

**Quality of Life for Individuals with Developmental Disabilities
in a Supported Apartment Living Program**

by

Heather A. Milton

A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfilment of the requirements of the degree of

MASTER OF SOCIAL WORK

Department of Social Work
University of Manitoba
Winnipeg, Manitoba

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ABSTRACT

This study had two main purposes. The first objective was to increase knowledge of the factors that positively contribute to quality of life as experienced by participants with intellectual disabilities in the New Directions for Children, Youth, Adults and Families Supported Apartment Living Program. The second objective was to evaluate program services of this program that provides supports to individuals with developmental disabilities who have chosen to live independently in the community.

The research involved elements of Participatory Action Research including the innovative technique "photovoice" which allows participants to speak through the use of photographs, and featured the collection and analysis of data by 9 participants. The participants took pictures of factors in their environment they considered to be important to their quality of life. The participants analyzed and categorized their photographs according to the quality of life domains including, rights, self-determination, emotional well-being, physical well-being, personal development, personal relationships, social inclusion and material well-being (Schalock, 1997). Two focus groups were then conducted with other participants of the Supported Apartment Living Program at which the photographs were used to initiate discussion about what factors contribute to their quality of life.

The results indicated that living independently and adequate services provided by the Supported Apartment Living program at New Directions contribute to participants' quality of life in all domains. The results of this study will be of interest to agencies and their funders that are planning on developing or expanding community supported living programs for individuals with developmental disabilities.

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CHAPTER 1: INTRODUCTION

Quality of life for many individuals with intellectual and/or mental health concerns has evolved over the past century from custodial care in an institution to living independently in the community with or without supports. The pace of this process has been uneven and filled with controversy. The recent decision by the Government of Manitoba to spend millions of dollars renovating an institution to improve the conditions for the individuals who still live there has met with strong opposition from supporters of community living who advocate for closing institutions and opening communities to people with disabilities.

The continuum of community care for individuals with intellectual disabilities ranges from large residential living units through to independent living with or without supports. The supported living concept supplies the framework to provide flexible, individualized, community based supports that honour the person's choices regarding housing, employment and recreation. The supports are attached to the person and ideally are able to adapt to changing needs in response to the ongoing assessment of the person-environment fit (Karan & Bothwell, 1997). Supports can include environmental adaptations, training in community and independent living skills and the expansion of social support through increased recreational and social opportunities. Self-determination is respected in that the individual has the right to choose the supports he/she wants with the expectation that supports will be adapted/added/ reduced as needed. Research appears to indicate that increased normalization supports positive changes in quality of life and supported living offers the most normalized environment in the range

of community options. The number of supported living programs offered by non-profit agencies is growing and adding to the knowledge of the elements of quality of life enhancing services in the programs is one of the goals of this research.

Research Setting

The Supported Apartment Living program is one of several programs established by New Directions for Children, Youth, Adults and Families to provide support to individuals with disabilities living in the community. The Supported Apartment Living program was developed in response to the identification of specific needs of individuals who wanted to live as independently as possible in their own apartments in the community. The program and the services offered have continued to evolve, adding or expanding services in response to participants' needs. As noted in the following literature review researchers have identified isolation, loneliness and poverty as difficulties encountered by supported living participants. The Supported Apartment Living program has services designed to reduce the effects of poverty including, among others, an on-site food bank, light meal program, laundry facilities, and housing supports. Services offered to expand each participant's social support network include, among others, the availability of the two staffed lounges for leisure activities and classes, the individualized staff support for assistance with relationship issues, problem solving and social skills, and the organized group activities such as camping and barbecues.

Research Population

The Supported Apartment Living program provides services to approximately 30 participants with an additional 10 on the referral list. All the participants have an intellectual disability and some have a dual diagnosis of intellectual disability and a mental health concern. Most of the participants have experienced living in group homes, foster homes, parental homes, institutions or a combination of these. Some of the participants have been in conflict with the law. Although some of the participants obtain infrequent employment they are all in receipt of Employment and Income Assistance and all have incomes below the poverty line.

Research Questions

There are three main research questions in this study. They are listed below.

1. What factors positively contribute to the quality of life of participants in the Supported Apartment Living program at New Directions for Children Youth, Adults and Families?
2. What services provided by the Supported Apartment Living program do the participants find the most valuable in contributing to their quality of life and why?
3. What services (if any) do the participants think should be added to the program and why?

Methodology

Prior to the 1960's, society assumed that the poor quality of life experienced by the institutionalized intellectually disabled person was the unfortunate but unavoidable outcome of the intellectual disability. The perception that quality of life was the outcome of the dynamic interaction between an individual and his/her environment, and, that changes in one would effect changes in the other, coupled with the acknowledgement that institutions were disabling environments, supported the de-institutionalization, normalization and community living movements. There is now general agreement that all individuals, regardless of degree of intellectual disability, have an opinion about their quality of life and that this subjective opinion should both correlate with the individual's sense of well-being and take precedence over other objective criteria (Coulter, 1997; Schalock, 1990). Recognition that the individual's viewpoint should take precedence fostered the development of research techniques designed to elicit this viewpoint.

Research methodology evolved from the use of primarily objective measurement, with the information gained from proxies and staff, to the use of strategies focused on gaining knowledge of the individual's opinions and preferences. There is general agreement that the quality of life experienced by individuals with intellectual disabilities is composed of the same core elements as quality of life for all populations and that quality of life research should reflect this.

Participatory Action Research, with the addition of the innovative technique of photovoice, which allows participants speak through the use of photographs, is one example of research methodology designed to gain the individual's point of view as a

stakeholder and to effect positive change (Gavin, 2003). As further explained in chapter 3, this research project incorporates elements of Participatory Action Research including photovoice. Several features also mark this project as a case study.

The research project employed multiple methods of data collection from multiple sources. The researcher met with program staff to explain and distribute handouts of information about the research project. The researcher facilitated one information/recruitment group session with Supported Apartment Living participants, then met individually with each of nine program participants and accompanied them as they used disposable cameras to photograph elements in their environment that they deemed important as contributing to their quality of life. The researcher used field notes to record the explanation of the significance/value they attached to each picture. The researcher then interviewed each participant about the services they most valued in the Supported Apartment Living program. The researcher and the participant analyzed the photographs by sorting them according to the following eight quality of life domains; emotional well-being, physical well-being, personal development, personal relationships, social inclusion, material well-being, rights and self-determination (Schalock, 1997). These eight quality of life domains provide a framework for quality of life assessment and are further discussed in chapter 2. The participants and the researcher mounted the pictures on poster boards with each board representing one quality of life domain.

The researcher facilitated two focus groups that used the poster boards to stimulate discussion from the focus group participants about their perceptions of quality of life in each of the domains. The focus groups were videotaped. Data from the nine individual photovoice research and the field notes from the photovoice participant

interviews, combined with the transcripts from the focus groups, were analyzed to identify elements contributing to quality of life for the participants in each domain, which services provide by the Supported Apartment Living program were most valued and to identify information about any additional service they would want added.

Research Significance

This research project makes a contribution to the disability field in the following ways:

- a) The study generated knowledge about which factors contribute most positively to quality of life for individuals with disabilities, including importance of safe housing, pet ownership and supports provided by the program. This information can be used to improve the quality of life for individuals with disabilities in community settings.
- b) The study provided information from participant feedback about the program services considered most helpful in Supported Apartment Living programs. This knowledge can be used to improve program delivery for individuals with disabilities living in a variety of community settings. The participants in this Supported Apartment Living program were positive about the program and the services provided. Conclusions derived from the research, as discussed in chapter 5, include a discussion on the program elements that are effective in alleviating the problems of loneliness, isolation and poverty identified in the literature review as barriers to improving quality of life in supported living environments. This knowledge is useful for any agency that is considering starting or expanding a Supported Apartment Living program.

- c) This research makes a contribution to disability research in the use of the innovative technique of photovoice.

The next chapter provides a review of the literature and a discussion on the influence of the evolving concept of quality of life on the history of de-institutionalization and the development of community living options, with additional sections on dual diagnosis, and the main literature themes.

CHAPTER 2: REVIEW OF LITERATURE

The literature review will begin with a discussion of the path from institutionalization to supported living, followed by an examination of the research and measurement of quality of life, dual diagnosis, supported living environments, and a brief section on Participatory Action Research. The influence of the evolving concept of quality of life along the path will be discussed in each section. Supported living is a process of providing individualized, flexible, community supports that respect the person's choices about where and with whom to live, work and spend leisure time. The supports are attached to the person and may include environmental adaptations, skills training, physical assistance, recreational and social opportunities and other services as required (Karan & Bothwell, 1997). Case management will be discussed in the quality of life and dual diagnosis sections and in the discussion on supported living.

Participatory Action Research

The vast majority of quality of life research on individuals with intellectual disabilities over the last fifty years has used traditional qualitative and quantitative research methods. The individuals had little input into the research process, the published research results or how the research was used. Research on the quality of life as experienced by individuals with intellectual disabilities and/or mental health concerns has evolved from the use of primarily objective criteria, which may not have reflected the individual's own point of view or values. Current thinking acknowledges that the

individual's point of view and values takes precedence over other, more objective, criteria.

