, enduring, and connected relationships. Hole et al. (in press) found that these pre-existing friendships between caregivers and SAs contributed to securing a "good match" while ensuring a HSP with "an existing skill set." This is particularly noteworthy given the centrality of the HSP/SAs relationships as it points policy and practice implications that focus on creating, nurturing, and maintaining these key relationships: for example, the importance of planning - both transition planning as well as ongoing planning and support as relationships evolve and change over time (see Hole et al. in press).

Another key finding relating to the HSP/SA relationship(s) was the HSPs' role in facilitating social inclusion. Amado et al. (2013) found that relationships were key to social inclusion. In the present study, social inclusion was often achieved through the HSP sharing their social capital with the SA. SAs were included in family/friend gatherings. HSP family and friends invited SAs to attend sporting events, concerts, movies, and other community activities. Some SAs living in home share had been able to expand their social capital through participation in community groups and churches. Condeluci et al. (2008) describe social capital as the relationships that provide the foundation for trust, social reciprocity, norms, culture, and community. Further, social capital is a key factor that leads to a happy, healthy and fulfilling life. It is important to life success because it is associated with working, living, and engaging in community (Condeluci et al., 2008). Thus, this sharing of social capital through the HSP/SA relationship(s) for the participants in our study was important because many SAs had limited social capital. As in other research (e.g., Marquis et al., 2010), over 50% of the SAs in the current study had no involvement with family and friends and only three SA had consistent relationships with family. This finding is consistent with Marquis et al.'s (2010) research that found that overtime as SA age and parents pass away, family involvement decreases.

Further, and similar to previous research (e.g., Amando et al., 2013; Marquis, 2010), the 25 SAs that participated in this research had few unpaid relationships; their friends were often other SAs served by the agency and/or paid support workers. The SAs often saw the HSP (a paid caregiver) as a "friend". The notion of "paid" friends remains contentious (e.g, Amado et al., 2013). That said, "[a]lthough not a substitute for natural friendship, validating relationships between people living and working in services have the potential to provide people with disabilities with a sense of attachment, emotional integration, and stability, reinforcement of worth and the development of confidence in entering other relationships" (Marquis et al., 2010 p. 422). In the present study, HSPs fulfilled multiple roles in the lives of SA and, further, it appeared the HSPs had genuine affection and concern for the SAs living with them. Perhaps, as suggested by Marquis et al. (2010), acknowledging and supporting the HSP/SA relationship(s) may be a way to support SAs to develop skills to cultivate and maintain friendships, an important component of social participation. Further, given that people with intellectual disabilities often require support to develop their social capital (Condeluci et al., 2008), HSPs and home share coordinators may find and create ways to promote and encourage the sharing of social capital to promote social inclusion.

A unique feature of home share was the fluidity and unique nature of the HSP/SA relationship; the relationship was different for each HSP/SA pairing characterized by varying degrees of support and independence. As Stainton et al. (2008) stated, "[Home sharing can be] conceptualized on a continuum with high levels of support and a long term, stable relationship with a support provider on one end and low level of supports and a less involved relationship on the other" (p. 9). This continuum was evident in findings. A quality and flexible HSP/SA relationship seemed to support improved QoL for SAs through the accommodation of SAs diverse abilities, values, and desires.

Another poignant finding of the present study is that home share has the potential to positively impact the independence of the SA participants in the personal and the self-determination domains. SAs achieved increased cognitive, social, and practical competencies as well as improved personal controls that included the increased ability to express goals, expectations, and choices. Participants reported improved communication, reduction in the use of medications, and increased employment. Further, SAs expressed more ability to make decisions and control their environment in the home share. These areas of growth were regarded as achievements by SAs, HSPs, and FMs alike. The diversity within these domains reflected the differences in adaptive and cognitive functioning as well as variation in personal preferences, values, and desires among SAs, as would be expected in person-centred planning initiatives (Schalock, 2004).

