

Living and Participating in Community

Living and participating in the community: Experiences of people living independently with support.

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July 28, 2015

A thesis submitted to the Faculty of Graduate Studies of
the University of Manitoba
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Disability Studies

University of Manitoba

Winnipeg, Manitoba

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Abstract

Background: The aim of moving people with intellectual disabilities (PwIDs) from segregated and institutional settings to community living was to promote their full participation in the community. Past studies have identified that living arrangements play a key role in affecting participation of PwIDs in the community. Yet, the role of living arrangements in affecting participation has received relatively scant attention, especially from the insider's perspectives.

Purpose: This qualitative study sought to gain an insider's perspective from PwIDs in understanding the meaning of community participation, and the role of different community living arrangements in promoting community participation of PwIDs.

Method: A descriptive approach with content and thematic analysis was used to answer the central enquiry, that is the relation between community participation and community living from people's perspectives. Five people with intellectual disability who were living independently with support were interviewed for this study. The participants were identified as people with intellectual disability through recruitment process and had an experience of living in more than one type of living arrangement.

Findings: Participation is identified as engagement in household and community activities, having social connections with friends and families, being employed and being a part of community. Among all three types of living arrangements; group home, foster care and independent living with support, none of the living arrangement was identified as ideal for community living. However, independent living was preferred more than group home and foster care living considering active and meaningful support, community engagement and freedom to choose. To address the relationship between community living and community participation, a

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model of full participation was developed constituting four themes; 1) level and type of support, 2) learning experiences, 3) freedom and choice, and 4) privacy and safety.

Conclusion: Community participation of PwIDs was identified as involvement in meaningful and learning activities as required by the person and being a part of community. No gold standard for ideal community participation emerged from the study. It is concluded that the elements of participation are more important for successful community living and not solely the type of living arrangement.

Implications: Study findings add to the overall knowledge of community participation and community living in literature. The elements of active support, meaningful engagement, freedom and choice, and safety and privacy can assist in identifying solutions for better community living for PwIDs. The elements of better community participation can provide practical implications for improving community living through spreading awareness among support workers, policy makers, disability supporters and people with varied disabilities.

Acknowledgements

I would like to take this opportunity to thank my Thesis Advisor, Dr. Emily Etcheverry, for all of her invaluable support and guidance throughout this process. I am so thankful for all of her encouragement, recommendations, and above all, continuous believe that I can do better. You have been a tremendous teachers and happily offered me your thoughts and resources to solve innumerable problems encountered during accomplishing my masters degree.

I would like to thank Dr. Nancy Hansen for her dedication towards me to continuously improving my knowledge that helped me to work on this project with more interest and dedication. I would also like to thank Dr. Diane Driedger and Dr. Charmyne Dube as members of my Advisory Committee, for their important and valuable feedback, questions to consider, and suggestions for improving my research. All of these were greatly appreciated.

This research could not have been accomplished without the many stories I had the privilege of hearing through people with intellectual disabilities who were interviewed for this study. I would like to thank each of them for their time, and for sharing with me their personal stories, in order to understand their experiences of community participation.

Lastly, I would like to thank my family, my parents, brother and sister. Thank you for the many talks we had, and the support you offered as I worked towards completing my Masters Degree. Your love, encouragement, and confidence in me kept me going during the tough times, and your genuine excitement for me made the happy times all the more pleasurable. Lastly, I would also like to thank my fiancé, Deepak Joshi , for all of his support and encouragement. Without your assistance, I would not have been able to complete this degree. Thank you for being by my side – both through my struggles, as well as my successes.

Preface

This thesis has been an educational and learning experience for me. Having a background in the rehabilitation field, I had always been intrigued by the diverse nature of lives people lead and issues they deal with, on daily basis. During my work experience, I gained a deep insight into disability and how is it viewed in present society. Very soon I found out that my interest in disability was paralleled by the lack of work that has been done regarding disability in society. Driven by my goals and interests, I undertook a Masters in Disability Studies. It provided me the platform to learn more about disability, and other dimensions of disability in our society. My main focus was to learn more about people's participation in the community. It was early during the master's program that I decided to work on community participation and explore about community participation in the lives of people with intellectual disability.

During my master's degree, one of my long term goals was to keep the person's voice at the forefront. It all started out with the independent study course I took with my thesis advisor. It helped me envision my thesis. The success of my independent study project accelerated my zeal to develop in-depth understanding and further exploration of participation of people with intellectual disabilities in the community.

I realized soon enough into the thesis that it was the right decision. I was motivated and surprised with my own involvement with the project. The journey of learning through this thesis project remained quite informative as well as rewarding for me. When I first decided to interview people with intellectual disabilities, I was not sure about what I was going to experience. I was familiar with the information given in different studies however; I was more interested in seeing what people themselves had to say. I was enthusiastic to listen to their stories and their views about themselves, their lives as well as their experiences of other people in the community. I also

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wanted to know how they live their life and what challenges they face.

Meeting people with varied level of intellectual disability and knowing more about them has framed a significant part of my thesis work. I was amazed with their responses and had a wonderful experience while interviewing the participants in my study. I acknowledged that people with intellectual disabilities share similar views, experiences and expectations of their lives as do others. The interviews with the people helped me visualize the importance of asking people with disability about their choices, needs and interests. I learnt that people with disabilities have a lot to say about their lives, often which is underestimated or neglected in our society.

The whole interview process was an enriching learning experience for me. Their stories helped me to better understand the value of listening to people with disability about their views and expectations. I found that I was able to communicate with my participants by listening and adopting different ways to communicate. I used visual cues to communicate in different ways and I can say that the participants I met were fully capable to speak about themselves.

This research is a step towards acknowledging the views of people with disabilities and a valuable addition to work in the research area of disability from people's perspectives. They are the best source of information that can guide researchers, policy makers, and support workers about what sort of support they need to have full participation in society. As we share the same community, it is our responsibility to make them feel they belong here.

I believe that community participation of PwID requires more research. Future research is needed that includes the perspectives of PwID and that addresses the choices and levels of support needed for full participation and inclusion. I would be able to use the knowledge I

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gained through this thesis in my work as a physiotherapist. I would like to work further in areas where I can promote inclusive community participation for people with disability.

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1.0 Introduction

1.1 Statement of the problem

The shift away from large institutions to community living was a major change in the lives of people with intellectual disabilities (PwID's) (Mansell & Beadle Brown, 2010). During the past 30 years, many institutions were closed and people with intellectual disability were moved into the community. The primary goal behind moving PwID's from institutional settings to community living was to promote their societal inclusion and full participation in society (Henckes, 2011). Shutting down institutions not only included closure of buildings, but also reflected a bigger change to discourage the practice of segregation, isolation, and stigmatization of PwID's. The research on deinstitutionalization and community living provides some discussion on social meaning, quality of life, and inclusion of PwID's in society (Amado, Stancliffe, McCarron, & McCallion, 2013; Kozma, Mansell, & Beadle-Brown, 2009). However, limited information is available that address the clear and conceptual meaning of full participation in community living especially from PwID's perspectives.

The aim of community living is to enable full participation of PwID's that is beyond mere physical inclusion (Bertelli et al., 2013). In particular, community living is expected to facilitate full participation of PwID's in making their day-to-day choices, to freely participate in social and personal activities, to engage with family and friends, and to provide opportunities to be involved in domestic activities (Emerson & McVilly, 2004). Complementing this expectation, findings from some research shows that moving people from segregated and institutional settings to community improved their living conditions, satisfaction level, quality of life and freedom to participate (Kozma et al., 2009). However, movement of PwID's into community settings does not guarantee improvement in their full participation or overall quality of life (Chowdhury &

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Benson, 2011b). Furthermore, the understanding of specific strengths or limitations of different community living arrangements in the lives of PwID's is also sparse.

Previous studies exploring community living and participation of PwID's have focused on the place of living, staff support, family involvement, and opportunities for freedom and choice. Size of residential arrangements is discussed as an important factor that affects social inclusion and community participation of PwID's (Stancliffe, Abery, & Smith, 2000; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). For instance, group homes may provide better participation in leisure and household activities but may limit the freedom of choice (McConkey, 2007). Similarly, semi-independent living may allow more freedom and social satisfaction than group homes, but may not be successful for people with severe and profound intellectual disabilities (Stancliffe et al., 2000).

Authors focusing on community living for PwID's have explored different aspects of community living such as community integration, cost factors, staff-client interaction, and service models that are offered in different living arrangements for PwID's (Heller, Miller, & Factor, 1999; Kozma et al., 2009; McConkey, 2007; McConkey & Collins, 2010). Thus, there are varying factors within different living arrangements that affect the participation of PwID in community. However, the results from all the studies on various types of community living do not provide a clear picture regarding the role of different living arrangements in affecting participation of PwID's in community. The conceptual value of community living is limited and the true meaning of full participation of PwID's in social and community life still requires detailed elaboration.

Therefore, future research is needed to fill the gap to a) understand the meaning of

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community participation from the perspectives of PwID's' living in different community living arrangements and b) to understand how their living arrangements affect their participation in the community.

1.2 Significance of the study

Research on disability has often emphasized the importance of incorporating the insider's perspectives (Bertelli et al., 2013; Hammel et al., 2008). Studies exploring the lives of people with intellectual disability always emphasized the need to incorporate people with intellectual disabilities and their perspectives. This recommendation acknowledged that the perspectives of people with disability is required for both, to fully understand different barriers and to identify possible solutions.

Most of the studies on community living involves research based on people with close association to PwID's or had been focusing on the proxies. It is important to understand that intellectual disability may limit the ability of PwID's to express their needs and choices but does not exclude them from their right to be in society. PwID's are a vulnerable group and their rights and needs must be taken into consideration when making suggestions and policies pertaining to them such as developing a community living arrangement to facilitate their participation. In this study, the insider view from PwID's provides the basis for understanding their perceptions. Additionally the process helped the researcher in identifying and defining factors that influence the participation of PwID's living in different community settings. Incorporating the direct views and experiences of PwID's provided a unique platform for describing community participation of PwID's while living in different community arrangements.

The findings of this study contribute to the understanding of the broader picture of

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community participation and community living. Additionally, the results of the study may assist organizations or agencies providing support to PwID's in understanding their needs and choices, and possible improvements to assist PwID's participation in community.

Overall, the research may encourage staff, support workers, family members and organizations to understand the meaning of community participation from the PwID's perspective. The study may also create awareness for understanding the insider's perspective and the need for further discussions while conducting research on community living in future.

1.3 Purpose Statement

The purpose of this qualitative study was to gain an insider's perspective from people with intellectual disabilities in understanding the role of different community living arrangements in promoting their community participation.

1.4 Research Objectives

The objectives of this study were:

1. To identify the views and experiences of PwID's about community participation while living in their current and previous living arrangements. The focus was on, what does community participation mean to PwID's and how is it achieved while living in their living arrangement?
2. To identify barriers and facilitators in achieving community participation associated with living arrangements.
3. To identify possible suggestions that can facilitate community participation of PwID's

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while living in their respective living arrangement.

The overall aim of this study was to gain an in-depth understanding of community participation and the role of different living arrangements in achieving community participation from the insider's perspective.

2.0 Literature Review

The intent of this literature review is to discuss current research that informs this study. The aim is to understand the meaning of community participation from the perspectives of PwID's, describe types of residential settings available for PwID's and the relation between living arrangements and level of PwID's community participation. Emphasis of the literature review was to define the concepts of community participation and community living while relating them to the International Classification of Functioning (ICF) model (WHO, 2001) and social model of disability as conceptual frameworks. Overall, this literature review explored what is currently known about PwID's community participation and types of living arrangements, while identifying the gaps in the literature that require further research.

Method of review

To review the current literature on community participation and living arrangements for PwID's, a literature search was performed using following electronic databases: Scopus, PubMed, CINAHL, ERIC, Google scholar and PsycINFO. In addition, a reference list of key articles and specific journals related to the topic were hand searched to identify any potentially useful articles. Hand searching of key journals was conducted to gather useful references on community living and participation of PwID's. Key journals that were hand searched for retrieving relevant articles included- *American Journal on Mental Retardation*, *Journal of Applied Research in Intellectual Disabilities*, *Journal of Intellectual Disability Research*, and *British Journal of Learning Disabilities*. The literature search was expanded for each concept using synonyms and commonly used words (Table 1). The articles published only in the English language were screened for the inclusion in a review.

<u>Keyword</u>	<u>Alternate words</u>
Community Living	Living arrangements, residential homes, supported living, independent living, group homes, foster homes, semi-independent living, shared care
Community participation	Involvement, engagement, inclusion
People with intellectual disabilities	Intellectual disability, developmental disability, learning disability, cognitive disability, mental disability

Table 1 . Key concepts and related search terminologies included in the literature review.