Definition

Participatory Action Research (P.A.R.) is defined as "a research approach that consists of the maximum participation of stakeholders, those whose lives are affected by the problem under study in the systematic collection and analysis of information for the purpose of taking action and making change" (Nelson, Ochocka, Griffin & Lord, 1998, p. 885). P.A.R. values the individuals' experiential knowledge, incorporates change as part of the research, and has been used successfully with marginalized populations. It values empowerment, supportive relationships, social change and learning as an ongoing process (Nelson et al., 1998). P.A.R. appears to be a good fit with current thinking that, in researching quality of life, the individual perspective is most important. Participation in the research should be a validating and empowering experience for the individuals resulting in positive changes.

Photovoice

Photovoice is the use of "photography as a medium for self-expression, a tool for self-advocacy and a way of empowering those on the fringes of society" (Gavin, 2003, p.1). Using documentary photography enables marginalized individuals and groups to give a picture of their lives (Gavin 2003). Photovoice is a good fit with P.A.R. as it uses and values the experiential knowledge of the stakeholders, seeks to gain their perspective and is an empowering and positive experience for participants.

From Institutionalization to Supported Living

The Current State of Institutional Living

Prior to the decades of the 1970s and 1980s, many of the intellectually disabled lived in large institutions removed from the community. The de-institutionalization movement, strengthened by the concepts of quality of life, self-determination, normalization and community living, began to influence attitudes about the quality of life of the institutionalized population living with intellectual disabilities in the 1960's and 1970's. The result was the ongoing process of depopulating the institutions and moving the individuals into a wide range of community living options. This process has been uneven, controversial and difficult for individuals, their families and the agencies supporting them, but seemingly unstoppable. Institutions are largely depopulated and community options continue to grow (Braddock & Hemp, 1997; Keigher, 2000; Kim, Larsen & Lakin, 2001).

The De-Institutionalization Process

A review of the history of de-institutionalization, the role played by an evolving concept of quality of life and how the knowledge gained from this history shapes current thinking and provision of services is helpful in understanding current trends.

The Historical Characteristics of Institutions

Prior to the 1970's, institutions provided custodial care for individuals with intellectual disabilities. Characteristics of custodial care included the role of staff as care

providers and the individual's role as long term patient with little choice over most aspects of daily living. Rules were restrictive. The intervention orientation was focused on deficits and programs and strategies for rehabilitation or empowerment were very limited. The patient role, orientation, and rules all functioned to maintain the dependency of the disabled individuals (Parkinson, Nelson & Horgan, 1999). Institution-oriented practices included rigid routines, depersonalization and limited social interaction between staff and residents (Hemming, Lavender & Pill, 1981). Institutional care perpetuated a poor quality of life because it denied dignity and self-respect to patients (Taylor & Bognan, 1990). The question was whether institutions could continue to be used considering the poor quality of life they provided.

Early Attempts of Institutional Reforms in the US – From Big to Small

Many U.S. states attempted to reform/adapt existing institutions in the 1970's to make them more therapeutic (Braddock & Hemp, 1997; Cooper & Picton, 2000).

Therapeutic institutions are characterized by a reduction in institution-oriented practices, a focus on normalization practices such as opportunities for community interaction and provision of recreational and rehabilitation programs aimed at increasing behavioral competence (Hemming et al., 1981).

The outcomes from some research demonstrated that moving individuals from large traditional institutions to smaller improved units with more therapeutic practices could result in improvements in behavior and a higher quality of life (Cooper & Picton, 2000; Hemming et al., 1981). Cooper and Picton (2000) used primarily quantitative research methods to assess quality of life outcomes, community living skills, quality of

care and challenging behaviors for individuals moved from a large institution to either refurbished units in institutions or small group homes in the community. Data was gathered pre-relocation, and at six months and three years following relocation. A quality of life questionnaire measured quality of life overall and on four subscales (satisfaction, empowerment/independence, competence, productivity and social belonging /community integration). The questionnaire was given to the individual clients if the client was considered to be verbal or to the staff informant if the client was considered to be non-verbal. Community living skills were assessed by researcher observation and with a questionnaire completed by staff informants that rated performance and opportunities for independence. Challenging behaviors were evaluated with a behavior scale completed by staff informants that measured the frequency of self-injurious, injurious to others, destructive to property and unusual or disruptive behaviors. Quality of care was measured using a sheltered care environment scale of 36 yes/no questions administered to caregivers.

Results indicated modest gains in quality of life for both relocated groups and decreased behavior problems in the inter-institutional movers. The decrease in challenging behavior could be attributed to both the improvements in the living environment of the refurbished units and the training in behavior management skills given to the staff. There were no significant gains in performance of community living skills for the group moved to group homes in the community.

The researchers own criticism of this research included the lack of a non-relocated control group, the small sample size, gathering of data on quality of care from staff who may have been biased, and the very limited amount of direct input and feedback from

clients. The only opportunity to gain the perspective of the client was the quality of life interview and the use of staff informants when clients were deemed non-verbal raised a question about the validity of the findings (Cooper & Picton, 2000). The researchers concluded that inter-institutional movement did result in modest gains in quality of life and that further research demonstrating the benefits of community placement over institutionalization and of the relocation of individuals from traditional institutions to upgraded and improved institutions was needed.

Quantitative research on the relocation of matched pairs of individuals from large traditional institutions to new, smaller, 8 person units on hospital grounds used scales to measure adaptive and maladaptive behaviours, management practices, the degree of social deprivation in the large institutions, and an observation and coding system to assess quality of care in the small units. Data was gathered at 4 months, 9 months, 1 year and 2 year intervals after transfer (Hemming et al., 1981).

Results indicated positive gains in language development, responsibility and domestic activity (adaptive behaviours), but mixed or negative outcomes on maladaptive behaviour scales and increased use of anti-psychotic drugs in the smaller units. Several factors which may have impacted on the findings included; a decline in staff morale in the small units, a lack of employment opportunities for relocated individuals who had been employed in the institution, a decrease in access to recreational facilities, very limited opportunities for community integration in the new units, and the return of lower functioning individuals who exhibited maladaptive behaviour in the new units to the main institution because of problems dealing with the behaviour. In addition, management practices in the main institution evolved during the two-year period and reflected a

reduction in institutional oriented practices and an increase in therapeutic practices. (Hemming et al., 1981). The quantitative methodology did not provide direct feedback from the individuals on their subjective perception of how the relocation affected their quality of life.

Success of inter-institutional relocation depended on the characteristics, practices and resources of the new location (Cooper & Picton, 2000; Hemming et al., 1981). Hemming et al. suggested that individuals be prepared in advance for the transfer and Cooper and Picton (2000) stressed the importance of ensuring that opportunities for personal development were available in the new residence.

An additional question was whether the gains in quality of life for the intellectually disabled through relocation into community residences was worth the disruption to individuals and their families. If it was worth it, the next question was which characteristics of community residences would best meet the needs of individuals with different functioning levels (Cooper & Picton, 2000).

The Reality of De-institutionalization in the US

Relocation into community residences did not always improve the quality of life for the individuals. The rapid pace of de-institutionalization and the shortage of community homes in the United States led to the use of large for profit companies accessing public funds for housing for the intellectually disabled. The scandalous pattern of neglect, deaths, cover ups and huge profits made by some for profit companies highlighted the danger of using companies whose hierarchy of need placed profit as the main goal and consumer needs secondary (Keigher, 2000). The implications of these

scandals support the current thinking that best practice involves person centered planning, attaching funding to the intellectually disabled individual, accreditation for agencies based on outcome studies, and, above all, the need for integrity and vigilance in assessing community resources (Keigher, 2000).

The Fight Against De-institutionalization.

De-institutionalization was and is disruptive to the individuals being moved, their families and to the health and social services systems. A study of family reactions to a transfer of their intellectually disabled relatives from a large institution to smaller institutions revealed that 81% percent of families opposed the move of their relatives (Heller, Bond & Braddock, 1988). In 1983 some families in a town in Illinois joined together to oppose the decision to close the institution and move their relatives. The families pursued a lawsuit that delayed the closing of the institution and the transfer of their relatives for months. Family concerns included fears that their disabled relatives would have difficulty coping with the change because they would be separated from staff and other residents who were important to them and would miss the familiar routines. An additional concern was that the new placement would not be able to offer the same high level of medical care provided by the institution to relatives with serious medical health issues. The families had trouble accepting the closure and did not believe that their relatives would benefit from normalization and community living (Heller, et al., 1988). Most research indicates however, that the families usually reversed their attitudes and were satisfied with the results of the relocation in the months following the move (Heller et al., 1988; Kim et al., 2001).

Heller et al. (1988) noted that many of the families most opposed to the transfer out of the institution were those who had experienced extremely high stress during the earlier decision making process to institutionalize their relatives. An explanation was that the impending transfers reawakened the painful feelings of failure and guilt most families experienced when deciding to place the family member in an institution.