Cocks et al. (2014) asserted, “[residential supports] should be driven by individualized support and accommodation - what they term individual support living” and also referred to as person-centred planning or personalisation (as cited in Hole et al., in press, p. 24). Our research supports the growing literature that supports person-centred planning as fundamental to enhancing QoL (e.g., Cocks, et al., 2011; Lawlor, et al., 2013; Schalock, 2004). And, based on our research, the home sharing model, when working well, seems to be compatible with and supportive of person-centred planning. Importantly, people with intellectual disabilities want to be engaged in meaningful decision-making about their lives (Cocks et al, 2014; McConkey et al., 2004); and, meaningful engagement in decision-making about oneself is perhaps the most important aspect of ensuring a “Good Life” (Schalock et al., 2002). Unfortunately, however, McConkey et al. (2004) found that while many people with intellectual disabilities could actively engage in the planning for provision of accommodations and support for them, there was lack of engagement in this area of decision-making. Interestingly, many SAs in the present study who had moved from a group home to a home share were in fact engaged in the selection of home share arrangements (e.g., deciding on a room in the home, separate suite, or side-by-side duplex) and influenced the support services they accessed. This demonstrates that home share as a residential option has the potential to support and complement individualized supported living or person-centred planning. There were, however, concerns expressed that in some cases limited options were provided to individuals both with regards to alternative residential support models and the timing and planning process of the move to home share.

Similar to Hole et al. (in press), there seemed to be a clear connection between an individual's satisfaction with their HSP/SA relationship(s) and their sense of emotional well-being in the present study. The findings indicated that when a good match is made, SAs also experience the environment as predictable and stress-free. SAs and FMs described improved sense of emotional well-being since moving from a group home into a home share. SAs and FMs articulated examples of improved self-concept, less aggressive behaviours, and decreased use of medications, and described the home share as a more predictable and supportive environments with consistent care. Cocks et al. (2011) found that housing arrangements can facilitate an individual's growth and development that in turn contribute to improved well-being. In this current study, some SAs were not considered good candidates for home share but when a “good match” was found, these individuals seem to blossom. Based on the level of contentment among 24 of 25 SAs, it is fair to assert that within this study, the home share model was able support emotional well-being for these participants.

This study demonstrated that for 24 of the 25 SAs represented, home share supported QoL gains: increased independence, improved social participation, and enhanced emotional well-being. Further, similar to our recent work (Hole et al., in press), these findings underscore the importance of the HSP/SA relationship(s) and the match. The current study extends this finding in that this research incorporated a focus on QoL, and with that focus we found that the success of home share at supporting and positively impacting QoL hinged on the HSP/SA relationship(s). When this relationship was supportive and respectful, QoL improved. The centrality of the HSP/SA relationship(s) to home share success and facilitating QoL has important learnings for practice particularly in relation to planning and making a "match": planning should take into account the significance of the HSP/SA relationship(s).

LIMITATIONS

This research provided a snapshot in time. It was a small sample representing the experience of only 25 SAs; consequently, the findings are not statistically generalizable. The relationship between the HSP/SA appears to be pivotal to the success of home share. Home share does seem to be a model that can facilitate improved QoL for SAs but further research is required to determine if these findings are supported by future research. Further, this research did not control for variations in the level of need or other behavioral or health related concerns, as such, it is not able to comment directly on the issue of how home share can accommodate a range of needs or levels of disability. That said, in a much larger study (Hole et al., in press) with a sample of 62 participants, adaptive functioning was not a factor influencing the success of home sharing; instead, the quality of the HSP/SA relationship(s) was a central factor. Finally, this research did not take into account the specific level of service people received. While all SAs received some service, the study does not report comparative data on the specific level of services which could influence the results.

CONCLUSIONS

Overall the current study supports the view that when done well, in accordance with best practice guidelines, home share can offer a positive residential experience and positively impact the quality of life of individuals involved. It does, however, need to be emphasized that such outcomes are not a given and their remains risks associated with home sharing. Adhering to the core values of choice, self-determination, and person-centred planning are, as with any residential model, critical to ensuring positive outcomes. Home sharing is one option that people may want to consider but should not be the only option. Further, it is essential that any consideration be based on sound planning, preparation, and an effective transition process.

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