2.1 Participation as an important concept.

Participation is a valued and ultimate goal of PwIDs, disability organizations, policy makers, rehabilitation workers and other stakeholders (Hammel et al., 2008). Participation, as defined in the International Classification of Functioning, Disability and Health refers to the "involvement in a life situation" (World Health Organization (WHO), 2001). ICF states that participation in communal life is influenced by environmental factors as well as personal factors. Environmental factors includes the physical, social and attitudinal environment in which people live (World Health Organization (WHO), 2001). Personal factors include: personal freedom, choice, satisfaction and values.

The ICF classification briefly describes a person's ability and disability, including the barriers and facilitators as environmental factors that influence functioning and participation of the person (Schneidert, Hurst, Miller, & Üstün, 2003). The environmental factors component of

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the ICF model aligns with the social model of disability, which determines disability as a socially created issue as opposed to a problem with the individual (Oliver & Bochel, 1991; Abberley, 1987). The social model also proposes that disability is a socially created problem and not an attribute of the person. According to social model of disability, barriers to participation are due to inflexible and inaccessible physical and social environmental issues that require political response or solutions (Albrecht, Seelman, & Bury, 2001). Thus, from the views of the ICF and social model of disability, it can be concluded that environmental factors play a key role in defining the participation and disabling barriers of a person in the community.

Participation of PwID's is thus influenced by their living place, services available, access to those services and the attitude of society. Participation is a complex and multidimensional construct and there are no set standards for defining and measuring participation (Dijkers, 2010). The classification and conceptualization of participation has been done in a variety of ways. The ICF classification system measures level of participation using scales and questionnaires to describe what an individual can do in a standardized environment and what an individual does in their daily life activity, which is influenced by environmental and personal factors (World Health Organization (WHO), 2001). The classification does not place much emphasis on self perception and deriving meaning of participation from participant's views and experiences. Furthermore, it is essential to determine what level of choice, assistance and involvement that person defines as full participation (Badley, 2008). Thus, there are a number of considerations specific to PwID's that need to be appreciated before considering ways to determine and measure participation of PwID's in community.

Self perceived participation is a recent concept in the area of disability to measure and conceptualize participation. There were only 6 studies found (Abbott & McConkey, 2006;

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Beadle Brown, Hutchinson, & Whelton, 2012; Cocks & Boaden, 2011; Deguara, Jelassi, Micallef, & Callus, 2012; Kjellberg, 2002; Stancliffe, Lakin, Larson, Engler, Taub and Fortune, 2011) that included the people's perspective in defining participation. These studies attempted to include insider's perspective in defining the meaning and ways of participation.

One study that explored insider's perspectives of PwID's is by Hammel (2008). Hammel et al. (2008) conducted a focus group with sixty three people with diverse disabilities to self identify the meaning of participation. The study tried to gain insider's perspectives from PwID's to understand the meaning of participation, how participation could be characterized, and what are the barriers and support needed for participation. The main conclusion from the study was that participation is the right of every person including a person with an intellectual disability that should involve equal opportunity, respect, access to resources and inclusion in community. The study also concluded that participation should be pursued in terms of personal views, as opposed to measuring predetermined societal norms and standards.

Participation does not only include engagement in community and society but also the approach to personal meaning and satisfaction (Hammel et al., 2008). Considering the importance of perceived level of participation, Abbott & McConkey (2006) conducted a qualitative study to gather the information about perceived barriers to social inclusion and what could be the possible solutions to overcome social isolation. The study concluded that advocacy is very important in reducing social exclusion of all the marginalized from of society including people with intellectual disabilities. Thus, it can be concluded that in defining participation and identifying barriers to full participation, it is essential to include the perspectives of PwID themselves. There is need for further research to understand the meaning of participation from the perspectives of PwID's in detail.

2.2 Community Participation of people with intellectual disabilities.

Community participation is a valued and important construct in the life of PwID's (Verdonschot et al., 2009). Community participation refers to the involvement of an individual in social, cultural and economic activities that is appropriate for a person (Mansell & Ericsson, 1996). There are a number of studies that discussed community participation of PwID's (Wilhite, Keller, & Caldwell, 1999; Robertson et al., 2001; Abraham, Gregory, Wolf, & Pemberton, 2002; Verdonschot et al., 2009). Wilhite et al.(1999) conducted a study interviewing people PwID's using a self made questionnaire. In the study, participants identified visiting friends as the most important community activity as a measure of integration. Community participation also includes having social networks with staff members, friends, family members, and other people with ID (Robertson et al., 2001). Abraham et al. (2002) conducted a cross sectional study by interviewing 50 people with ID and using a slightly modified version of the Guernsey Community Participation and Leisure Assessment (GCPLA) tool (Baker, 2000). Participants were asked about how often they engage in community activities, use services inside and outside their home. Participants were asked whether they ever engage in a named activity and, if so, how often, 'only occasionally', 'every 2 or 3 months', 'every month', 'every week' or 'every day'? The data was collected and scored on a five point scale ranging from never, frequently, regular or daily. It was found from the study that community participation involves doing activities and engaging with peers, performing unsupervised activities, engaging in various social activities and maintaining self esteem.

Similarly, (Verdonschot et al., 2009) conducted a literature review to investigate community participation of PwID as reported in empirical research studies. The review included: domestic life, interpersonal interactions and relations, major life areas, and community, civic and

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social life as domains of community participation. It was identified from the review that PwID's are likely to be three to four times more unemployed than non-disabled and have more chances of being employed in sheltered workshops. It was argued that PwID's do not participate as much in community activities and leisure activities as compared to non-disabled people and peers with other disabilities. It was also identified in this review that people living in community settings participate more than people living in segregated settings. The review concluded that little is known about community participation of PwID's and there is not enough research that clearly defines and describes community participation of PwID's especially from insider's perspectives.

After reviewing the available literature on community participation of PwID's, two significant gaps can be identified in present literature: 1) There is no valid theoretical framework to define and construct community participation. 2) community participation is a subjective element that is influenced by environmental factors and availability of resources.

2.3 Community living and community participation.

There are a number of factors that influence community participation of PwID's such as place of living, staff support, family involvement, and opportunities for freedom and choice. Living arrangement is seen as an important factor affecting participation of PwID in the community (Bertelli et al., 2013). Environmental factors such as the size of residential arrangement affect social inclusion and community participation of PwID's (Stancliffe et al., 2000; Verdonschot et al., 2009).

Verdonschot et al., (2009) conducted a review of literature to describe different environmental factors that have an impact on community participation of PwID's. Factors identified as positively influencing community participation of PwID were; opportunities to

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make choices, environmental facilities; opportunities for resident involvement in policy making; small residential facilities; opportunities for autonomy; vocational services; social support; family involvement; assistive technology; and positive staff attitudes. Environmental factors identified as negatively affecting participation were lack of transport and social isolation. It was identified in the review that type and size of residential facility influence participation in community (Heller, Miller, & Factor, 1998). The study also identified that high level of community integration was associated with smaller living arrangements. Thus, living arrangement was seen as an important factor affecting participation of PwID's.

Living in community incorporates more likely use of community resources, having more opportunity to have relationships with people outside home and being a member of society. Being a part of community and utilizing maximum community resources is the goal of all community services working for people with intellectual disabilities. However, the goal of community participation for PwID's remains a challenging task. Living in community settings does not always ensure more participation and inclusion. Many studies have found that people living in different community settings have low participation rates in leisure activities, hobbies, visiting friends and other society activities (Verdonschot et al., 2009).

Thereby, current literature available on community living and participation did not provide a clear picture of different types of living arrangements and their contribution in achieving community participation.

2.4 Different types of living arrangements.

Since the movement from institutional setting to community living arrangements, there have been a number of places available for PwID's to live with minimal segregation. Common

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types of living arrangements that are identified in literature are: group homes, foster care home, independent living, semi-independent living, clustered and dispersed housing (Kozma et al., 2009). There are also some less common terms used for different types of living arrangements such as Camphill life-sharing communities (Fahey, Walsh, Emerson, & Guerin, 2010), personalized residential support housing (Cocks, Thoresen, Williamson, & Boaden, 2013), homelike living arrangement (Egli, Feurer, Roper, & Thompson, 2002) and campus style living (McConkey, 2007). Table 2 describes different types of community living arrangements that were identified in the literature.

Table 2 Different types of community living arrangements as described in the articles

Type of living arrangement	As described in articles on community living
Dispersed housing	Person holds a tenancy agreement for an ordinary house or apartment on either an individual or shared basis; in the latter instance usually with no more than two other persons. Support staff is provided according to assessed needs, and they visit on a regular basis. (McConkey, 2007, pg. 208).
Clustered housing	Specially built groupings of houses or apartments on the one site with shared staffing across the houses, around 15 tenants may live in the same cluster with tenancy agreements, in either single-person or shared

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	housing. (R. McConkey, 2007).
Group homes	These living arrangements are owned by service providers, has staff working on a rotational basis, sleeping overnight if required. Group home involves a household of 3 to 7 people with full-time support (at least during waking hours) by paid staff from an accommodation support agency for people with a disability. There may be times on weekdays when all residents are away from the house attending their day programs and no staff are on duty. Night support may be provided by awake shift staff or sleepover staffing, or there may be no staff present when residents are asleep. Staff are present at all other times (Stancliffe & Keane, 2000a).
Campus style living	Groups of houses with 6-8 people with upto 100 people on the same site. staff available for 24 hrs. (McConkey, 2007).
Independent living	Person with an intellectual disability lives independently, often sharing a house or apartment with other consumers and/or with service providers. Service providers may also be close by (for example in a neighboring apartment) instead of sharing living quarters. (Housing for Adults with Intellectual Disabilities, Canada mortgage and housing corporation 2014)

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Foster living OR Home sharing	<p><i>"A child who is not able to live with his or her birth family still needs and deserves a caring and supportive home. The best place for these children to live is with another family, a family that is able to accept the child as one of their own". (Duvdevany & Arar, 2004).</i></p> <p><i>"Home sharing is a residential option in which an adult with a developmental disability shares a home with someone who is contracted to provide ongoing support".(Community Living British Columbia, 2010)</i></p>
Semi independent living	Involves a household of 1 to 4 people living together with regular part-time support by paid staff from an accommodation support agency for people with a disability. There is no regularly scheduled overnight staff support (including no sleepovers). On average, the household is without paid staff support, for at least 28 waking hours per week when residents are at home (Stancliffe & Keane, 2000b).
Life sharing communities	For instance, Camphill community. Camphill community provides opportunities for adults with developmental disabilities to live, learn and work together with others in an atmosphere of mutual respect and equality. (Camphill Communities Ontario, 2010-2014)

2.5 Relation between living arrangement and community participation of PwID.

Literature available on community living validated that the living environment and the

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level of support in different living arrangements influences lifestyle and level of participation of PwID's (Stancliffe & Keane, 2000b). Area of living affects the participation of people in the community due to services and opportunities available in an area or type of living arrangement. McConkey (2007) conducted research with the aim of understanding the impact of living arrangement on social inclusion. The study examined the impact of two different living arrangements on resident's participation and involvement with friends, neighbors and community and contrasted the results with other traditional forms of residential settings. It was concluded from the study that type of living arrangement has an influence on level of social inclusion and use of community resources by PwID's. Similarly, Stancliffe et al., (2000) compared the outcomes and cost of community living among group homes and semi-independent living arrangements. One of the conclusions from the study was that semi-independent living arrangements provide more frequent and independent use of community amenities. Thus, the literature on different types of community living arrangements validated the impact of living place on participation level of PwID's.

There was a good amount of literature on deinstitutionalization and community living that discusses different factors and services that facilitate meaningful participation and inclusion of PwID's (Kozma et al., 2009). Most of the earlier literature focuses on the resettlement of people from long-stay institutionalization into smaller community-based settings. However, in recent studies several authors have attempted to analyze barriers and supports available for PwID's living in community settings beyond deinstitutionalization (Bertelli et al., 2013; Bond & Hurst, 2010a). Predominantly, the majority of articles have focused on the role of support staff in facilitating participation of PwID's (Fyson, 2010), service models such as active support (Stancliffe et al., 2000; Stancliffe, Jones, & Mansell, 2008) and person centered approaches

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(Solomons, 2000) that influence participation of PwID's in community. However, there are few articles that focused on the role of different community living arrangements in achieving social, domestic and community participation of PwID's.

2.6 Different types of living arrangements and influence on community participation

Different community living arrangements provide different outcomes in terms of participation. Kozma et al. (2009) conducted a review of literature on deinstitutionalization and community living that provided a comparison of residential arrangements available for PwID's. The review identified 14 articles that had discussed participation of PwID's in activities outside the home and the use of community services. The review identified two articles that concluded small living arrangements provide better community participation than larger settings (Ager, Myers, Kerr, Myles, & Green, 2001; Chou, Lin, Pu, Lee, & Chang, 2008; Felce, Perry, Romeo, Robertson, Meek, Emerson, & Knapp, 2008b). Three articles (Emerson et al., 2001; Howe, Horner, & Newton, 1998; Stancliffe & Keane, 2000b) confirmed better community participation in semi-independent and supported living arrangements than traditional residential services. Felce, Perry, & Kerr (2011) compared different residential arrangements and found that more community activities and household participation was achieved when people live in staffed housing than living in their own family homes.