Facility support from the staff of both the closing institution and the receiving institution coupled with the informal support the families received from relatives and friends was significantly associated with reducing family stress. The results supported the hypothesis that the relatives' negative attitudes towards the closure of the institution and the relocation of the intellectually disabled relatives would change following the move. Strategies recommended to ease family stress included; family involvement in the transition process through visits to the receiving facility and giving reassurance to families that physical health does not usually deteriorate in relocation, that problems would be managed, and that the potential for gains in quality of life for the family member were good (Heller et al., 1988). These suggestions continue to be relevant to case management in times of transition in the present.

De-institutional Results in the US.

In 1967, 194,650 intellectually disabled individuals lived in large state institutions in the United States. This number decreased to 59,737 in 1996 and continues to fall as more institutions close (Braddock & Hemp, 1997). Individual states followed different paths in de-institutionalization. Michigan for example, did not choose to put its resources into institutional reform and began closing its institutions in 1981, putting the

savings from the closures into family homes and other options in community living. Massachusetts chose to retain large institutions and develop community options simultaneously. Institutional care continued to eat up a disproportionate percentage of government funding as daily rates reached almost \$500 by 1996. The current trend in Massachusetts is the rapid expansion of community living options including supported living and individualized supports and an accompanying decline in institutional and nursing home use (Braddock & Hemp, 1997).

Institutional Reform in Manitoba

The Current State.

Manitoba has followed a path of retaining and upgrading the largest institution (Manitoba Development Centre) while developing a range of community living alternatives. The number of intellectually disabled individuals living in Portage Development Centre peaked at 1303 in 1968, declined to 936 in 1975 (Manitoba Health and Family Services, 1975) and to 424 in 2002/2003 (Manitoba Family Services and Housing, 2002/2003). The slow, steady decline in resident population resulted from declining numbers of individuals being admitted or readmitted, natural deaths, and discharges to community living options. The individuals considered most capable were among the first to be moved to community settings. Children and adults were relocated from Manitoba Development Centre to Pelican Lake Training Centre during the 1970s to participate in community living skills training as preparation for discharge to community settings (Department Of Community Services and Corrections Annual Report 1980).

Increased therapeutic practices in Portage Development Centre include the development of a community candidate list to facilitate discharges, community inclusion programs using paid companions to access community activities and a quality of life study of 161 residents that revealed the residents were satisfied with their quality of life. The Development Centre is now used for short- term admissions for psychiatric and medical assessments for individuals living in the community (Manitoba Community Services and Housing Annual Report 2002/2003).

While the numbers continue to decline in the institution, supports for families wishing to keep an intellectually disabled relative in the family home increase, and adult day care places, rehabilitation and training facilities, and community living housing options for intellectually disabled individuals continue to expand. However after 36 years of discharging individuals into community options, Portage Development Centre continues to house over 400 intellectually disabled individuals. In 2005 the Government of Manitoba announced the allocation of \$40,000,000 for the redevelopment of the Manitoba Development Centre. This decision sparked protests from disability rights organizations, some parents, former Manitoba Development Centre residents, people with disabilities living in the community, community living agencies/associations and others. Those opposing the governments' decision argue that the money would be better used to support community living options. De-institutionalization is an ongoing and rather acrimonious process in Manitoba.

The History and Evolution of Institutions in Manitoba.

Humanitarian concerns about the problems experienced by mentally ill individuals living in the general population, coupled with the influence of Great Britain, France and the United States, led to the establishment of large psychiatric hospitals and the institutionalization of the mentally ill in Canada. From 1871 until 1886 mentally ill individuals in Manitoba were kept in jails, in a Hudson Bay Company Storehouse or suffered in the community. The Selkirk Lunatic Asylum opened in 1886 and mentally ill individuals from Saskatchewan, Alberta and Manitoba were completely removed from the community and hospitalized there until Saskatchewan and Alberta opened their own psychiatric hospitals. Although the intent of hospitalizing the mentally ill in separate institutions was to protect them and alleviate their suffering, the overcrowded facilities, lack of resources, and provision of custodial care in the institutions combined to provide a poor quality of life for the individuals living there (Sussman, 1998).

The discovery and use of psychotropic medication in the 1950s and 1960s dramatically changed the treatment of the mentally ill in North America. The mentally ill population was de-hospitalized as large psychiatric hospitals discharged patients into the community or into smaller general or community hospitals. In 1981, the Canadian Psychiatric Association recommended the establishment of a range of housing options, life skills training, personal supports and vocational training for the mentally ill population living in the community (Watt & el-Guebaly, 1981).

However, just as moving from an institution to a community residence does not assure the intellectually disabled individual a higher quality of life, neither does a move

from a large psychiatric hospital to the community automatically give the psychiatric consumer a higher quality of life. In 1988, the Government of Canada acknowledged that the closure of large psychiatric hospitals had not been balanced by equivalent growth in community resources resulting in inadequately funded community resources being unable to meet the needs of psychiatric consumers. Many mentally ill individuals were living dangerous lives of neglect, homelessness and deprivation in the community. Institutional services continued to receive a disproportionately high amount of mental health funding (Epp, 1988). Community living is not about closing institutions, nor is it, in itself, a treatment. Community care involves provision of safe housing, adequate supports and services to provide an acceptable quality of life (Sussman, 1998).

As previously stated the de-institutionalization movement was controversial and is still in progress but community living for the intellectually disabled is now the norm. The institutions are gradually being emptied and few people are being admitted.

Research on the Effects of De-institutionalization

Early research on the effects of de-institutionalization produced inconclusive and mixed results. As previously mentioned Cooper and Picton (2000) review of research studies concluded that it can not be assumed that moving intellectually disabled individuals into the community will always be beneficial to them. The new environment needs to offer increased choice and autonomy to effect an increase in quality of life.

A study reviewing United States research done between 1976 and 1988 on behavioral changes in the intellectually disabled population moved from institutions to community placements concluded that some positive changes occurred in adaptive

behavior (Kim, Larson & Lakin, 1989). A follow up review of the research studies in the United States between 1988 and 1999 by the same researchers was very positive about the behavioral changes witnessed in individuals who had been de-institutionalized (Kim, Larson & Lakin, 2001). Challenging behaviors either significantly improved or did not change and adaptive behaviors improved. Community based behaviour management and crisis support systems were demonstrably effective in managing crises and preventing costly and disruptive hospitalizations. The discussion section in the 2001 review noted that the increases in positive outcomes could be attributed to the improved behavior supports in the community placements coupled with the knowledge and skills gained from years of experience in managing behavior. The discussion also noted that these results could also be partially attributed to an increased quality of life resulting from improved services and supports. Improvements in quality of life of the individuals moved from institutions to the community were noted in increased adaptive behaviour, reduced challenging behaviour, improved material well-being, community integration and social presence and, of greatest significance, self reports of greater satisfaction, productivity, independence and in general, a higher quality of life. Research on cost effectiveness noted that in 1999 in the United States the average cost for an institutionalized individual was \$104,000 and average cost for an individual supported in the community was \$30,000 (Kim et al., 2001).

Criticism of early research in the United States on de-institutional outcomes included the strong focus on measuring any increase or decrease in problem behavior and inadequate focus on the receiving environment and it's ability to actually provide increased opportunities for growth and autonomy. An additional criticism was the

restricted number and range of outcomes, many of which focused on behavioral outcomes rather than quality of life outcomes (Cooper & Picton, 2000; Schalock, Keith, Hoffman & Karan, 1989). The goal of de-institutionalization was the improvement of quality of life for people with intellectual disabilities and the measurement of success should be the degree to which it achieved this goal (Emerson, 1985).

Much of the seeming disparity of study results done over time and in different places on quality of life outcomes of de-institutionalization may be a result of methodological differences in what was being measured, how it was being measured, and what findings were being emphasized. For example, the previously discussed Cooper and Picton (2000) research on relocation involved people moving from one institution to supported community residences and to other institutions with differing levels of support. Hemming et al.'s (1981) research involved transfers from a large institution to new small units on the institution grounds with limited opportunities for community integration for the lower functioning individuals and a problem with poor staff morale. Methodology was primarily quantitative in both of these studies and the subjective viewpoint of the individuals who were being relocated did not appear to be of primary importance. Proxies and staff informants were frequently used to assess changes in quality of life and strategies to overcome roadblocks in gaining information from the individuals were not used in one study (Cooper & Picton, 2000). The Hemming et al. (1981) research did not use a quality of life questionnaire or an interview with the individuals being relocated. Quality of life of individuals was assessed from management practices and measured changes in individual behaviour with no direct feedback from individuals about how the relocation affected their quality of life.

Research Studies on the Effects of De-institutionalization

The use of systematic training in independent living skills with 79 individuals relocated from state mental health facilities, state mental retardation facilities or family homes to community living (staffed or individually shared apartments in the community) was researched using objective, quantitative measurement and qualitative, subjective feedback and information from the individuals (Schalock & Carver, 1979; Schalock, Harper & Carver, 1981). The 79 individuals entered into an independent living training course where they were first assessed on an Independent Living Skills Screening test to measure the following skills: personal maintenance, clothing care, home maintenance, food preparation, time management, social behavior, community utilization, communication, and functional academics. An individualized plan was developed to deliver skill training to address deficits identified in the screening. The 12 months independent living skill training was designed to provide the individuals with the skills to successfully transition to an increasingly independent life style. Individuals were moved into either staffed or shared apartments when they were competent on 85% of the skills in the independent living component. The individuals finished this training and were given competitive employment training following placement.

The supported living environment provided increased autonomy and independence. Staff provided weekly contact for the first six months, then contact every three months and gave assistance when needed. 75% of clients from both the staffed and individual shared apartment groups received assistance with one or more of the following skills; shopping, managing a checkbook, professional appointments, leisure time,

medication use and employment applications. The outcomes for the relocation and training were very positive as 69 individuals were still in their independent housing two years later (Schalock & Harper, 1978).

A follow-up study was done three years later (Schalock, Harper & Carver, 1981).

Decisions had been made during the intervening 3 year period to:

- a) Terminate the individuals involvement in the program if he/she was employed in a competitive work environment and doing well in the independent housing (27 individuals).
- b) Continue the placement with the same supports.
- c) Move the individual to a shared apartment without staff if the individual was coping well in a staffed apartment.
- d) Return the individual to a more restrictive setting (group home, natural home or foster home).

Fifty five of the 69 individuals met the successful placement criteria of staying in either a staffed or shared apartment for five years. Unsuccessful placements (14) were attributed to bizarre behaviour, poor nutrition, legal difficulties and poor home maintenance. The discussion section addressed these findings, stating that these 14 individuals needed more support than had been provided and the ongoing program began to provide regular intensive assistance and training in the individuals' apartments.

The 27 group (a) individuals successful in community living and fully employed, reported feeling positively about having their own apartments, the freedom to "do their own thing", their participation in normalized activities in the community and use of community resources. Individuals did express a desire to have more friends. The quality

of life of these 27 individuals, considered objectively, appeared lonely and negatively affected by poverty issues. The research discussion emphasized the need for community agencies to teach quality of life skills and to provide ongoing training and support for individuals living independently in the community.

Supported living concepts assume that improvements in residents' quality of life will primarily be the result of improvements in their living environments and that increasing opportunities for normalization enhances quality of life (Vandergriff & Chubon, 1994). The supported living environments in the Schalock and Carver (1979) and Schalock et al. (1981) studies offered opportunities for personal development and autonomy and had a high degree of success in giving the individuals the skills and competence to live in the community. Increasing quality of life can be an outcome of positive changes in individual characteristics, environmental manipulation to remove or reduce blocks to normalization or increasing the person-environment fit. The Schalock and Carver (1979) and Schalock et al. (1981) research attempted to address all three components.

The information gained from studies on the effect of de-institutionalization on individual quality of life is useful in designing services for the individuals still being discharged from institutions to the community. It is also useful in planning for the intellectually disabled adults raised in family homes and living with aging parents who are no longer able to care for them.

Intellectually disabled children born in this generation will not likely experience custodial care in institutions. They will likely be involved as consumers in debates over which environments are able to offer the best quality of life, which supports they need

and which activities and choices they value in their lives (group home or supported apartment living, work placements or paid work force).

Quality of Life

The Debate of the Concept

The concept of quality of life has been the focus of much attention, debate and study over the past decades (Schalock, 1997). Prior to the decade of the 1960's, the poor quality of life experienced by institutionalized individuals was perceived by society to be primarily a function of their intellectual or mental disability and so could not be improved. The realization that quality of life is the result of the dynamic interaction between the individual and his/her environment, and that changes in one effected changes in the other, coupled with the recognition that the institutional environment provided a poor quality of life, supported de-institutionalization. The current trends of self-determination, normalization, autonomy, inclusion and community integration are embedded in this understanding of the concept of quality of life.

Schalock (2000) viewed the concept of quality of life as being embraced in the 1980s but not yet fully understood. For example there were a plenitude of differing definitions, discussion over which dimensions should be included, and questions over what should be measured and what measurement methods should be used. The concept of quality of life gained increased clarity in the 1990's.

The question of whether an individual with an intellectual disability would automatically have a diminished quality of life, and whether the degree of disability would dictate how diminished the quality of life would be, has influenced decision

making over the years. Persons with profound developmental delays were often among the last to be de-institutionalized (Cooper & Picton, 2000). Researchers hypothesized that developmentally delayed individuals with higher intelligence would experience higher quality of life following de-institutionalization than individuals with lower intelligence (Vandergriff & Chubon, 1994).

However it is common knowledge that individuals with similar disabilities and abilities have differences in both subjective and objective quality of life, as do individuals in the general population. There is no correlation between a person's wealth or educational level and their quality of life, nor is there between intellectual ability and quality of life. The early assumptions that diminished intelligence ensured a diminished quality of life perhaps reflected the researchers' own set of values. Many measurement instruments only measured objective criteria and did not measure meaning, goodness and spirituality (Coulter, 1997).

As Coulter (1997) stated, individuals may well be assessed on objective criteria as having a diminished quality of life but report that they feel their life is good. This complexity is recognized in the World Health Organization's definition of health as a multi-dimensional state of well-being including physical, mental and social dimensions. All individuals, regardless of their level of cognitive functioning, have a point of view about their personal well-being and the goodness of their quality of life and it is their point of view that is most important and should take precedence over other more objective criteria.

Reaching an Agreement

There is now general agreement that quality of life must be viewed as subjective and correlate with the individual's sense of well being and his or her point of view (Schalock, 1990; Vandegriff & Chubon, 1994). People experience the same circumstances differently and one person may place a high value on a circumstance that would not be seen as an asset by another person (Butterworth, Steere & Whitney-Thomas, 1997). Although the subjective quality of life of the individual may not agree with the predictions or observations of others, the individual's perspective takes precedence over all other points of view (Schalock, 2000). There is now general acceptance that quality of life of an individual with an intellectual disability reflects the same core values as quality of life for the general population and can and should be measured the same way across all populations. As well, the value an individual attaches to each dimension will change across his/her life span (Renwick, Brown & Raphael, 2002; Schalock, 1997).

"Well- being is broadly conceived to mean the level of life quality i.e. the extent to which pleasure and satisfaction characterize human existence and the extent to which people can avoid the various miseries which are potentially the lot of each of us" (Andrews, 1974, p.280). Recognition that satisfaction and pleasure are embedded in a good quality of life has long been acknowledged but are now recognized as being part of the outcome goals for programming to enhance quality of life (Renwick, Brown & Raphael, 2002).

Schalock (2000) envisioned quality of life as a social construct and a sensitizing notion that expressed the individual's perspective, included the individual's environment

and had, as its principle, the improvement of the individual's quality of life. Taylor and Bognan (1990) viewed the concept of quality of life as sensitizing us to listen, observe, learn and care about how the intellectually disabled have experienced their lives and how they feel about it. Schalock (2000) perceived that the quality of life concept could provide a framework enabling us to focus on improving the person-environment fit. Renwick et al. (2002) believed the measurement of quality of life should be embedded in the degree of enjoyment and satisfaction the person is deriving from his/her life and identified three domains of quality of life: being, belonging and becoming. 'Being' essentially defines who the person is and includes physical health and appearance, psychological health and adjustment and feelings and spirituality. 'Belonging' refers to the person's physical belonging in his or her home neighborhood and work place, social belonging with family and friends and community belonging including access to community services. 'Becoming' refers to the actions the person takes to achieve his goals in employment, leisure and attainment of skills and knowledge.

The Quality of Life Dimensions

These domains and sub domains are congruent with and generally included in Schalock's (1997) core dimensions. Schalock viewed the enhancement of quality of life as reflecting a person's desired conditions of living related to the dimensions/domains specified in Table 2.1.

TABLE 2.1: Schalock's Quality of Life Domains

DOMAIN	EXEMPLARY INDICATORS
1) Emotional Well-Being	increased safety, stable and predictable environments, general psychological well-being
2) Interpersonal Relationships	friendships and intimacy are fostered, families supported
3) Material Well-Being	ownership, possessions, employment
4) Personal Development	education and functional rehabilitation
5) Physical Well-Being	health care, mobility, wellness, nutrition, recreation
6) Self-Determination	choices, personal control, decisions, personal goals
7) Social Inclusion	community role, community integration, volunteerism, dignity
8) Rights	privacy, voting, due process, civic responsibility

Many of the individual components of the domains affect more than one domain.

The following examples will illustrate this point.

Recreation.

Recreational programs and facilities are one of the main settings for social integration for people with intellectual disabilities. Many support staff and families perceive social integration as the participation of intellectually disabled people in activities with people without disabilities. However individuals with intellectual disabilities did not agree with this perception. They enjoyed their friendships and activities with disabled peers and valued participating with them in structured activities in

the community (Mahon, 2000). They also valued recreational opportunities in community settings with both intellectually disabled peers and non-disabled peers.

Identified blocks to community integration in leisure activities in recreational settings with non-disabled peers included poor social and communication skills, health problems, disruptive behavior and high visibility of the disability. Teaching social and communication skills to individuals with intellectual disabilities was recommended to help promote social integration. Mahon (2000) recommended environmental changes including provision of training for the staff of community facilities in supporting disabled individuals in integrated programs and the removal of any physical barriers to participation. Social integration and inclusion is promoted when persons without disabilities participate in integrated activities with persons with disabilities because the non-disabled persons will gradually focus less on differences and more on shared interests in recreation (Mahon, 2000).