Community participation was found to be better achieved in small settings. Bertelli et al., (2013) performed a review on the relationship between community participation and size of residential arrangements. The review concluded that small apartments and cluster centres are more efficient in providing community participation than larger settings. Another systematic review done by Verdonschot et al. (2009) concluded that community settings provide more community participation than segregated settings.

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Most of the studies considered and discussed semi-independent living centers in detail, while other type of living arrangements were not thoroughly analyzed. Stancliffe & Keane (2000b) and Emerson et al., (2001) concluded that semi-independent living provide more community integration than traditional residential settings. One of the conclusion was that semi-independent living allows more freedom and social satisfaction than group homes, but may not be successful for people with severe and profound intellectual disabilities (Stancliffe & Keane, 2000b; Felce, Perry, Romeo, Robertson, Meek, Emerson, & Knapp,2008a). It was concluded that concluded that semi independent living has better outcomes in terms of cost, choice and community activities than fully staffed group homes.

After reviewing the literature on different types of community living, it could be concluded that there is no clear outcome that can be drawn from literature about the role of different types of living arrangements and participation of PwID's in community, especially from the perspectives of PwID's.

2.7 Independent living and community participation.

Independent living represents a less restrictive and more facilitative environment for PwID's (Kim, 2012). Independent living can be defined as enabling independence by receiving the right support when it is required (Morris, 2004). The person living independently purchases or rents their own apartment or house and have liberty where and with whom to stay (Davis, 2006). Independent living is based on the idea that every person regardless of ability has a right and opportunity to express their views, make choices and control their lives (Kim, 2012). Literature on independent and small community living arrangements showed that small and personalized living arrangements provide individuals with more freedom of choice, opportunities and autonomy for decision making as compared to larger and more clustered settings (Robertson et

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al., 2000; Robertson et al., 2001; Keane, Stancliffe & Sian, 2000). However, it has been argued that independent living may not be successful for all (Kozma et al., 2009). Bond & Hurst (2010b) conducted a study to explore the views of nine PwID's about the reality of independent living. Semi-structured interviews were conducted with PwID who were living alone. The major themes that emerged from the study were: Feeling of isolation, practical issues of living independently, support issues, choice and control, vulnerability, health issues and impact of having ID. The literature demonstrated that independent living may not be the final aim of PwID's and it is not always successful with all PwID's.

2.8 Summary of literature review

It is clear from the literature that participation of PwID's in community is affected by type of living arrangement and level of participation achieved in that particular living arrangement. All types of living arrangements are intended to facilitate full participation of PwID's, but, the meaning goes beyond mere physical inclusion. Living in the community is assumed to facilitate freedom in making their day-to-today choices, having freedom to participate in social and personal activities, engagement with family and friends, and involvement in domestic activities (Emerson & McVilly, 2004). However, it was not clear whether or not these goals are achieved in all types of living arrangements available in the community. Furthermore, the views of PwID's themselves were largely absent on the issues. Moreover, there was less literature discussing and conceptualizing community participation from the view point of PwID's.

There are different types of living arrangements available for PwID's that aim towards active participation of PwID's taking their needs, choices and freedom into consideration. Freedom of choice, availability of the resources and satisfaction, self esteem, independence, social and community integration are some of the aspects that should be fulfilled by every type

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of living arrangement to achieve the goal of full participation in community.

While the current literature suggested that small living arrangements provide better participation of PwID's, very little is known about the experiences and views of PwID's about community participation in these small arrangements from the voice of PwID's themselves and what they consider worthy in terms of fully participating in community. Furthermore, past literature has overlooked insider's perspectives while defining the role of living arrangements in achieving participation. Most of the current literature relied on questionnaires, surveys and interviews with proxies. While these methods provide valuable information on a topic of interest, they are unable to capture an important component of community participation from insider's perspectives.

In summation, community participation of PwID's is the primary goal of community living and thus in-depth knowledge is necessary from the perspectives of PwID's. This study aimed to gain knowledge from insider's perspectives of PwID's about living arrangements and their participation in community.

3.0 Methodology

3.1 Research design and plan

A qualitative descriptive approach with general thematic analysis was utilized for this study. Qualitative descriptive methodology provides a description of events and experiences of real life situations (Sandelowski, 2000). According to Sandelowski, (2000) "the qualitative descriptive study is the method of choice when straight descriptions of phenomena are desired" (pp. 339). This approach works well when the research aim is to remain close to the collected data and in-depth description of the information is required. Qualitative description is suitable for gaining basic and clear answers to the concerns and responses of participants involved (Sandelowski, 2000). This study attempted to understand the meaning of participation from PWID's perspectives, and how different living arrangements influence their community participation. The experiences of people were relayed in their original format as described by the participants. The collected information was also used to analyze and interpret the relationship between the community participation and the community living.

The use of a qualitative description approach was justified for several reasons. First, there is a paucity of information about the role of living arrangements in achieving participation from insider's perspectives. This study presented the experiences of participants in their own words with an overall aim to express individual's perceptions as accurately as possible. Secondly, this qualitative study attempted to facilitate an in-depth understanding of the issues while simultaneously considering the breadth of information addressing the gap in literature. From the participants' perspectives, this methodology allowed describing the experiences using the voice of PWID's. Thirdly, the study also attempted to set a platform for further research taking the

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perspective of PwID's into consideration in defining their needs and choices. Considering all these reasons, a qualitative description approach was well suited to direct the research questions of the study.

Participants were adults with intellectual disability who were living independently with support at the time of study. This was done under the assumption that they possess necessary abilities to be active in the community and also may have experiences of living in more than one type of living arrangement. PwID's who were living independently were also assumed to have sufficient capability to be able to be a part of this research without much assistance in communicating. The data collected from study participants focused on discovering the meaning of community participation from the perspectives of PwID's, how PwID's identify themselves as a part of community and what are their focus and lived experience in society. Using qualitative descriptive methodology, an attempt was made to remain close to the data and collected information was presented with minimal self-conceptualization and abstraction of data. General thematic analysis helped to summarize the data and identify the relationship between their living arrangement and community participation. An attempt was made to generate a broader appreciation of community participation and the role of living arrangement. Meanwhile, focus remained on bringing the PwID's voice to the forefront.

3.2 Study participants

Participants were recruited from organizations supporting PwID's living independently with support. Living independently with support meant PwID's had choice and control over the assistance required in day to day activities, in different life areas and other practical situations (Duggan and Linehan, 2013). Participants were selected on the basis of the inclusion criteria

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(Appendix C) and their ability to inform the research topic. Out of eight respondents to the recruitment process, only five people met the inclusion criteria and were invited to participate in the study. Selected participants were PwID's who were living independently with support and who had an experience of living in more than one type of living arrangements. The following inclusion criteria were considered when recruiting the participants of the study:

1. Participants should be verbal and able to speak for themselves. Participants who were identified as having an intellectual disability and who were able to talk about living in community were recruited. Since the study was looking at the experiences of people themselves, it was necessary that they can talk about their experiences of community living and their involvement in various activities. To ensure we are not using proxies like other research studies it was important that they were able to communicate independently and understand the research simultaneously.

2. Experience of living in more than one type of living arrangement: Adults who had intellectual limitations and have had an experience of living with support in more than one type of place were included in the study. Since the aim of this study was to understand the role of living arrangements in achieving community participation, people having experiences with two or more living arrangements were assumed to be better able to describe and compare their experiences of living in the community. The experiences of living at more than one place also helped participants in identifying various unique barriers and compared their experiences with past living place.

3.3 Recruitment process

Five individuals participated in this study. Study participants were PwIDs who were

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living independently with support in the community. Study participants were recruited with the assistance from organizations that provide support or assistance to PwID's for engaging in the community and living independently in society. Adults who had intellectual disability and met the inclusion criteria were recruited.

The participants of the study were recruited on voluntary basis with the assistance from organizations supporting PwID's living independently in the community. The organizations worked with an understanding that PwID's have the right to fully participate in community and all resources should be provided to PwID's when needed. Different organizations that provide services to PwID's were sent an invitation letter (Appendix A) to request their assistance in identifying participants of the study. An invitation letter was sent through email for gaining permission and their support in identifying participants for the study. Few organizations agreed to provide assistance for participants' recruitment that included providing a site for displaying recruitment brochure (Appendix B) to be seen by participants.

After receiving ethics permission from University of Manitoba and access approval from organizations supporting PwID's, the organizations were contacted in person and provided with the recruitment brochures to be placed at different sites to be seen by potential participants. The participants were recruited based on the specific inclusion criteria (Appendix C) of the study. As per the information in the recruitment brochure, potential participants were asked to contact the primary researcher to indicate their interest in participating and to arrange a time for an interview.

Eight people contacted the primary researcher via telephone call with the help of their support workers, but only five matched with the inclusion criteria of the study. The telephone

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conversations with participants included introduction of the primary researcher, and attending to participant questions or concerns about the study. Selected participants were asked for suitable date and time between 10am to 3 pm on any day when he or she would be available for an interview. The interviews were conducted at any mutually agreed public location, a site that was suitable and safe for both participant and the primary researcher to conduct an interview.

Participants were provided with a number of options including private library or space in their supporting organizations where they can be interviewed. Four participants decided to have an interview in a private space provided by the organization. One participant chose to be interviewed in a private room in public library.

Participants were informed that they can bring a family member, worker or a friend with them if they wanted. Study participants were briefed about a plain language consent form (Appendix D) that was signed before the interview session. Participants were also informed that the interview session will be audio taped with their permission.

3.4 Interview session

The interview sessions were held in private space either provided by the organizations or in the public library, as requested by the participants. The primary researcher reached each site half an hour prior to the meeting to ensure all the arrangements. After the initial greeting, the primary researcher gave a brief description about the study and asked if the participant had any queries or concerns about the study. Two participants agreed to be interviewed alone and three participants came with their support worker or a friend. After the initial introduction, each participant was informed that he or she would need to sign consent for the study. Full consent (Appendix D) was read to the participant and was explained in simple language. The language of consent form was kept plain and easy to understand. The participants were informed that they

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can refuse to sign or participate in the study at any point in the study. The support workers were also present during the consent signing and were requested to sign a pledge of confidentiality before the interview began. The participants were also informed of the right to discuss the consent form with the person accompanying them in the absence of the primary researcher.

After obtaining consent from the participants, the interview sessions were conducted. The participants were free to take his or her time and breaks before, during or after the interview. However, none of the participants took any break. The interview sessions were recorded after the permission. Only one participant refused to record the interview, so the information was collected in the form of field notes for that participant. Rest of the four participant's interviews was recorded. After the consent taking, the participants were asked if they had any concerns or questions related to the study, the participants were then asked if he/she was ready for the interview and the interview sessions were started. The interviews lasted approximately one hour for all five participants.

Semi-structured interviews were conducted using open ended questions. An interview guide (Appendix E) was used during the interviews. Participants were asked about their views on participation in community, engagement in social activities, perceived level of satisfaction and involvement in community while living in their present as compared to previous living arrangements. Questions related to their experiences of living in their current and previous living arrangements. The interviews included questions such as how much involvement they had in social activities in community and how their living arrangements impacted their participation.

Interviews included questions about how the participant described community living and his or her participation in community activities. Questions were related to barriers/facilitators

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they face in community participation while living in present and previous living arrangements. The question also included their major social and community life goals, education and employment and the impact on these components of participation due to their living arrangements. Considering the intellectual abilities of the participants, sentences were kept simple and easy to understand. At multiple occasions, when participant were having difficulty understanding the interview questions, sketches were used as cues to encourage participants to understand the questions. These visual cues assisted participants to explain their experiences in better way.

After each interview, the participants were provided with a thank you note and \$20.00 as a token of appreciation. Field notes were also written during and after each interview session that included physical observation, the participant's body language before, during and after the interview sessions and overall feeling about the topic of research. Field notes assisted with understanding and making connection between received information and understanding their views on the research topic during the analysis part of the study. Any further details observed were also added in the field notes.

3.5 Ethical considerations

Ethical approval for the study was obtained from Research Ethics Board (REB) of University of Manitoba and Ethics board of one organization. The key ethical considerations associated with this study are discussed below.

Voluntary participation. The participant's decision to take part in the study was voluntary. The participant had the right to refuse participation or withdraw from the study at any stage. It was explained in plain language that his or her participation was entirely voluntary and

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he or she was free to withdraw from the study at any time and for any reason. The participant's decision to withdraw from the study or not to participate at initial request did not affect their access to any services or relationship with any organization or concerned individuals.

Consent. Before the interview session and involvement of the participant in the study, the participants were informed that he or she would need to sign a consent form (Appendix F) for the study and that would be fully explained to the participant. Consent was gained before the interview session when the participant met with primary researcher. Full consent was read with the participant and every detail was explained. The consent form of the University of Manitoba REB has been adapted into simple and plain language to ensure that the participants are able to understand every section of consent form thoroughly. A consent form (Appendix F) with both academic language and plain language was provided with the ethics applications to both the University and the Organization to ensure the consistency of plain language consent form that was provided to the participants.