Recreation contributes to the domains of emotional well being, interpersonal relationships, personal development, physical well-being and community inclusion through the use of community facilities with disabled or non-disabled peers. Recreation also contributes to the domain of self-determination as decisions about which recreational activities to participate in and with whom affords an opportunity to exercise choice.

Social Support.

Social supports are an integral component in quality of life and affect the domains of emotional well-being, interpersonal relationships, friendships, physical well-being, self

determination and social inclusion. Social supports range from material assistance such as getting food and finding good housing to emotional supports such as social interactive contact, fun, recreation and advice. Instrumental social support includes activities that provide services such as those performed by waitresses and sales clerks (Walsh, 2000). The manner in which such instrumental social support is delivered is important to individuals using local community businesses as it can promote a sense of community inclusion and is reflected in statements by individuals that they consider individuals who regularly deliver these services as friends and acquaintances. Social supports are recognized as contributing to physical and mental health and overall satisfaction with community living (Coulter, 1997). Social supports affect emotional well being by alleviating stress through the provision of physical and material assistance, affirmation and guidance (Parkinson et al., 1999; Walsh, 2000).

Social supports have been assessed as a factor in reducing stress in times of transition and as being protective against harmful stresses (Gerhart, 1990; Karan, Lambour & Greenspan, 1990; Parkinson et al., 1999; Walsh, 2000). The main effect model, (Walsh, 2000) posits that the very existence of social supports provides a sense of security and a feeling of well being and self worth that enables one to handle adversity without experiencing great upset. The stress-buffering model (Walsh, 2000) holds that the awareness and availability of social support contribute to a reduction of stress and perception of harm and contribute to problem solving. Thus, although the individual feels stress, social support helps by reducing the heightened anxiety that can overwhelm clear thinking and decision making. "Social support acts as an auxiliary ego to reduce levels of emotional upset. Supportive others serve to compensate for our perceptual

deficits, reminding us of our identity and monitoring our overall social functioning"

(Walsh, 2000, p.57). The expansion and strengthening of social support systems is an important component of case management. Case management skills include the ability to both be an advocate for individuals and to teach self- advocacy skills to the individuals. The role of case manager involves assisting individuals to achieve the outcomes they want in the domains of quality of life. Continued focus on achieving outcomes chosen by the individual ensures that the supports offered are consistent with improvement in quality of life.

Social Support and Transition. The first task of the case manager may be to assist with the transition of the individual from a traditional residence to a supported living apartment. Transition theory is helpful in understanding, preparing for and managing behavior during times of transition (Karan, Lambour & Greenspan, 1990). The transition from a restricted environment to a community residence requires a major adjustment for the individual. Behavioral changes, including higher levels of challenging behavior, are a normal part of the process. The behavior is an outcome of the individual's confusion and anxiety about the new setting and accompanying sense of loss of the familiar setting and routine. This "relocation syndrome" has been recognized as contributing to the number of individuals returned to institutions (Hemming et al., 1981). Transition theory advocates tending to the individual's emotional needs for security and adapting the environment to meet these needs. Transition planning recognizes the importance of preparing the individual for the move and for the involvement of the persons personal support network in the move. Personal support reduces the person's vulnerability to stress. The key to

successful transitions is for the individuals to gain a sense of personal competence and control over choices and decisions. The systems role is to provide the supports for the individual to gain the needed skills and competence (Karan et al., 1990). Transition theory is helpful in fostering successful adjustment to community living and is supportive of tailoring the supports to the individual's needs, a tenet shared by supported living.

The provision of opportunities to develop networks of social support and any needed social skills training to ensure the individuals have the skills needed to find and maintain a social support network can be a goal of case managers. Persons with disabilities may need additional help in developing social supports, because of lack of social skills, lack of opportunity to interact, difficulty with mobility, and community reaction to their participation. Expansion of their social support could have a positive effect on their coping because they would have more sources of support. The challenge for casemanagers is that many individuals or families may be reluctant and resistant because their view of the community may have been shaped by negative experiences (Walsh, 2000). Frustration at being unable to gain access to education and training and by encounters with inadequately trained staff at recreation centers feeds this resistance (Mahon, 2000; Walsh, 2000). Case managers' understanding of clients' resistance enables them to continually advocate for clients and to support them in reaching out for new services (Walsh, 2000).

Social Support and Community Living. Consumers' participation in community activities strengthens the social bond and promotes the common good (Walsh, 2000). Community living involves reciprocal obligations. Consumers can increase integration by giving to as

well as taking from the community. Performing activities that help the community and others has two positive effects. Participation boosts consumers' self-esteem by making one feel he/she is participating in and contributing to the community and this contribution has a positive effect on the community perception of individuals with disabilities. Examples include helping out after a disaster, volunteering at agencies in the community and participating in community cleanups. Increasing consumers' abilities to give as well as take also increases the durability and strength of relationships (Walsh, 2000).

Knowledge of the individual's need for different types of support, including emotional supports, can be gained through an initial assessment of the individual's current social supports and the deficits in this network. The individual's home and workplace environments can be adapted to make them more responsive to needs and less stressful (Gerhart, 2000; Walsh, 2000). Case managers can network on behalf of clients, provide resources, expand clients' social and recreational networks, assist with the reconnection with families if the family is supportive, access self-help training and educational opportunities and provide opportunities to form new friendships. Case managers may also intervene with families and networks to build up these supports. Expansion of social networks and social supports is a highly useful role for staff in supported living programs (Walsh, 2000). Good social supports have a positive effect on many domains of quality of life.

Housing.

Housing is another component that influences quality of life in several domains. Current family and community concerns about intellectually and/or dually diagnosed

populations include personal safety in unsafe community environments, increased substance abuse, increased criminal behavior and increased numbers of the intellectually disabled/dually diagnosed populations in the prison and homeless populations (Keigher, 2000; Perske, 1994).

Imprisonment is another form of institutionalization. The American Association of Community Psychiatrists (2003) in their position paper on persons with mental illness behind bars discussed the high incidence of incarceration of persons with serious mental illnesses. In 1991 a literature review by the Correctional Services of Canada discussed the difficulties faced by intellectually disabled individuals in adjusting to community living after discharge from large institutions which, although removed from the community, at least offered safe housing and the basic necessities of life. Although intellectual disability does not cause anti-social behaviour, the intellectually disabled individual may engage in anti-social behaviour because he/she feels rejected by and alienated from society, lacks basic necessities and steals to acquire them or perhaps, is manipulated or victimized by others into committing criminal acts (Endicott, 1991).

Intellectually disabled, mentally ill and dually diagnosed individuals experience an extremely poor quality of life in the general prison population (Endicott, 1991). Prisons and jails are examples of highly restricted environments offering few opportunities for self-determination and choice. Overcrowded conditions, lack of rehabilitation and recreational programming and the individual's perception of increased vulnerability due to the presence of violent criminals exacerbates mental illness and contributes to his/her further de-compensation in prisons and jails. The isolation and

sensory deprivation experienced in high security units also increases the probability of decompensation and suicide. (American Association of Community Psychiatrists, 2003)

Access to the services available in a supported living environment (medication support, substance abuse counseling, recreational opportunities, assistance with legal issues and with the functions of daily living) are recommended upon release to reduce the likelihood of psychiatric hospitalization or re-incarceration (American Association of Community Psychiatrists, 2003)

Unsafe community environments and homelessness contribute to decompensation in the mentally ill (Parkinson et. al., 1999). Increased depression was noted in individuals who were forced to live in locations and homes that they did not choose or want.

Parkinson et al. noted that lack of privacy is a concern to consumers living in boarding home environments. Large boarding home living involving sharing bathrooms, kitchens and living rooms with several other individuals negatively impacts on a person's sense of privacy and personal and material safety. Personal empowerment is a critical component in quality of life but large residences with high levels of supports foster dependency. The staff performs the tasks of daily living (cooking, cleaning, shopping) and individuals do not develop competence in these supported living skills. Residents have few choices and live with many rules governing personal conduct. Internal integration into the residence is the focus and individuals are not supported in external integration into the hospitalization or reincarnation community (Parkinson et al., 1999).

Benefits of Housing. Integrated community housing offering stability and choice was positively correlated with reduced social stigma and decreased social isolation and

contributed to success in community living (Parkinson et al., 1999). Satisfaction with housing contributed to increased satisfaction with quality of life (Schalock, 1997). People with intellectual and physical disabilities and mental health concerns need to have necessary resources near by. Their neighborhood needs to be close to the needed shopping, recreation, services and, above all, needs to be safe. Poverty issues and a lack of decent low cost housing negatively impacts on the availability of affordable and adequate housing. Supported living agencies can use resources to assist individual consumers to find housing, can team with other community agencies to renovate and use existing housing and can use qualitative, quantitative and social action research to advocate for policy changes at systems levels. Parkinson et al. (1999) recommended that agencies advocate for rental supplements for individuals with mental illness to enable them to find good, integrated housing. The researchers suggested that the provision of sufficient additional supports during short term mental health crises to enable individuals to remain in their own homes rather than be re-hospitalized would be cost effective and less disruptive.

Unsafe and/or very restricted environments have a negative impact on quality of life in the domains of emotional well-being, physical well-being, personal development, social inclusion and self determination, rights to privacy and security and material well-being. Safe, stable housing that is integrated into the community increases quality of life in the same domains. Supported apartment living offers consumers the choice of having a roommate or living alone. The opportunity to exercise choice and autonomy is empowering. The shift in social status and self concept from being a resident in a boarding home to becoming a community member living in an apartment integrated in the

community and chosen by oneself significantly enhances quality of life. The range of choices available in supported living include grocery shopping, decorating the apartment, staying up to watch a late movie instead of having a set bedtime, being able to have visitors and having privacy and security increases autonomy and self determination. Supported apartment living has lower levels of staff support but provides training in community living skills and promotes self-help and use of natural support (Parkinson et al., 1999). The increase in personal competence in the ability to perform daily tasks is empowering.

Personal development, education and functional rehabilitation are important to quality of life and to success in community living. Schalock and Jensen (1986) discussed person- environment fit and recommended assessing individual skills and the environment to determine appropriate interventions. The acquisition of community living skills and /or rehabilitation or vocational training increases the individual's competence and contributes to success in work or volunteer placements and in supported living. The skills needed in the desired setting can be determined and taught. Environments can be adapted to increase the fit with the individual's capabilities. Increasing the congruence between the requirements of the environment and the individual's desires and capabilities provide an increased quality of life and can be part of agency policy (Schalock & Jensen 1986). Supported living programs with a focus on individualized services can play a significant role in increasing individual competence. Case managers in supported living agencies can also assist with finding affordable and safe housing and paid and volunteer employment.

The Benefits of Quality of Life Research

Recognition that quality of life is the result of an ongoing interaction between the individual and his/her environment and that improving the environment can improve the person's quality of life has pushed society into reinventing itself to be increasingly open and inclusive. De-institutionalization was a social movement resulting from what had been regarded as a personal problem being re-framed as a social problem requiring a political solution (Whitney-Thomas, 1997). This shift in societal attitudes has not only been beneficial to the intellectually disabled population but to the physically disabled, mentally ill, dually diagnosed and multiply disabled populations as well. Although each individual step has been debated, the reality now is that most public education is integrated, recreational programs are accessible, most public buildings are wheelchair accessible and community supports are available to individuals and families.

The concept of quality of life as a dynamic interaction between the individual and his/her environment can be incorporated into the policies and planning of governments, agencies and community services. Careful attention to the core values and /or domains that make up a life of quality and recognition of the primary importance of individual choices and preferences will ensure that future trends operate to improve quality of life (Schalock, 1997).

Measurement of Quality of Life

Ethical considerations about the measurement and assessment of the quality of life of persons with intellectual disabilities have been raised as a concern. We do not measure and assess the quality of life of the general population nor do we measure individuals'

intelligence and use the results to classify them in specific categories. Great care must be exercised to ensure that quality of life assessment is used only for beneficent purposes, to enhance individuals' quality of life based on knowledge gained of their needs, values and choices. This beneficent outcome can be effected in several ways. Knowledge gained from research in general about what services and environmental changes contribute to enhancing quality of life can lead to distribution of resources that promote these gains. Knowledge gained about the choices and preferences of the individual can contribute to the building of resources and supports that facilitate his or her wishes (Coulter, 1997).

Schalock, Keith, Hoffman and Karan (1989) described three approaches to quality of life assessment:

- 1) Social Indicators Research focuses primarily on objectively measured criteria (health, housing, friendships etc.) and is not as useful for assessing the individual's perspective of his/her quality of life.
- 2) Psychological Indicators Research focuses on the individual's levels of satisfaction with different aspects of their lives.
- 3) Goodness of Fit Social Policy Research advocates that quality of life studies identify unmet needs in populations and use the results to influence social policy to gain increased resources to meet the identified needs.

The Importance of Quality of Life Research

The following studies will demonstrate the importance of quality of life research with individuals with disabilities.

The previously discussed Schalock et al. (1981) research included qualitative and quantitative research and provided extensive training for intellectually disabled individuals moved from institutions and family homes into independent supported living apartments. The positive outcomes of the research were attributed to the assessment of individual needs, provision of skill training needed to succeed in community living and continued agency supports. The positive outcomes of the individuals in the study support the view that quality of life is the result of an ongoing interaction between the individual and his or her environment. The improved supported living skills of the individuals and the more open environment of the supported living arrangement both contributed to a successful outcome.

Kim et al. (2001) reported that individuals with severe intellectual disabilities and challenging behaviors have followed the same pattern in adapting to community living and have gained the same types of benefits as the less disabled. Challenging behaviors are at least partially a function of environmental influences on the individual. The utility of this research is that it supports community living for individuals with severe intellectual disabilities and/or challenging behaviours and encourages environmental adaptations to remove or reduce barriers to inclusion. Positive changes in environments can contribute to positive changes in behavior and increased quality of life regardless of degree of intellectual disability.

Qualitative and quantitative research compared quality of life for individuals living with serious mental illness (schizophrenia) who had been discharged from institutions and were living in either community boarding homes or hostels in Australia. Research results indicated that both the boarding home and the hostel groups strongly

preferred life in the community to life in the institution (Horan, Muller, Winocur & Barling, 2001). The hostel system had been established in the 1960s' and 1970's to meet the need for low cost housing to accommodate mentally ill individuals being released from institutions. The hostels were large complexes and had shared kitchens and living areas with paid staff providing the meals, medication and spending money. The boarding homes resembled large houses, were more integrated into the community and offered residents more privacy and opportunities to participate in the household tasks. The boarding homes provided a more normalized environment than the hostels. The researchers used a quality of life interview to measure objective, subjective and global quality of life. Boarding home residents rated their quality of life higher than the hostel residents on subjective, objective and global quality of life. On the subjective indicators boarding home residents reported higher life satisfaction, less victimization and more spending money. Objective indicators for both groups suggested an impoverished quality of life especially in use of leisure time and lack of recreation but the individuals reported general satisfaction with their residences and satisfaction with the quality of their lives. The research is interesting and valuable in that it clearly illustrates that the subjective perspective of individual quality of life may differ greatly from the objective perspective and that the subjective perspective needs to be heard. The researchers noted however, that the residents' subjective expression of satisfaction with their quality of life in boarding homes and hostels should not be used to delay improvements in services to promote an increased quality of life. The research indicates that increasing normalization is reflected in higher perceived subjective quality of life. The residents preferred life in

the community to life in the institution and preferred life in boarding homes to life in hostels (Horan et al., 2001).

A comparison of the non-capital costs of group homes and semi-independent living in homes in the community and the objective and subjective quality of life outcomes as experienced by the matched residents living in each was researched in Australia (Stancliffe & Keane, 2000). Semi-independent living, as described in the article, is very similar to supported living and was defined as a household of one to four people with part-time staff support. Residents were without staff support for a minimum of 28 waking hours a week and did not have overnight staff. Group homes were defined as households of three to seven people with full time staff support during waking hours. Group homes usually had overnight staff.

The research method used multiple qualitative and quantitative assessment methods. A quality of life questionnaire and a questionnaire developed to assess loneliness were given to the residents in their homes to ascertain their subjective opinions of their situations. Residents were also interviewed about their feelings of safety and degree of victimization using a questionnaire developed for this research. The research method used with the residents was qualitative.

Staff questionnaires used quantitative methodology and included an inventory to measure adaptive behavior, (motor skills, social and communication skills, personal living skills, community living skills) and maladaptive behavior (frequency and severity of hurtful to self, hurtful to others, destructive of property, disruptive, socially offensive, withdrawn or inattentive, uncooperative behavior and unusual or repetitive habits). A community living questionnaire was completed by staff and included personal care,

domestic management, health care, money management, social network, use of mainstream community services, community participation, participation in domestic tasks, stability of place of residence, living companion turnover and natural support. Natural support was defined as regularly receiving help, advice and/or guidance from a person who was not paid. Information about the number and cost of all staff hours was obtained from supervisors and staff. Capital costs were not included.

The individuals in semi-supported living showed less social dissatisfaction, increased use of community facilities, increased participation in caring for the living environment and greater empowerment. The study did not find any significantly improved outcomes for the group home individuals. The reduced staffing levels for the individuals in supported living had not resulted in poorer outcomes and the cost of semi-supported living was significantly less than the cost of group homes. The discussion of the results theorized that in the absence of staff, individuals have to make choices and decisions for themselves and have to perform household tasks rather than rely on staff for assistance. Staff may be more involved in teaching and promoting individuals' competence and independence skills if they are aware that staff will not be there for some periods of time and the individuals will need to use these skills. The provision of high levels of staff may actually interfere with the development of independent living skills.

This research is valuable because it has a wide range and number of outcomes, uses multiple instruments in qualitative and quantitative methodology with carefully matched residents, assesses objective and subjective criteria and validates the importance of continually assessing the support needs of each individual to promote autonomy and independence. The discussion also suggests that individuals can be moved from group

homes to independent living as they develop community living skills. The provision of services contributing to improved outcomes resulting in higher quality of life are more likely to be funded if the costs are not higher than the costs of existing alternative services (Stancliff & Keane, 2000). This research demonstrated that the significantly lower costs of semi-independent living staff supports did not negatively impact quality of life for residents and the increased opportunities for choice and growth of skills in the more normalized semi-independent living arrangements increased quality of life on some outcomes. Public awareness of win-win outcomes of reduced costs and increased quality of life could help increase community support and funding for supported living.