The participants were informed that if they do not understand any part of the consent, there was no requirement to sign it. Participants were also informed that if they decide not to participant in this study at any stage, their access to services of the organization would not be affected. The participants were given a choice to be with a support person during the interview and were also allowed to discuss the consent with him or her. Participants were free to discuss the consent with their support person in the absence of primary researcher as well.

Protection of Vulnerability. This study involved data collection through interviewing people who may be considered vulnerable. It was assured that their physical and emotional safety was not at risk. It was also assured that participants completely understood the study aims

and process. The consent form was simplified in terms of language so it could be easily understood by the participants.

Confidentiality. Any personnel who assisted in the recruitment process was requested to sign a pledge of confidentiality (Appendix G) including participants' friends and support workers who were present during the time of interview. Upon enrollment in the study, each participant was assigned a specific number (P1 to P5). All documents, including interview transcripts, were kept confidential by using the participant's assigned study number. Only the authorized study team members had an access to the information. All documents were kept in locked filing cabinets and/or password-protected computer files. Each participant's cover sheet and consent forms bear personal identification details of the participant, were stored in a locked cabinet with the study advisor and separately from the other data files of the participants. Audio recordings taken during the study were kept on a secure, password-protected computer. The audio recordings were then deleted once data analysis was complete.

Cost to the participants. There was no cost to the participants for their involvement in the study. Participants in the study were provided with an honorarium of twenty dollar and a thank you note as a token of appreciation and for their time and contribution.

3.6 Data Analysis

Data collected from the participants was first analyzed with a qualitative content analysis approach as described by Graneheim and Lundman (2004). Content analysis aims to keep the process as close to the text as possible. This approach is useful where the information comes from the participants instead of pre-defined standards. In this study, the focus was on content manifested by participants through describing the meaning of community participation and their

experiences of living in different living arrangements.

In addition to thorough description of collected information, the underlying meaning of the text was also analyzed and interpreted to discuss the relation between living arrangements and participation in community. A general thematic analysis approach as described by Braun and Clarke (2006) guided the analysis of the study. Thematic analysis is the method for identifying, analyzing and reporting themes within the data (Braun and Clarke, 2006). The following steps using an iterative process were used for the analysis of collected data:

1. Data cleaning and familiarization with the data: All interviews were transcribed verbatim on a word processing document. The transcription of the interviews assisted with reviewing the minute details and provided more time to thoroughly go through the data. Each word file was given a specific number (P1 to P5) according to the sequence in which participants were interviewed. The field notes and reflections were also named according to the number assigned to each participant. All files were printed and the backup for each file was stored on a password-protected computer. Separate folders were prepared for information collected from each participant that included transcribed interview sheets, field notes, reflections and the diagrams used to assist participants during the interviews. Through this way, each participant's file was identifiable though the number assigned to each participant and ensuring privacy at the same time.

After the transcription process, the primary researcher went through the data in depth, to get familiar with the depth and breadth of the content. It involved 'repeated reading' of the data in an active way that guided the primary researcher to search the context and patterns of what has been shared. Each interview was transcribed in the same week that the participant was

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interviewed. Notes were taken after each reading of the transcription that guided the interview of next participant. Concurrent data collection and transcription helped and guided the interview session with the next participant.

After all interviews were completed and transcribed, whole data set was read carefully prior to forming the codes. During this phase, notes were taken to identify any patterns and determine if any formative codes were visible.

2. Generating initial codes: After initial familiarization with data and generation of few ideas, initial coding begun. In the process of coding, data was organized into meaningful groups. The coding process included word-for-word reading of the interview transcripts, labeling of words or parts of sentences with pencil. Each sentence was read carefully and significant words were marked. In the coding process, parts of sentences or words were coded and un-coded multiple times during the process. The labels or codes represented important pieces of information. The primary researcher also maintained memo notes in the process of coding. The codes were discussed with the study advisor and revised, edited, and suitable additions were made. Having two people involved helped the process by enduring nothing is missed during the tedious task of coding.

3. Subcategory and category formation: After the initial coding, there was a long list of different codes that were extracted from the raw data (transcripts). In this phase, focus shifted from codes to the broader picture. All the relevant codes were combined together to identify meaning and condensed data. The raw data and codes were re-read and the primary researcher started to identify, name, and define sub-categories. The codes were compared based on similarities and differences and condensed into 33 sub-categories.

These sub-categories included all the codes that made sense together. During the development of sub-categories, the codes were reviewed taking research aim into consideration. The subcategories were rearranged and combined into 10 categories which related directly to the research objectives.

4. Searching for themes: All the relevant categories were considered together to identify potential themes. An analysis chart was developed to form a relationship between codes, sub-categories and categories so as to develop themes. Some of the sub-categories were used in final theme generation and some of them formed categories. In the end, four themes were developed from the organization of the existing data.

5.Reviewing themes: This stage included refinement of initial identifiable themes. Some of the initial themes merged or separated into different themes as the analysis process went further. The principles of internal homogeneity and external heterogeneity (Pattons, 1990) were used as principals in identifying final themes. This was assured that the themes were clear, identifiable and distinct from each other. Themes were developed through reviewing and refining initial categories and making changes if they did not fit together. It was also taken in consideration that the themes made connection with the broader picture and research objectives. When there was no new refinement and development of themes and the picture of thematic framework seemed ready, the process of condensing and refining information was stopped.

6.Defining and naming themes: After the development of a thematic map of the data, the four themes were further refined. It included identification of each theme and analyzing it from all the possible aspects. Each theme was assessed for its contribution to the broader picture as well to the research questions. Each theme was given a name that aimed to describe underlying

meaning and content.

7. Producing the report: At this stage, final analysis was done that guided towards writing a report. The report was the description of all the themes with valid and reasonable story from the raw data. It helped in understanding the results and how themes were developed. The discussion involved description of generated themes as well as arguments related to research questions.

The themes developed during the process were linked to each other and the research questions. The process of analysis from coding to themes to interpretation was iterative. Notes were kept that were used to make an audit trail of the findings and representations of final data. Throughout the process of data analysis, during codes and themes development from raw data, the study advisor (Dr. Emily Etcheverry) was contacted and periodical discussions were held to ensure guided progression of the data analysis. In addition, the study results were discussed with the study supervisors (Dr. Nancy Hansen, Dr. Diane Driedger and Dr. Charmayne Dube) to ensure that the process followed and associated outcomes made logical sense from the collected data.

To maintain the trustworthiness of this study, the researcher engaged in various strategies so as to logically represent the findings. This study attempted to establish its trustworthiness by maintaining the credibility, transferability and dependability of the results. Credibility is related to presenting the true picture of the participants' experiences. The focus of the study was to gain peoples' perspective on community participation and how their living arrangements impact their participation in community. To address this goal, PwID's were asked about their experiences and views instead of relying solely on proxies or other people in close association. Including PwID's

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to define their own participation in community increased the credibility of the findings, as it was coming directly from people who have challenges to participate in community. Additionally, the method of collecting data was semi-structured interviews that gave liberty to participants to express their views and define their participation as per their perceptions. The continuous guidance from research members gave a supervised and logical direction. The primary researcher sought agreement from study advisors at various stages of data collection and data analysis. The inclusion criteria of people having experience of living at more than one place helped in identifying study participants. This process helped in gathering information from participants who could provide maximum information about living arrangement and were able to compare levels of participation in community.

To facilitate transferability in this study, participant's characteristics such as level of independence, ability to advocate for themselves and previous life experiences played an important role in determining where and under what conditions the study findings were transferable. It was assumed that each person has his or her unique perspective about level of participation in community and his or her living arrangement. However, it was hoped that the study can give a good picture about what is important for PwID's while participating in community and how this population describe their participation while living in group home, foster care and independently.

Using content and thematic analysis approach with an iterative process in data collection and analysis provided an opportunity to cover both depth and breadth of the study objectives. In addition, the use of participants' quotes in presenting the results also added to the study dependability. It allowed the consistency between raw data coding and development of categories or themes from it.

3.7 Data Handling

The confidentiality of participant's information as well the security of the data was considered important during the study process. Each participant was assigned a specific number that was used to identify data collection files. All personal details of the participants were kept confidential and only the primary researcher and study supervisors had an access to that information. The audio recorded interviews and transcribed verbatim documents were secured and stored in a locked space and password protected files. After completion of thesis, all raw data including printed copies will be manually destroyed in confidential shredding. Electronic copies of data files were stored in a password-protected computer and will be deleted from the hard disk after the study completion.

4.0 Results

Results from the study were analyzed using both descriptive and interpretive approach. The description of results starts with a brief overview of study site and characteristics of participants. Participants' characteristics are described in terms of type of places they have lived, and different experiences of participation. A content analysis approach is used to derive the experience of living in foster care, group home and independent living. The same approach is used to analyze the meaning of community participation from participants' perspective. The use of content analysis allowed the analysis to be close to the collected data where information came directly from participants. The data review focused on content manifested by participants through describing the meaning of community participation and their experiences of living in different living arrangements.

Following the description of living arrangements and community participation, the underlying meaning of the text was also analyzed and interpreted to discuss the relation between living arrangements and participation in community. A general thematic analysis approach was used to identify, analyze and report the established themes.

4.1 Study site

Data collection of the study took place from January to March 2015. The interviews were conducted at the private rooms provided by the organizations or in the public library. These rooms were booked a day prior to each interview session. Four participants were interviewed in rooms provided by the organization and one participant opted to be interviewed at a public library. The interview room in the public library was safe and private with the capacity of four people. Only the primary researcher, participant and support person were present during the interview sessions. All the interview sites were safe and chosen by the participants.

4.2 Participants characteristics

In total, five individuals participated in the study were identified as PwID's with the experience of multiple types of living through the recruitment process. All participants were adults with the age group ranging from 25 to 40 years. Two participants were male and three were female. One of the participants identified themselves as having a minor mobility disability. All recruited participants had experiences of living in more than one type of living arrangement and were living independently with support at the time of study. Four participants had previously lived in foster care and three had previously lived in group homes. Two participants had experiences of living in both foster care and group home environments.

4.3 Experiences of PwID's living in different types of living arrangements

The discussion of living arrangements illustrates the detailed experiences of PwID's while living in "group home," "foster home," and "independently with support." Their description of living in these different types of living arrangements is summarized in Figure 1.

Group Home. Participants shared their experiences of living in group home. Participants discussed their experience of living with other people, learning basic life skills and having support from workers. Group home living was identified as a learning environment where participants used to work under the guidance of support workers. There was a limited choice and freedom in group homes and participants had to follow the rules and regulations. Nevertheless, group home living was appreciated by a few participants but did not seem to be a preference as a permanent place for living. There were both positive and negative aspects related to group home living as described by participants.

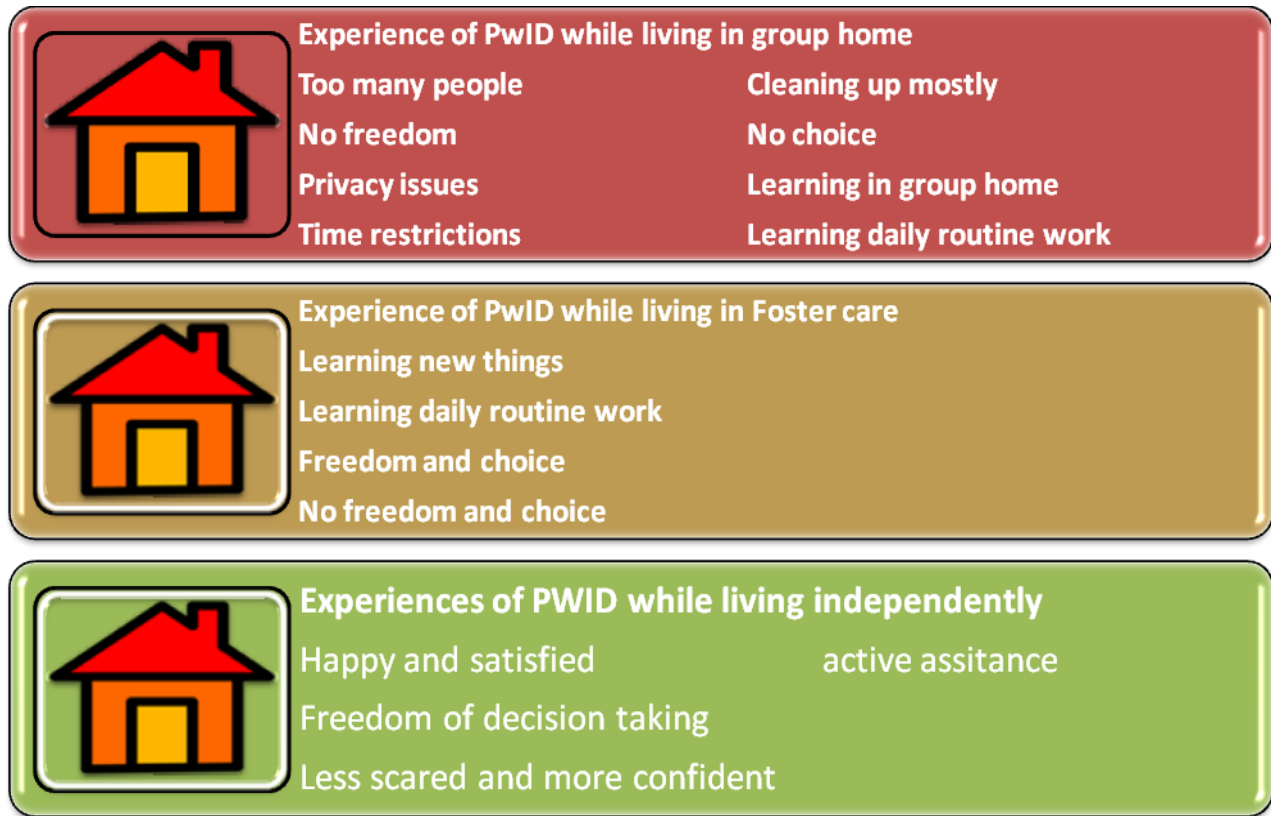


Figure 1: Experiences of people living in different types of living arrangements.

The number of people living in a group home was a major concern for most of the participants. Participants complained about having too many people in their living place that affected their privacy and freedom. It was difficult for the participants to live in a group home for long period of time. Most of the participants opted for other types of living places when asked.

One of the participants commented,

"I think there were lot... about 20... there were 20.... " I was not in group home for a long time.. I left it quite early.. I don't like to be there... there were too many people..".

Time restriction was also an issue in group home living. There were rules and restrictions which were to be followed on going out in the community. Participants had to be at home after certain period of time. These restrictions used to effect outdoor participation of participants. One

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participant added, "you can go out... but you have to come back at certain time... if you stay outside... you will be grounded...."

Additionally, participants also mentioned the burden of household chores. They used to clean their homes and perform house related duties in most of their spare time. Some participants found it hard to live there. Sometimes, unexpectedly, they were also involved in fights.

Participants limited sense of freedom also affected their views about group home living.

".....there were not good people.. shouting.. people fight.. anyone can be in my room... I don't like that.. it was hard..... no privacy. "we were busy doing household work.. cleaning up mostly..I used to wash dishes... and work... but I don't had my own money.. I was cleaning and cleaning... every time... it was hard.. "

There were some positive aspects about group homes as well. Support workers taught basic life skills and daily routine work to participants that proved helpful for independent living. The focus of support tended to be on personal management, cleaning of their house and other domestic work. One participant stated, "yeah... I was learning there like when I find my own place... what you have to do there... what you learn here."

Overall, the experiences of people living in group homes were good in their initial time of learning phase. However, participants were not satisfied with privacy and lack of freedom while living in group homes. Most of the participants preferred to leave their group home after learning daily routine work or when they were confident about their environment and ability to live independently. Not surprisingly, all participants preferred to live independently as opposed to being in a group home.

Foster Care. Similarly, experience of living in foster care was helpful for some and limiting for the others. Experiences were related to learning basic life skills and building social

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connections with foster families. Most of the participants had their private room and were learning daily life skills under the guidance of their foster parents. Participants, who valued living in foster care, appreciated their freedom and support while living with the foster family. These participants were happy and contented with the experiences they had in foster care.

On the other hand, participants who had difficult experiences were not too happy with living in a foster home. Participants pointed out the uncertainty about living there. One participant with rough experience while living in foster care added, "they can be good... but they can be bad as well... look where you live... and come out of there if you can... it's not good...."

Mostly, these foster families were people known to the participants or to their family. Similar to group home experiences, there were restrictions on going out from the home. One participant stated, "like if you go out and come late, they keep you in house... grounded." There were incidences where foster family provided needed support and care, but a few participants experienced bad behaviour from their foster family as well. All together, the participants had mixed feelings about living in the foster care setting.

Independent living with support. Independent living with the support was mostly preferred by participants as opposed to group homes or foster care setting. The experience of living in group home and foster care was described as helpful in many ways, but participants chose to live independently. A number of reasons were mentioned that motivated participants to live on their own.

Living independently with support was viewed as a place or environment that provided freedom and control over one's own life. Participants were the decision makers for the type of support and level of assistance. Participants experienced more privacy and level of safety in

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independent living as compared to other types of living arrangements.

Freedom was highlighted as the most important factor in choosing independent living. After moving to independent living, participants had the freedom to go out, make friends, and stay outside. Decisions related to food, friends and families were under the control of the participants themselves. The participants took pleasure living a life where they could decide for themselves. Having freedom to choose, added to their experience of independent living. Participants identified themselves as happier and more satisfied with independent living.

I have learnt a lot.... I can take care of myself.. I always wanted to do that...yes.. I know what to do outside..... I can talk to people.. I can go outside and do what I like... . talk to different people.. you know a lot of stuff when you meet people.. there are also good people there.

Surprisingly, safety was identified as a concern while living independently with support. Participants highlighted that they sometimes get scared outside their home and they have difficulty meeting and trusting other people. One participant stated, " it's been tough... that's why I don't want to have too many friends... or go out much... It's not safe... I try to reach my home as soon as I can... it is not good outside in night... it is scary".

However, some participants indicated that they were less scared and more confident outside after moving to independent living. The ability to participate with outside world and engagement in activities of their choice helped participants to choose independent living on group home or foster care.

"I am good.. I am not scared now.. I can talk to people.. I can go outside.. do what I want to do..... I was scared earlier.. but now I am not that scared.. I am doing good..".

Overall, Independent living was preferred by all the participants as it provided more

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freedom, privacy and choice in their everyday life. Participants had different views regarding the level of safety. Living in an independent setting also affected their participation inside and outside their home.

4.4 Participation as described by participants

Participation was viewed as involvement in day-to-day activities, engagement in household and outside activities, having social connections, being employed and being a part of community. Participants identified different components through which participation can be defined. Every participant provided their own description about the activities they do to participate in community as well as in their homes. However, the descriptions can be summarized as illustrated in figure 2 to include: engagement in activities, engagement with peers, support workers and family, and being a part of community.

Engagement in activities. Participants acknowledged their involvement in daily routine activities when asked about activities they do outside their home. Different activities such as playing, learning new things, going for shopping, attending school and banking were mentioned as activities participants used to do outside their home. In most of the cases, the pursuits of engagement involved finding an individual hobby, socialization, personal preferences, and use of available resources.

I do computers... and whatever... pictures.. play around.. I learnt a lot..they help me in shopping.. and budgeting... Another participant added, " like Osborne.. just for a coffee or whatever.. and come back.."... my job is to go to school every day...

A number of activities were mentioned that helped participants to go out, meet people and make connection with others in society. Meeting people outside, going to a beach, taking to people and making friends were discussed as activities occasionally performed by participants.

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All these activities exemplified involvement in different community activities while living in various living arrangements.

"... I used to go out.. sit outside... and do whatever.. sitting.. and roaming around with friends.. and they ask you go for a picnic.. outside.... and we meet people.. and come back..".



Figure 2: Components of community participation as described by participants

Participants outlined their participation outside their home environment as well. These activities included going to beach or camping with others. These activities helped participants in spending time in activities they like. However, few participants were bored and preferred go for some productive work too.

" I like to play games.... at TV.. and watch games.... in foster care we used to go to beach sometime. " I used... make bed... vacuumed the rug... clean walls... cooking... cleaning up mostly..... something to do... ". and... on weekends.. I

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just watch movies.. and.. do stuff.. "

Engagement with peers/support workers and families. Participants acknowledged engagement with peers, support workers and families provided an opportunity to actively participate in the community. Workers used to help participants in learning day-to-day activities such as laundry, grocery shopping, budgeting and paying bills. Furthermore, the efforts of support workers, who helped participants to become more independent in their daily routine, were appreciated. Workers provided emotional support that helped participants to trust workers and to build trust in others.

"hmm.. ya.. they help... they used to.. help me.. cleaning my room.. doing my laundry.. and... do my dishes... cook my meal.. come by.. and say.. I am done now.. see you.. then go...".

"...my worker.... she helps me budgeting.. if I need help in grocery shopping.. stuff like that.. like I have two times a week. and she do stuff with me.. go shopping with me.. if I need to pay bills.. or I need to move.. or find a place.."

Meeting and visiting family on occasion was identified as a social activity performed by participants. Having friends and family provided emotional and moral support to participants and made them feel well supported and connected to society. Some of the participants reflected on this:

"yes.. something.. I visited my mom on Christmas.. I like meeting my nephews and niece.. I like there.. but then I come back home.. I don't like being outside much..".

"yes.. not many.. but I meet them when I like.. I meet my boyfriend's family.. they are good people.. I am happy now.."

Being a part of community/society. Participants showed interest in working and engaging in productive activities. Earning money and doing some productive work was related to participation.

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"ya.. I want to do something.. I don't want to watch TV all the time.. it's get bored.. it's nothing on TV... that keep you busy... you know..

"coz I want to find out another job..... its part time.. or dishes.. if I can learn how to gas.. like you know gasoline.... I can do that.. it takes time for everything. you just can't go bang bang bang.. ".

Jobs or work were considered important to earn money and to do something to learn and grow. Working was an important factor for participant to feel independent and confident.

Vocational work was viewed as helpful in doing something productive. One participant stated, "I used to work... making boxing... and making food... packing... and all that... I used to go there every second week...."

Support workers also helped some participants with employment and identifying resources in society. Working or earning money was identified as important by participants to be more independent and worthy. One participant added, "they ask me if I need support or stuff like that...like they can help in getting job or something....".

4.5 Types of living arrangements and affect on community participation.

One of the primary aims of this study was to explain the relation between living arrangements and community participation of PwID's. To address this research objective, participants were asked questions related to their participation while living in group home, foster care and independently with support. Throughout the interviews, participants were continuously encouraged to address community participation in relation to their living arrangements. Thematic analysis was used to analyze the data to describe participants' perceptions in relation to the link between living arrangements and community participation. From thematic analysis, four themes emerged: Level and type of support, learning experiences, freedom and choice and, privacy and safety.

4.6 Themes

Theme 1: Level and Type of support

Support workers seemed to play a major role in the life of PwID's. The level and type of support from workers emerged as a major theme from the analysis of data collected from participants. It was identified from data collection that level and type of support influenced participation in community. A difference was noted in assistance provided by workers while living in group home, foster home and independent settings.

Assistance from workers in group home was described as both limiting and helpful. There was relatively less freedom to make own decisions about where and how assistance is needed from the support staff. Participants needed to follow orders from support staff members who were the decision makers for the people living in the group home. The following quote exemplified differences in the level and type of support while living in group home.

"Hmm... ya... they help... they used to... help me... cleaning my room... doing my laundry... and... do my dishes... cook my meal... come by... and says... I am done now... see you... then go. We used to do cooking... cleaning up mostly... making your own bed... changing your bed... they used to order us what to do...."

On the other hand, assistance in foster living was largely dependent on foster parents. Assistance from foster family was greatly appreciated by some of the participants. Living in foster care was a good learning experience for some. One participant reported, "yup, my aunty taught me... how to cook and do laundry... my aunty let me have all my freedom... and she do stuff with me... go shopping with me... if I need to pay bills... or I need to move... or find a place..."

The assistance in group home and foster care was largely related to household work and there was lack of personal connection. Participants were usually busy in household work and

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there was less time for their own activities. There was lack of support from foster parents, and sometimes parents used to overload foster child with household work. One participant complained, "I used to clean... take care of their home... but If I watch TV or don't do my things... she used to beat me...."

Most of the participants noticed a change in their 'level of support' after shifting to independent living from group home or foster care. Support level was different and better in independent settings. The workers allowed participants to make own decisions about the type of help they need. The participants were encouraged by supporting staff to actively participate in making day-to-day life choices. One participant who had lived in a group home and changed to independent living discussed the support from staff in the independent living program,

"My worker she helps me budgeting... if I need help in grocery shopping... stuff like that... like I have two times a week... and she do stuff with me... go shopping with me... if I need to pay bills... or I need to move... or find a place...."

Support workers in independent setting provided assistance as required by the participants. Workers used to work 'with' participants, not 'for' them. One participant living independently with support from organization discussed, "...She buy grocery with me... cook with me... and take me to appointments... like where I have to go... she go with me... she let me buy whatever I want... I am happy now...."

Workers also provided emotional support to participants that helped them in trusting their workers and other people in society.

"..... I was scared... but I trusted doctors... they are saying right... (support worker) helped me to understand... it was tough... now I am ok.."

Overall, a lot of differences were identified in terms of level and type of support from

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workers after moving from group home or foster home to independent living. In group homes, support was equal for everyone regardless of the participants' wishes. Foster care experience was positive for some and negative for the others in terms of assistance. Support in independent settings was appreciated by most of the participants as it translated into more freedom and decision making about assistance required.