Analysis of the Research Studies.

Early measurement of quality of life focused on objective indicators including use of community facilities, health, material well being, etc. but failed to include subjective information on the individual's own opinion about his/her feelings of happiness, satisfaction with his/her life. Current thinking is that the individual's perspective is the most important measure of an individual's quality of life (Szymanski, 2000).

Schalock (1997) reviewed research using multivariate designs and measurement to identify 20 predictors and variables on measured quality of life of individuals with either intellectual disabilities or chronic mental illness. Predictors included personal characteristics (age, gender, diagnosis) which can not be changed, but noted that programs can have positive effects on most of the other variables including the objective life conditions of employment status, daily living activities, housing, social support and social relations. Care provider variables such as staff quality of life, work satisfaction and

work stress impact on the individual's quality of life and can be improved by management practices which include team building and problem solving, consensus building, and a steadfast and clear commitment to quality improvement (Schalock). Quality of life outcomes are unique to each individual and do not fit well into structured programs. Supported living agencies with individual programming and flexible supports offer the best environments to incorporate these variables into goals and outcomes but doing so often requires system change (Karan & Bothwell, 1997).

Studies on supported living have consistently rated the quality of life of individuals in supported living as higher than other types of residences. In a study comparing quality of life of six different types of housing ranging from large campus institutions to supported living the individuals in supported living were assessed as having the highest quality of life (Vandergriff & Chubon, 1994). A review of studies which examined quality of life outcomes for psychiatric consumers comparing custodial living, supportive living and supported living for psychiatric consumers found that supported living increased independent living skills, decreased homelessness and reduced hospitalization rates (Parkinson et al., 1999). Schalock et al.'s (1981) previously mentioned study reviewed the supported living placements of 69 intellectually disabled individuals placed in independent community housing three years previously. The study results concluded that 55 individuals had been successful in the placements as assessed on four quality of life variables including friendship patterns; community access-patterns, leisure time, employment, and finances. The literature review on housing alternatives for psychiatric consumers written by Parkinson, Nelson and Horgan (1999) concluded that supported living increased resident stability and independent living skills, reduced

homelessness and reduced hospitalization rates. Concerns about isolation and the need for increased social relationships for people in supported living were raised in all of these studies. The availability of social support is crucial to success in supported living.

Quality of Life and Supported Living

Supported living, ideally, increases normalization and creates opportunities and choice for individuals with disabilities. There is recognition that quality of life improves as normalization increases and that increased choice also contributes to increased responsibility and a need for good problem solving skills. According to Karan and Bothwell (1997) there are fifteen principles of supported living. These include respecting the individuals' decisions about where to live in the community and with whom, which supports are required to provide the best quality of life for the individual in the home and in the community and who will provide these supports. These supports must be flexible and able to adapt to the changing needs of the individual.

The shift in society from an industrial to a service economy combined with the influence of quality of life research is reflected in the changing role of service providers. The service provider is to determine the consumer's desired outcome and to provide services enabling the individual to reach that outcome. This is a major shift from the expectation that the agency would provide set programs and the individual would fit into them. Wrapping services around individual needs requires organizational change including increased flexibility in scheduling for staff as the individuals may want/need services outside of normal working hours. Goals for consumers would be determined by

gaining knowledge of individual preferences rather than program availability and agency resources (Butterworth et al., 1997; Gardner, Nudler & Chapman, 1997).

Research and stated consumer preference provide encouragement and credibility to the establishment of supported living programs. However, there continues to be opposition to supported living (Karan & Bothwell, 1997). Boards and staff of agencies resist implementing supported living programming because of fear of decentralization, worry that expenses will increase, that there will be job loss, apprehension over the loss of familiar structures and programs, and reluctance to relinquish the role of decision maker for the role of facilitator. Family concerns about their family members living in conventional residences being relocated to supported living included fear of giving up a safe and permanent environment and losing services. Both family members and agency staff expressed doubt that the individuals were capable of making good decisions in a supported living environment (Karan & Bothwell, 1997). Staff and family fears seem to echo the fears expressed about deinstitutionalization in the past and perhaps could be eased by giving education, reassurance and support to staff and families.

Dual Diagnosis

Defining Dual Diagnosis

Dual diagnosis is defined as the presence of both a developmental disability and a psychiatric diagnosis or general mental health concern (Benner & Walker, 2001). A number of factors contribute to the difficulty of accurately diagnosing psychiatric illness and mental health concerns in individuals with intellectual disabilities. One of the factors is the diagnostic overshadowing effect. This is the tendency to attribute the individuals'

problems to their intellectual disability while failing to recognize the symptoms of a coexisting psychiatric or emotional disturbance (Benner & Walker, 2001). The intellectual disability is the more disabling and would be considered the primary diagnosis making it easier to overlook the psychiatric disturbance. A second factor is the separation of services, funding and staff training for mental health and intellectually disabilities. Separation into two systems enables each system to expect the other system to provide services to individuals with dual diagnoses and contributes to each system feeling less adequately prepared to provide service (Fletcher, 2003). One unfortunate effect has been that the intellectually disabled population with accompanying psychiatric illness has not gained all the benefits of the mental health advances over the past two decades (Fletcher, 2003).

Another factor contributing to the difficulty of accurate diagnosis of mental illness in the intellectually disabled is that symptoms may be confusing to the diagnostician. For example, is the individual's "imaginary" friend a hallucination or a child-like coping strategy? (Benner & Walker, 2001). Mental illness expressed in an individual with dual diagnosis may appear very different than in an individual without intellectual disability. Difficult behavior may be a symptom of phobia rather than disordered behavior. Speech and language impairments make it difficult to express emotions, needs and wants and contributes to use of difficult behavior (Benner & Walker, 2001; Deb, Thomas & Bright, 2001; Fletcher, 2003; Sturmey, 2002).

De-institutionalization and Dual Diagnosis

Until about twenty years ago one theory about the incidence of mental illness in individuals with intellectual disabilities was that they were at lower risk for developing psychiatric illness because they were protected from some intellectual and psychological stresses (Deb et al., 2001). The de-institutionalization movement increased the visibility of individuals with dual diagnoses as they were living in community setting rather than isolated in institutions. Increased visibility contributed to greater attention and recognition of dual diagnosis (Fletcher, 2003). Current thinking is that intellectually disabled individuals are at increased risk of developing psychiatric illnesses because of negative social conditions such as rejection, exclusion, stigmatization, and inadequate social support and environmental conditions such as poor and unsafe housing and poverty. Poor coping skills, speech and language deficits and a higher incidence of central nervous system impairment increases the vulnerability (Deb et al., 2001; Sturmey, 2002).

Prevalence rates for dual diagnosis range widely from a low of 10% to highs of 40% or greater. The difference in rates is a result of differing criteria for inclusion. For example Deb et al. (2001) excluded autism, dementia, behavior disorder and alcoholism and derived a prevalence rate of 14.45. In a separate study on prevalence of behavior disorders in the intellectually disabled population the same researchers found that 60.4% had at least one behavior disorder. Behavior disorders included aggression, self-injurious behavior, temper tantrums, over-activity, screaming, attention seeking behavior,

objectionable habits, night-time disturbance and destructiveness (Deb et al., 2001). The implication of dual diagnosis to health and social service systems is clear.

Although the full range of pathology that exists in the general population exists in the intellectually disabled population its presence may be expressed differently (Sturmey, 2002). Rates of prevalence of mental health diagnoses in the intellectually disabled vary but there is general agreement that the incidence of psychosis, schizophrenia and behavior disorders are higher than in the general population (Deb et al., 2001).

Effects of Dual Diagnosis

Individuals with intellectual disabilities who have good mental health are able to enjoy a good quality of life with satisfactory interpersonal relationships and a sense of emotional well-being (Fletcher, 2003). However, the presence of psychiatric illness with the intellectual disability as in dual diagnosis can be extremely disruptive in all domains of quality of life (Fletcher, 2003). Mental illness interferes with adjustment to living arrangements, family and support group relationships, satisfaction with employment and recreation and with the individual's general sense of well-being. Quality of life is reduced (Fletcher, 2003).

Approaches To Dual Diagnosis

Partnerships between mental health systems and agencies providing services for the intellectually disabled to achieve accurate psychiatric diagnoses and treatment plans for the dually diagnosed are now being developed. One example of this partnership is the Dual Diagnosis Consultation Outreach Team Program in parts of Ontario. The program's

clinical team collaborates with community based teams to provide psychiatric assessment and treatment, monitors therapeutic services, provides therapy and training to consumers when needed, provides supervision, consultation and education to the consumer's support network, and links consumers to community services (Dual Diagnosis Consultation Outreach Team, 2003).