Theme 2: Learning experiences in different living arrangements

Learning experiences while living in different types of living arrangements also came out as a theme from analysis of data. Learning included ability to do daily routine work, household and domestic activities, education, and vocational activities required to live independently. These learning experiences had an influence on community participation of participants and were identified to be varied in different places.

Learning in the group home was related to domestic and basic life skills. Participants learnt daily routine household work in group home and foster care so that they can use those skills to live independently. These activities seemed to be helpful for participants to grow and be more independent. One participant stated, "Yeah... I was learning there like when I find my own place.... what you have to do there... what you learn here (group home)." Some participants were not satisfied with learning in the group home. They also indicated that the learning was very minimal and restricted to household work.

"I used to watch TV... cleaning up... make bed... vacuumed the rug... clean walls... cooking."

"... ya... I do groceries... or clothes... or whatever... and ... this is good... but there in group home... I don't used to get paid...I was cleaning up mostly... at home... I used to wash dishes... and work... I was cleaning and cleaning... every time... it was hard.... "

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Foster care experience was helpful in learning daily routines such as cooking, doing laundry and taking care of home. Learning in foster care was more personal and supportive. Participants acknowledged their freedom while learning new skills in foster care. One participant who had lived in a foster home for a long period of time reported, "my aunty taught me... how to cook and do laundry... yup... my aunty let me all my freedom.... "

The participants acknowledged that the different skills developed living in group homes and foster care facilitated community living. However, none of the participant showed interest in living in group home or foster care after learning skills required to live independently. Both group homes and foster care were seen as temporary learning places and not as a permanent place to settle. Participants were ready to leave their group home or foster care after learning domestic and different household skills. They seemed confident to stay alone and make social connections with other people while living independently with support. One participant reported,

"I don't need group home now. I have learnt my things... I am going good now... I am not even scared now... I can talk to people... I can go outside... do what I want to do... I have learnt a lot... from these people... how I can take care of myself... I always wanted to do that..."

Another participant who moved from foster care to live independently, claimed "yes... I am... I learnt things... from here and there... I was not doing anything earlier... now it is good... I have my life... I want to do more..."

Learning in independent living had more to do with community activities and more social connections. Making friends, learning about work, earning money were discussed by participants as a part of learning to live independently.

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"Yes I have friends now... not many... but I meet them when I like... I meet my boyfriend's family... they are good people.... I am happy now...."

Overall, learning experiences in different living arrangements were facilitators for better participation in the community. Living in group home and foster care helped in learning basic life skills and facilitated better participation.

Theme 3: Freedom and Choice

It was identified that participants were more connected with the outside world when they had more freedom of choice and control over their decisions. 'Freedom and Choice' incorporated both opportunity to choose as well as acts of decision making on day-to-day basis. Furthermore, being able to make their own life decisions affected participation outside their home increasing the chance to go out and make connection with the outside community. Having freedom to choose and taking own life decisions identified to be a major factor affecting community participation and was influenced by place of living.

Group home living was identified with lack of freedom and choice. There were restrictions on 'going out after certain period of time' and there were rules regarding the time spent outside the home. Participants were allowed to go out into the community, but would have to come back at a certain time. If these rules were not followed participants would be restricted to home for a certain period of time. The authoritative nature of the environment was a source of frustration that affected their connection with support staff. These rules affected freedom of participants and control of their own life.

One of the participant claimed, "like if you go out and come late... they keep you in house grounded...." Another participant added, " you get grounded for few weeks sometimes... then you get no choice... every day... no matter what... you can cook... but you can't say... like excuse me... can I go out to get chips or whatever... no... you are grounded...."

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Lack of freedom in day-to-day activities was also a concern for participants. There was a lack of choice in deciding what they wanted to eat. It was solely the choice of support worker what to buy for them in most of the group homes. Participant used the term "feed us" to describe the role of workers in group home, it was mentioned in the interview, "no... they buy their own groceries... like we don't say... okay... like I want bread... some ham... no... not our choice... those guys feed us in group home."

Some of the participants living in foster care also had similar experiences. There were rules related to the time spent outside home and foster parents wouldn't allow their foster person to spend much time outside the home. One participant added, "like if you go out and come late... they keep you in house grounded".

There were also good experiences in foster care and participants were happy with the freedom in foster care. One participant shared, "my aunty let me all my freedom... whatever I want to do... wherever I want to go. She took us to a family trip to Toronto...." Participant who had satisfying experiences in foster care did not find much difference between freedoms in foster care or in independent living, however, they appreciated their freedom while living independently with support.

"Well... hmmm... well it was okay staying in foster care because I still talk to that women since now and go visit her sometimes, but I am happy now... I can do what I like... nobody is watching you.... "

Independent living experience was different in terms of freedom and choice. There was more freedom to stay outside and meet people. Independent living provided an opportunity for participants to have full control of their own life. One participant who compared between foster

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care and independent living stated, "ya.... if I want to go out for a weekend... I can talk to a worker... to go out... I need someone to baby sit... sometimes...it helps." There was freedom in going out and planning their day according to their wishes. The pleasure of taking decisions and having freedom of choice added to their satisfaction with independent living. One participant stated,

"I am good... I am not scared now... I can talk to people... I can go outside... do what I want to do... and come back when I want... I can take care of myself... I always wanted to do that...."

"I have my own home now... my own place... where I can do what I like... I can buy stuff that I like... I don't have to ask for money if I need something... I can go outside... I can have friends... I can meet people whom I like... I can meet my boyfriend and his family... they buy presents for me and I buy for them... it is going good.... "

Overall, participants acknowledged a change in their freedom and choice while living in different types of living arrangements and appreciated their freedom in the independent settings.

Theme 4: Privacy and Safety issues

Privacy and safety were major concerns for participants while living in different types of living arrangements. These concerns were affecting their participation in the community. There was more privacy while living independently as compared to in group home and foster living. However, safety was an issue in all three types of living arrangements.

There was comparatively less or no privacy in foster care and group home. Participants did not have their own room or they had to share their room with others. After moving to independent living, the sense of privacy and safety was highly appreciated by the participants.

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The participants were happier and satisfied as compared with group home and foster care. Independent living had a few problems, however, participants preferred to be on their own. One participant who moved from foster care to own apartment stated,

“It’s easier now... because they are not watching me now... more privacy... stuff like that.... Another participant added, “I like my privacy... nobody is going mad at me.... I am independent... I can do what I like....I have my own life and ...I am trying hard....”

Regarding safety concerns, there was more risk related to personal safety and security in foster and group home. Concerns were related to fear of unknown people. There was a sense of loneliness and fear to talk with other people. One participant who went to a foster care quite early in her life stated, "I was kid... but away from home... with unknown people... it was scary... there was no one.... I don't used to talk to anyone.... I was scared...."

Meeting new people and going out alone were some of the concerns for participants while living independently as well. There was a common fear of being exploited by people in community. The fear and safety concerns were reported as one of the major barrier in participation of PwID’s outside their living arrangements. Most of the participants assumed that they were safe in their house and should not go out until necessary. One participant added, "it's been tough... that’s why I don’t want to have too many friends... or go out much.... It's not safe... I try to reach my home as soon as I can...it is not good outside sometime... it is scary."

There were initial difficulties in trusting people or taking help from strangers as participants moved to live by themselves. Living by themselves, was identified as a difficult but worthwhile experience. The participants appreciated the assistance they got from organizations focusing on PwID’s to live independently. One participant having an experience of living in

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group home stated,

"... like you have to be careful when you go out... like I meet you out there... I might have seen you before... like I know I can trust you... like I am not going out and let anyone... to take my advantage... but I do everything myself... it is hard... and these people help me...."

Another participant having foster care experience living independently added, "You have to trust him or her... like what is going to do with you... like whatever...."

Some participants were more confident outside when they started living in independent setting. The ability to participate with the larger community and engagement in activities of their own choice, helped participants in building trust with others. The self-confidence helped them to choose independent living over group home or foster care.

One participant stated, "I am good... I am not scared now... I can talk to people... I can go outside... do what I want to do..... I was scared earlier... but now I am not... I am doing good...."

Overall, safety materialized as one of the main concern. A number of factors were discussed by participants about trusting people, meeting strangers or staying late outside. Participants acknowledged a wide variation in the level of privacy while living in the different types of living arrangements and appreciated their privacy in independent setting. On the other hand, there was less variation in the level of safety with the change in their living arrangements. Safety and privacy were identified as central factors in community participation.

4.7 Summary of Results

A number of elements of different living arrangements were identified that affected

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involvement of participants inside and outside their home. Participants shared a number of positive and negative experiences of living in group home, foster care and independent living. Participants appreciated their learning experiences in group home but pointed out the lack of freedom while living there. Experiences of living in foster care were satisfying for some but negative for others. There were issues related to freedom, choice, privacy and support in both group home and foster care living. Almost all the participants preferred independent setting over other living arrangements. Independent living was identified as providing freedom of choice, privacy and more participation in community.

Participants defined participation in community through a number of perspectives. Participants discussed engagement in household and community activities as important components of participation. A number of activities were mentioned by participants related to daily routine, leisure activities and connection with other people outside their living places. Also, participants considered connection with support workers and family important. Being a part of community by doing some productive and meaningful work was also acknowledged.

It was identified that there was difference in support, learning experiences, freedom and safety in all three types of living arrangements that affected community participation of participants. Level and type of support was identified as an important factor affecting community participation of participants while living in group homes, foster care and independent living. Support in group homes was identified as more authoritative with less freedom and choice. Support in foster care was both facilitating and limiting. The type of support experienced in independent settings was appreciated by all the participants as it provided more freedom and choice.

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It was identified that participants had good learning experiences in foster care and group home that helped them to be better prepared to live on their own. Learning in group homes and foster care was more related to household work and learning in independent settings was related to social skills and community engagement.

5.0 Discussion

A number of key components were identified from the experiences of participants in relation to community participation and community living. Some of the findings from the study were well supported in the literature and some of them were new as identified through the analysis of collected data. The 'level and type of support' and 'freedom of choice' were identified as important themes and have been previously discussed and can be easily supported by the literature. However, other elements of participation such as 'safety issues' and 'learning experiences,' identified in the study, have rarely been discussed in detail in relation to community participation.

Community participation of PwID's has been referred to as the involvement of an individual in social, cultural and economic activities that is appropriate for the person (Mansell & Ericsson, 1996). In a study conducted by Dijkers (2010), researchers described participation as a complex and multidimensional construct, and concluded that there are no set standards for defining and measuring participation. The description of community participation available in the literature complemented the findings of this study. That is, participation was identified as engagement with workers and family, having social, personal, professional connections with outside world, and being a part of the community. The sense of participation spanned from learning domestic activities, paying own bills, doing grocery shopping and meeting friends. Every individual identified his or her own unique way of engaging in community. The nature, level and the scope of participation described in the study by each individual varied from one to the other. However, the similarities and deviations while defining participation enabled this study to gain broader understating of the central inquiry. For instance, engagement in household work, as a component of participation, was mentioned by most of the participants. In contrast, only a

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few participants talked about going out with friends and families outside their home. Overall, participation was identified as involvement in activities that are required for daily living, having connections with fellow members of society and being involved in community as seen as appropriate by the person.

One of the important findings depicted from the data was related to the lack of information among participants about community participation. There was a lack of knowledge among participants about activities, they can engage in, outside their home. When participants were asked about their regular routines and places they visit, participants had little to say. In most cases, they discussed their daily live activities such as going for grocery shopping, paying bills and doing daily household chores. There were a few instances related to picnics, trips and engaging in other community events. However, none of the participant mentioned community events, or any other type of social engagement except with close family members. It could be assumed that participants had a few choices or freedom to do diverse activities in the community. It could also be interpreted that they were less aware about the ways to be involved in activities outside their living arrangements. In both of the cases, living arrangement was one of the factors that affected their participation in the community.

During the process of analysis, community participation was interpreted to be strongly associated with the type of living arrangement. There were visible differences in the level of participation in group home, foster care and independent living arrangements. The four elements that linked community participation with different types of living arrangements were: level and type of support, freedom of choice, learning experiences, and safety of participants.

Level and type of support was identified as a major theme that resulted from the study.

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Literature on role of support workers has stated that the level and type of support has a major impact on the lives of PwID's. A Study done by Beadle-Brown, Hutchinson and Whelton (2012) reported the positive effect of active support on PwID's experiences and claimed increased participation of PWIDs. Koritsas, Iacono, Hamilton and Leighton (2008) defines active support as a model of care that empowers PwID's to fully participate in every aspect of life with the right support from support workers or family members. Researchers concluded that active support living enhances overall quality of life of PwID's along with increased participation. There are a few studies that commented on the role of staff and the way of supporting PwID's. A study done by Abbott and McConkey (2006) concluded that staff members at living arrangements should embrace a supportive rather than only a caring role. The nature of providing a greater supportive role should include more opportunities for making choices through adopting a fine balance between assistance and caring thus maximizing participation.

Similar results were found in this study and freedom to choose was repeatedly emphasized over most of the activity domains. There was lack of freedom in group home and foster care that was affecting participation in community. The limited freedom became a barrier in community participation of participants in group home and foster care living. Comparatively, independent living provided more freedom and choice and allowed participants to choose what they want. Independent living arrangements were identified to provide more freedom and choice compared to other types of living arrangements.

There were two, less explored, themes identified in this study that are not discussed in literature with respect to community living. Safety was identified as one of the major factors affecting community participation of participants. Safety was one major concern that affected participants' involvement in community while living in all three types of living arrangements

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including independent settings. Participants expressed their concerns regarding the resistance they faced in meeting new people and building trust in others. They carried constant fear of being exploited, taken advantage of, or being ill-treated. Surprisingly, safety concerns were also pointed out as an issue in independent living settings. Participants remained unsure of going out, without their support workers, due to the safety concerns and limited trust of the community environment. However, they voiced that the safety concerns were less important compared to the drawbacks of more dependent living in foster and group homes.

Another theme that emerged from the study was related to learning domestic, household and social skills. Participants appreciated learning about daily routine work while living in group homes and foster care. Although the learning was mostly related to household work and daily routine, participants acknowledged its value as compared to independent living settings where they have to take their own decisions and support workers or foster parents were not always there to help. Initial training and support in accomplishing daily living skills at the group homes and foster care provide a useful platform to participants to be better prepared for skills needed when they live independently. This proved to be a useful and reassuring experience for PwID's later on as an independent member of society. It seemed that group homes or foster care may be a worthwhile learning experience during the transition period prior to the independent living.

It is argued that more supportive living arrangements, like group homes may provide initial assistance that can help PwID's to be on their own. Nonetheless, it should be ascertained that the basic sense of individuality must not be neglected at group home or foster living arrangements. The living arrangements should provide active- supportive assistance with full freedom of choice to residents. Assistance should be meaningful, encouraging involving individuals themselves. The type of living arrangement and availability of facilities often become

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irrelevant if the elements of freedom, choice, active support and meaningful learning are not followed.

Thus, with the analysis of data and summarization of positives and negative factors affecting participation of PwID's living in different types of living arrangements, one key observation that appears to be of prime value is consideration of full participation of PwID's. With in-depth interpretation of the information shared by the study participants along with the knowledge from previous studies, the ideal community living could be guided by the four key elements: (1) level and type of support, (2) learning experiences, (3) freedom and choice, and (4) privacy and safety in any living arrangement. The intersection of these four key elements (Figure 3) in any community living arrangements can ensure community participation of PwID's to the maximum potential. This model depicts that any type of living arrangements can provide better support and participation when individual identity and needs are considered.

Individuality of each participant emerged as an important concept in the study. It was evident from the shared experiences of the participants that intellectually disabled people are not merely a group but they have individual needs, choices, and requirements. The type of living arrangement best for the entire population of PwID's cannot be generalized to any one setting. The importance of uniqueness and individuality of PwID's has been repeatedly argued in previous literature. Kozma (2009) and Mansell and Beadle-Brown (2009) stated that outcomes and success of living arrangement greatly depend on individual variability and not solely on size of the living arrangements. It is also important to understand their individual needs to be able to support them in a better way.

Additionally, it is important to consider who is deciding the place of living for PwID's

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and what criteria are being considered while making decisions on behalf of PwID's. In this study, the decisions about living arrangements for the participants were made by either the parents or supporting organization except for independent living which was participants' own choice.



Figure 3: The relation of community living and community participation

A study done by Deguara, Jelassi, Micallef and Callus (2012) highlighted the importance of choosing one's own place for living. The article recognized the importance for PwID's to

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choose their own place for living and other people should not decide it for them . It was highlighted that PwID's need assistance in their life depending on the level of accessibility of their surroundings.

Thus, to achieve the goal of full participation in community, PwID's should be provided with active and meaningful support, learning opportunities, freedom of choice, and appropriate privacy and safety as required by the person. While all of these elements may assist in increasing participation of PwID's in community, there could be more factors to consider. However, it is hoped that this study might be useful in analyzing community living and participation in more detailed and organized way from insider's perspectives.

5.1 Limitations of the study

The present study indicated the fact that living places have a major role to play in the level and type of participation of PwID' outside in the community. However, the results cannot be generalized to everyone with intellectual disabilities. The study was performed on a small scale with only five participants that might have limited our knowledge about PwID's and their opinions on living arrangements. Another limitation is that participants who showed interest and participated in the study were supported by one organization only. The recruitment of participants from one organization might have influenced the views and experiences of participants.

Furthermore, participants in this study only had experiences of living in group home, foster care and independent living. Other types of living arrangements such as semi-independent living, clustered or dispersed settings and other modern type of living types were not analyzed, as participants did not have the experience of living in such places. These other types of living

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arrangements may influence community participation differently than living arrangements discussed in this study.

Important selection criteria for this study were that participants were living independently with support and able to communicate on their own without a proxy. It was assumed that people living independently will be able to express their views directly and will be more experienced than people living in other type of living arrangements. However, it is acknowledged that people who have not had the experience of living independently may have different views about living arrangements and community participation.

Consequently, transferability of the results may be limited. A longer study period, with more participants and sites could have increased the depth of collected data and thereby could have influenced the results by providing more detailed and elaborated understanding of living independently.

6.0 Conclusion

The idea of participation in community, does not seem to be restricted to mere physical space but also takes account of the values and principles followed in such living places. Existing literature evaluates and discusses participation, support staff, and service models in different living arrangements. However, the literature does not provide a clear picture regarding the role of different living arrangements in affecting participation of PwID's in the community. The conceptual meaning of community participation is limited and the relation between community participation and community living has not been evaluated in detail. This study addresses the need to better understand community participation and includes the perspectives of PwID's living in the community.

This study attempted to understand the views and experiences of PwID's in defining community participation and consequences of living in different types of settings. It was concluded from the study that there are number of living arrangements available for PwID's in community. Independent living is assumed to provide better inclusion and participation than others. However, we found that living independently is not the solution for everyone. People are different and so are there needs and aspirations. Everyone is unique in their needs for support and resources to be able to live in the society.

The model presented in this study identifies the elements that can guide better participation of PwID's living in the community. The elements of active and meaningful support, freedom of choice, safety and privacy were seen as more important than type of living arrangement in affecting community participation. Thus it is concluded that it is not solely a type of place but the elements of participation that are important for successful community living.

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This study attempted to capture the subjective experiences of PwID's about community participation in different types of living arrangements. The evidence of the dynamic interplay between people and their living places at personal, social and community level was apparent throughout the study. The findings provide encouragement for future research on measuring and defining participation from people's perspectives as opposed to pre-defined norms.

Based on this study, several key directions for community living could be suggested. First, there is dearth of knowledge regarding community participation and type of living arrangement. There are a number of studies done to compare and contrast different types of living arrangements. However, there is a need for further evaluation of the values being followed in different types of living arrangements available in community in relation to participation. Further research is necessary to better understand the association between community living and community participation on larger scale.

It is also important to create more awareness among support workers and foster parents about the needs of PwID's and how they can be better supported. The elements of choice, freedom, meaningful engagement, and active support need further consideration in literature and from the perspective of PwID's.

Another area to explore could be to work on community living and gather suggestions from workers, families, friends and PwID's themselves to advocate for inclusion in community. Research could be done to review current policies and regulations in different living arrangements that limit participation of PwID's in community. Further research could help in improving quality of life in different living arrangements. Each of the elements of participation identified in this study can be elaborated and examined individually to develop purposeful and

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acceptable living solutions.

This study may be useful in assisting support workers and organizations involved in community living and community participation of PwID's. Taking into account the importance of engagement in activities, privacy and safety, freedom and choice, can help support workers, foster parents and organizations to ensure better community participation of PwID's.

Additionally, this study may help policy makers of organizations supporting PwID's to guide and revise existing practice and develop much needed policies to help make society a more inclusive place.

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Appendix A: Invitation Letter

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Invitation Letter to agencies/organizations providing support to people with intellectual disabilities living independently with support

Dear Sir or Madam,

I am a Graduate student pursuing MSc. in disability studies at University of Manitoba. I am contacting you as it is my understanding that your organization provides support to people with intellectual disabilities living in community.

We are conducting research focusing on the experiences of people with intellectual disabilities about participation in community. The purpose of this qualitative study is to gain an insider's perspective from people with intellectual disabilities in understanding the role of different community living arrangements in promoting their community participation. In particular, we are interested in learning what does "community participation" mean to people with intellectual disabilities who have lived in different types of community living arrangements. We are also interested in knowing how their living arrangements affect their participation in the community.

We are looking for adults who have intellectual disability, living independently with support and who have had an experience of living in more than one type of community living arrangement. We would like to ask if your organization would be able to assist with the recruitment process. Specifically, would you be able to help with recruitment by providing a location in your organization for brochures to be seen by potential participants or by providing recruitment information via email or other electronic media that is used by your organization?

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For quick reference, we are looking for individuals who meet the following criterion and are interested to participate in this study:

1. Adults who have intellectual disability and living independently with support.
2. Individuals who are interested in talking about their experiences of living and participating in community.
3. Individuals who have had an experience of living in more than one type of living arrangement (for example. group home, residential settings, independent living etc).

Please note that participant's will be informed that the access to services in your organization will not be affected by participation in this study. If you have any questions regarding the study, please feel free to contact the principal investigator, Pratima Dheeman at [REDACTED] or email at dheemanp@myumanitoba.ca

Thank you for your time and consideration.

Sincerely,

Pratima Dheeman

M.Sc. Disability Studies

University of Manitoba

[REDACTED]

Email ID: dheemanp@myumanitoba.ca

Questions and Answers

1. What I will be doing?

Come for an interview for an hour and I will ask you questions about your living place and your participation in the community.

2. Why should I participate?

To help researchers understand what you and others think about living and participating in the community. You will get a chance to talk about your experiences of living in different places and participation in the community.

3. How the information will be used?

I will write a report about living and participating in the community as you and others living independently with support will describe it. The information collected from you will be used to understand experiences of people who live with support. No name or identity will be shared in the report that I will write.

4. How can I contact you?

You can contact me through phone at [REDACTED] or email me at communityliving4@gmail.com.

"Living and participating in the community"

A Research study

What is your experience of Living in the Community?

I would like to know your views on living and participating in the community.



- **Are you living on your own with support?**
- **Have you lived in more than one place?**
- **Would you like to talk about your experiences of living and participating in the community?**

Contact me, if you would like to be a part of the study.

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My name is Pratima Dheeman and I am doing a study with my advisor as a part of my masters degree program.

Aim and objectives of the study:

The aim this study is to understand the experiences of people with intellectual disabilities about living and participating in the community.

We would like to know your views about community participation and how your living places affected your participation in the community.

Study Design

- I will interview you for an hour and will ask questions about places you have lived and your participation in the community while living in different places.
- You can come alone or with a support person for the interview.
- The place could be a public spaces such as public library or any other public location where we can meet and discuss.

If you are interested in being a part of this study, please contact me by phone or by asking your support person.

You can choose the date and time of your interview

- There will be an interview for one hour.
- There is no cost to you.
- You will receive \$20 as a token of thanks.

You will be asked to talk about:

- Where you live and what you like to do in the community?
- What are different things you do when you go out?
- Who helps you? What you like or dislike about it?
- Questions about different living places you have lived
- What limits you to do things in your community

If you want to be a part of study or have any questions, please contact:

Pratima Dheeman
Student at University of Manitoba
[REDACTED]
email: communityliving4@gmail.com

Appendix C: Inclusion Criteria

Participants of the study will be:

1. Participant should be verbal and able to advocate for themselves. The participants of the study will have varied extent of intellectual disability. Participants who are identified as having an intellectual disability and who are able to talk about living in community will be recruited.

Since the study focuses on the experiences of people themselves, it is necessary that they can talk about their experiences of living in the community and activities they do to participate in community. Thus to understand people's perspectives as opposed to using proxies for the answers, it is important have participants who can communicate and describe their perspectives.

2. Experience of living in more than one living arrangement: Adults who have intellectual limitations and have an experience of living with support in more than one place will be included in the study. Since study aim is to understand the role of living arrangements in achieving community participation, people having experiences of two or more living arrangement will be able to better describe and compare their experiences of living in community. The experiences of living in more than one place will also help participants to identify the barriers and facilitators and they face while participating in the community.

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Appendix D: Research Participant Information and Consent Form (Only Plain language)

Research Project Title: Living and participating in the community: Experiences of people
living dependently with support.

Principle Investigator:

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Living and participating in community

R3T 2N2

Phone: [REDACTED]

E-mail:nancy.hansen@umanitoba.ca

This paper is called a consent form. It is yours to keep. It will tell you about the research that we are doing and what you will be doing as a participant of the study. If you need some more information about this research or about anything in this paper, please ask me. I will go over this information with you to make sure you understand everything that is in it. Please take the time to read this carefully and you can ask for help if you do not understand anything.

Why are we doing this research?

We are interested in learning what does "community participation" mean to you. We are also interested in knowing how your living places helped you or did not help you in going out and participating in the community.

What we are going to do and How?

We are doing this research to know your views on where you live and activities you do in the community. You are the important part of the study. You should only participate in this research if you want to. It is totally your decision. No one can force you to participate in this study and there is no punishment for you to be involved or not.

The interview will be about an hour. You will be asked to talk about your living place and your participation in community. I will ask questions related to your living place, where you go out, what do you do on daily or weekly basis. If you wish, you can talk about your experiences. It is your choice to answer the questions and information that you want to share. You can also choose to skip a questions.

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I want to remember everything whatever you say. Since I will not be able to remember everything you say, I will record your voice in a tape recorder. It will help me to remember whatever you say. Your voice will be kept secret and no one would be able to listen to the tape except me and my research team. The recording will be only used for the study and not any other purpose. I will also write some notes during the interview so as to remember all important things you discuss.

Is there a risk if you participate? Are there benefits to participate in this study.

We do not think there is any risk to you participating in this study. However, some individuals may find it difficult to discuss situations in which they feel their rights have not been respected. If you feel uncomfortable during the interview and do not feel good to discuss more, you will be free to end the interview. There is no penalty if you decide not to participate in this study. If you need some help during the interview session or if you feel uncomfortable due to any question, please feel free to ask.

We feel that this type of discussion is important for society. People with varied abilities are coming out in the community and are members of society. There are different places in the community where people are living and participating. Your experiences will help us as well as other people like you who may have problems in understanding things.

Keeping your name a secret

As I said, I will tape record the interview. We do this so we can remember what you said. No one will know you were a part of the study because we do not use your real name, when I will write my report. We might call you a participant or will give you a fake name. Keeping who you are a

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secret is called confidentiality. I will ask question in simple and plain language so that you don't get confused.

Even though the tapes will have your voice on it, only the research team will hear the tapes, no one else will know. I will write a report using the words you say during the interview. Your name and identify will not be shared during writing my report. The tapes are kept in a locked place and I will not write down your real name in notes. Only the research team can view your information, not anyone else. I will keep your recording in secure place and no one will be able to listen it without your permission. Your recording will be deleted once I write it down in my report.

Being a part of this study

Each person who participate in this study will get \$20 for their help with this study. Being a part of this study is your choice. you should only do if you want to. No one will be mad or upset if you decide you do not want to take part. You can even change your mind part way though if you are not comfortable during the interview. You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities. You can still keep \$20.

If any questions come up during or after the study, you can contact the study staff: Pratima Dheeman [REDACTED] or study supervisor Dr. Emily Etcheverry at [REDACTED]. For questions about your rights as a research participant, you may contact the University of Manitoba, Fort Garry Campus Research Ethics Board Office at [REDACTED]

Living and participating in community

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

When you sign this paper, you are agreeing that you understand what is in this paper and agree to be a part of this study. You do not give up any legal rights by signing this paper. You can change your mind and not take part in this study at anytime. No one will be mad or upset with you. You can also decide not to answer a question that you do not want to. You should always ask questions if you are unsure about something or do not understand something.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. A group of people at University of Manitoba called the "Research Ethics Board" has made sure this research is okay to do. They might decide to look at this project more closely to make sure we are doing our project safely and properly. You can call 204-474-7122 if you have any problem that the researcher can't answer. Please keep this paper in case you want to read it again.

Participant's Signature

Date:

Researcher Signature

Date:

Appendix E: Interview Guide

The purpose of today's interview is to know your views and experiences of living and participating in the community. Before we start the interview, do you have any questions and concerns?

Starting questions

- Tell me about how many places you have lived?
- Do you get support while living at your current and previous places?
- What do you like to do in community?
- Do you get any support going out in community?

Transition comment

We will now discuss your participation in community in more detail. I would like to know how you participate in community. By that I mean, we all live in different homes. Sometimes with family, sometimes alone or with other people. While living at particular place, we go out, we do things outside our home, meet people and do different activities. When we go out of our home and do different things, we are participating in the community.

How much we go out, with whom we hang out with and what all we do outside our home gets affected by the place where we live in. Where we live, sometimes help us going out and doing things. And, sometimes we are not able to do things because of where we live.

I would like to know how your living place affect you going out and doing things.

Guiding Questions

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- What you do outside your home/what activities you do outside?
- Tell me about your regular day or week.
- Tell me about where else you go? Do you go by yourself or does someone go with you?

Living place/Home

- Does living at your current house help or make it difficult for you going out. How?
- Can you give some examples when your living place affected your visits outside.
- What about where you lived before? Were your experiences of going out different from your current place? How?
- Can you give some examples from your place where you used to live before?

Conclusion

We talked a lot about your living place and what all you do when you go out of your living place. Is there anything else you want to say about your participation in community activities and going out of your home.

Before we finish, we would like to go over the points to make sure we got everything right. Is there anything that you would like to add or change.

Thanks for your help and sharing your experiences.

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Appendix F: Research Participant Information and Consent Form

Research Project Title: Living and participating in the community: Experiences of people living independently with support.

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Version date: June 15, 2015

Living and participating in community

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This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This paper is called a consent form. It is yours to keep. It will tell you about the research that we are doing and what you will be doing as a participant of the study. If you need some more information about this research or about anything in this paper, please ask me. I will go over this paper with you to make sure you understand everything that is in it.

Purpose of the Research

The purpose of this qualitative study will be to gain an insider perspective from people with intellectual disabilities in understanding the role of different community living arrangements to achieve community participation.

Why are we doing this research?

We are interested in learning what does "community participation" mean to you. We are also interested in knowing how your living places helped you or did not help you in going out and participating in the community.

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Research protocol

Interviews will be conducted with each participant individually with maximum of ten participants. Participants will be asked a number of questions, based on their experiences of living in different community living arrangements and its impact on community participation. The interview session will last about an hour and will be tape recorded. There could be a support person present in the interview room as per the choice of the participant.

What we are going to do and How?

We are doing this research to know your views on your living place and activities you do in community. You are the important part of the study. You should only participate in this research if you want. Whether you want to participant in this study or not, is totally your decision. No one can force you to participate in this study.

The interview will be about an hour. You will be asked to talk about your living place and your participation in community. I will ask questions related to your living place, where you go out, what do you do in daily or weekly routine. If you wish, you can talk about your experiences. It is your choice to answer the questions and give information that you want to share.

I want to remember everything whatever you say. Since I will not be able to remember everything you say, I will record your voice in a tape recorder. It will help me to remember whatever you say. Your voice will be kept secret and no one would be able to listen to the tape except me and my research team. The recording will be only used for the study and not any other purpose. I will also write some notes during the interview so as to remember all important things you discuss.

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Risks and Benefits

We do not anticipate any significant risks to participants as a result of participating in this study.

However, some individuals may find it difficult to discuss situations in which they feel their rights have not been respected. There are no undue risks for the participants in this study.

However, we anticipate that the participants will value and appreciate the opportunity to discuss their perspective on their living arrangements and its impact on their community participation.

Is there a risk if you participate? Are there benefit to participate in this study.

We do not think there is any risk to you participating in this study. However, some individuals may find it difficult to discuss situations in which they feel their rights have not been respected. If you feel uncomfortable during the interview and do not feel good to discuss more, you will be free to end the interview. There is no penalty if you decide not to participate in this study. If you need some help during the interview session or if you feel uncomfortable due to any question, please feel free to ask.

We feel that this type of discussion is important for society. People with varied abilities are coming out in the community and are members of society. There are different places in community where people are living and participating. Your experiences will help us as well other people who have problems in understanding things.

Anonymity and Confidentiality

Qualitative data will be collected from the participants through interviews. The primary researcher will ensure that the name and identity of the participants are kept confidential. The primary researcher will explain that participants have right to make sure no one knows they have

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been part of this study. The conversation with participants will be discussed using plain and simple language and the voice will be recorded in an audio tape recorder. The recordings will be transcribed verbatim. All identifying characteristics (name of the person, name of places and organization) will be removed from the transcript and replaced with pseudonyms. Notes will be taken during the interview and will not contain any identifying information. All documents will be kept in locked cabinets and password-protected computer files. All documents, including interview transcripts, will be kept confidential by using your assigned study number in research offices. Only the authorized study team members will have access to your information. Audio recordings will be kept on a secure, password-protected computer and will not be used beyond this study without your consent. No information that will disclose your identity will be recorded. The audio recordings will be deleted once the study team members transcribe them. Records that identify you by name or initials will not be allowed to leave the investigators' offices. The investigators will be the only people who will have access to this information. Data collected from this study will be maintained till completion of this study, at which time they will be erased or destroyed.

Keeping your name a secret

As I said, I will record the interview. We do this so we can remember what you said. No one will know you were a part of the study because we do not use your real name, when I will write my report. we might call you a participant or will give you a fake name. keeping who you are a secret is called confidentiality. even though the tapes will have your voice on it, only the research team will hear the tapes. no one else will know. The tapes are kept in a locked place and I will not write down your real name in notes.

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Compensation and participation

You will be receiving an honorarium of \$20.00 in cash if you participate in this study. Your participation is entirely voluntary and you are free to withdraw from study at any time and for any reason with no repercussions or loss of honorarium. The support persons will be used during their paid hours and no additional reimbursement will be provided to support persons for their assistance during the study.

Being a part of this study

Each person who participate in this study will get \$20.00 for their help with this study. Being a part of this study is your choice. You should only do if you want to. No one will be mad or upset if you decide you do not want to take part. You can even change your mind part way though if you are not comfortable during the interview. You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities. You can still keep \$20.00. Your support person will not get any amount for being with you.

If any questions come up during or after the study, you can contact the study staff: Pratima Dheeman [REDACTED] or study supervisor Dr. Emily Etcheverry at [REDACTED]. For questions about your rights as a research participant, you may contact the University of Manitoba, Fort Garry Campus Research Ethics Board Office at (204) 474-7122.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

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Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

When you sign this paper, you are agreeing that you understand what is in this paper and agree to be a part of this study. You do not give up any legal rights by signing this paper. You can change your mind and not take part in this study at anytime. No one will be mad or upset with you. You can also decide not to answer a question that you do not want to. You should always ask questions if you are unsure about something or do not understand something.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Research Ethics Board (REB) of University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Research ethics board (REB) at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

A special group of people at university of Manitoba called the "Research Ethics Board" has made sure this research is okay to do. They might decide to look at this project more closely to make sure we are doing our project safely and properly. You can call The Research Ethics

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Board (REB) at 204-474-7122 if you have any problem that the researcher can't answer. Please keep this paper in case you want to read it again.

Participant's Signature

Date:

Researcher Signature

Date:

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Appendix G: Pledge of confidentiality

I, [name of the person], am volunteering for the project entitled: " Living and participating in the community: Experiences of people with intellectual disabilities living independently with support".

As part of my responsibilities, I will be:

- Assisting in recruiting participants;
- Helping in distribution of recruitment brochure
- Helping the participant in contacting the primary investigator of the study;

I understand that I will be working with confidential information and that all the participants in this study have been guaranteed the right to remain anonymous and to have their responses treated in a confidential manner.

As a result, I pledge to maintain the confidentiality and anonymity for all the information connected to this study.

Date:

Name:

Signature:

Witness:

Appendix H: Timelines of the Project

Project Activity	Estimated Time-line
Project period	September, 2014- June 2015
Proposal Defense	October 14, 2014
Ethics application	October 20, 2014
Initiate participant recruitment	December, 2014
Data collection	December , 2014 - January, 2015
Participant recruitment ceases	January 15, 2015
Data Analysis (concurrent with data collection)	December, 2014- February, 2015
Data Synthesis	February, 2015- March, 2015
Study report writing	March, 2015- May,2015
Project completion	June,2015

Appendix I: Study Budget

Project Requirement	Estimate
<p><u>Participant honorarium</u></p> <ul style="list-style-type: none"> ▪ Paid for one interview session per participant ▪ Maximum ten participants 	<p style="text-align: right;">\$20.00/ participant</p> <p style="text-align: right;">\$20.00 x 10= \$200.00</p> <p style="text-align: right;">Total = \$200.00</p>
<p><u>Office supplies:</u></p> <ul style="list-style-type: none"> ▪ Paper, costs for printing recruitment Brochure, invitation letters and costs of printing transcripts and study forms ▪ Stamps and envelopes for sending invitation letter 	<p style="text-align: right;">\$20.00</p> <p style="text-align: right;">\$10.00</p> <p style="text-align: right;">Total=\$30.00</p>
<p>Equipments</p> <ul style="list-style-type: none"> ▪ Audio recorders for interviews 	<p style="text-align: right;">\$80.00</p> <p style="text-align: right;">Total = \$80.00</p>
<p>Total budget of the project</p>	<p style="text-align: right;">\$310.00</p>