Benner and Walker (2001) state that treatment approaches in addition to pharmacology include use of the Positive Systems Approach which is a combination of training caregivers in techniques which reduce problem behavior, use of positive reinforcements, and environmental changes. Other effective strategies include individual counseling to teach needed skills as in anger management, relaxation techniques and problem solving skills in addition to other identified needs. Cognitive behavioral therapy using restructuring techniques and positive reinforcement is considered to be effective as is group therapy which provides group support for skill development in relationships, problem solving, anger-management and coping skills. Environmental configuration involves adapting the environment to the needs of the individual for safety, comfort and to allow as much autonomy as possible. All staff delivering services to the individuals should be trained in and using the same skill set to increase the generalization of learned skills in different settings and situations and to provide added reinforcement and practice of skills (Benner & Walker, 2001). Insight- oriented therapies tend to have limited effectiveness with the dually diagnosed population (Benner & Walker, 2001).

Individuals with dual diagnosis of mental illness and intellectual disability typically may have very limited social supports and the severity of the mental illness strongly correlates to the smaller size of the support group. This may result from a

combination of lack of social skill, the desire to withdraw which may be a symptom of the illness and sensitivity to the negative reactions from others to them in the community (Gerhart, 1990).

In addition to providing assistance with arranging and accessing medical appointments and medication, supported living can provide supports to help increase and strengthen interpersonal relations and emotional well being. Supported living policy incorporates the quality of life domains of self-determination, social inclusion, rights, personal development and material well being. Current best practice principles for provision of services to individuals with intellectual disabilities and mental health concerns are grounded in the concept of quality of life as an ongoing interaction between the individual and his /her environment. Ideally, careful attention is given to improving the person environment fit as the optimal way to improving quality of life (Schalock & Jensen, 1986; Schalock et al., 1981). Supported living has the flexibility needed to access supports from both the mental health system and the systems involved with the intellectually disabled population. Supported living provides supports in the community and advocates for normalized environments. Community inclusion is the goal (Renzaglia, Karvonen, Drasgow & Stoxen, 2003).

Main Literature Themes

The main themes emerging from the literature review of the influence of the concept of quality of life on the path from institutionalization to community living for the intellectually disabled, mentally ill and dual diagnosis populations are:

- 1) Quality of life is now separated from intellectual disability and can and should be measured in the same way across all populations using the same methodology. Quality of life for individuals with intellectual disabilities, mental illness or dual diagnosis reflects the same core values as quality of life for individuals without disabilities. Early research assumed that quality of life was dependent on degree of disability and that the greater the disability the poorer the quality of life
- 2) Quality of life is subjective, embedded in satisfaction and pleasure and changes over time.
- 3) Quality of life is a dynamic interaction between an individual and his/her environment with changes in one effecting change in the other and, further, that improving the person-environment fit enhances quality of life. This concept supported the closing of large institutions because they provided a disabling environment and poor quality of life.
- 4) Quality of life generally improves as normalization increases. Research consistently revealed that if safe and decent housing and needed services are provided, individuals preferred life in small institutions over life in large institutions, life in group homes over life in small institutions, and life in supported living environments over life in group homes. Supported living provides maximum normalization and was consistently chosen as the preferred living environment in research studies.
- 5) Quality of life is subjective and quality of life research should give precedence to the individuals' point of view and values, and maximize individual participation. Research methodology has moved from reliance on feedback from proxies to increased feedback from individuals. The importance of gaining knowledge of and validating the

importance of the individual's perspective and values has fostered the use of innovative methods.

Participatory Action Research methodology amalgamates these themes by maximizing the involvement of the intellectually disabled individuals in the research process. P.A.R. is considered to be especially useful in research on quality of life for individuals with intellectual disabilities (Whitney-Thomas, 1997).

CHAPTER 3: RESEARCH DESIGN

Description of Setting

New Directions for Children, Youth, Adults and Families

Founded in 1885, New Directions for Children, Youth, Adults and Families (New Directions) is a nonprofit agency that offers a variety of services with the sole purpose of improving the well-being of their clients - children, youth, adults, families and their communities. New Directions operates on the basic philosophy that the rights of every individual shall be fully respected at all times. This philosophy is ingrained within the staff and is prominently stated in the organization's publications available for public viewing. For instance, New Directions Annual Report states that "New Directions believes in the intrinsic worth and dignity of every human being" (Annual Report, 2002, p.7). The basis of this philosophy is that New Directions believes all their clients, including those that participated in this study, are unique individuals with various strengths and resources. These strengths and resources should be acknowledged and encouraged within each individual. The result of doing so is that each person is able to live in an independent and dignified lifestyle where their right to make personal choices is respected.

New Directions has embraced an ecological approach to deliver their services that embraces, in addition to an individual's strengths, weaknesses and resources, all systems at a personal and societal level. An understanding of individuals as a whole, including abilities and difficulties, enables the agency to be more helpful in supporting individuals in reaching their goals and having a satisfying quality of life. To accomplish this end-result or

individuals, New Directions offers a wide range of programs for children, youth, adults and families, including a group of programs for persons with developmental delay.

Supported Apartment Living Program

The Supported Apartment Living Program (S.A.L.) is one of several programs New Directions has established. The mandate of the S.A.L. program is to support individuals with developmental delay. This program was initially formed in response to the unique needs of participants who wished to live independently in the community. New Directions has stringent requirement(s) that must be met by an individual in order to participate in any of their programs. For the S.A.L. program, only one requirement must be met by a willing participant; an individual must have an intellectual or physical disability, a mental health concern, or both. When an applicant successfully gains entry into the S.A.L program, they have access to a variety of services that provide support in the areas of medication management, housing, food bank and light meal program as well as individualized community based support. Specifically, staff members provide individualized community support services to assist individuals in areas of community living. This includes daily living skills (i.e. budgeting and medication management), assistance with medical or legal appointments, recreational and social activities, and advocate on clients' behalf in the community.

Services Provided by the S.A.L. Program

S.A.L. Lounge. New Directions has designated a lounge specifically for S.A.L. participants. The Centre, upon inspection, presents as welcoming and spacious. Staff

members and participants ensure the lounge is kept clean and the furniture and equipment maintained in good working condition. A number of activities are available to S.A.L. participants in the Center's lounge, including: ping-pong, board games, videos, television with accompanying VCR. The lounge is staffed Monday to Friday from 9a.m. - 4 p.m. During these times, staff is also available to assist participants with the development of social, life and problem solving skills. The Resource Center also has a fully equipped kitchen, a food bank staging and storage area and an art activity room. In addition, art classes and an Aboriginal group meeting are held weekly in the lounge.

Medication Support. New Directions staff members offer medication management support assistance for S.A.L. participants. In respecting individual rights of S.A.L. participants, this assistance must be requested by the participants themselves and staff will not enforce medication compliance. The support the staff provides consists of: giving bubble packed medication, recording medication compliance, and encouraging participants to learn about the benefits and possible side effects of their medication by asking questions of their doctors and pharmacists.

Individualized Community Based Support Hours. New Directions realizes that participants need to access assistance outside the Centre while they live an independent and dignified lifestyle. Participants are provided with a support staff member who will work one-on-one with the participant. The staff member assists the participant in all aspects of community living including: skill development, daily living, recreational and

social activities, medical appointments and medication management, probation and court appointments, budgeting and money management.

Housing Supports. A strong focus of the S.A.L program is on housing. Housing is an important key to allowing participants to live in an independent and dignified manner while respecting their individual rights to live as they wish. To ensure adequate housing exists for participants, New Directions has taken several initiatives. The most prominent initiative taken so far has been a housing partnership with Westminister Housing Society. Currently, New Directions are negotiating on expanding their rent supplementation arrangement with Employment and Income Assistance (E.I.A.) social services.

Food Bank. Once shelter is provided, the second key to independent living is food. To ensure participants have the ability to feed themselves, S.A.L. has partnered with Winnipeg Harvest to become a Winnipeg Harvest food bank site. Initially, the S.A.L. program encouraged participants to access community based food banks. However, due to the number of difficulties encountered that made it ineffective, this was discontinued and replaced with a more successful program. Currently, food hampers are filled at the New Directions office and delivered to the participants' residences. Food hampers contain pictures of meals that can be prepared using foods in the hamper. This program is further enhanced by providing participants the opportunity to attend a weekly cooking class that prepares a meal which demonstrates how to use the foods in the hamper.

Breakfast/Light Meal Program. New Directions offer S.A.L. participants the opportunity to eat nutritionally well-balanced meals. The meals incorporate modeling of food preparation by using foods from the hampers provided by the food bank. The Resource Center offers a breakfast program in the lounge and participants may also request and receive light meals throughout the day. In addition, nutritious snacks are provided in the instructional and interactive classes.

After Hours Support. The purpose of the S.A.L. program is to offer support to participants. New Directions recognizes that support is sometimes required outside of normal business hours. Participants are provided with an after-hours emergency phone number if they are in crisis and require support. A staff member can be reached at anytime, 365 days per year.

S.A.L. Program Participants

New Directions currently has 30 participants, all of whom have intellectual disabilities, in the S.A.L. program and another 10 are on the referral list. Of the 30 participants who are currently in the program, 20 are male and 10 are female. Approximately half of these individuals have been in an institution in the past for varying periods of time. Almost all of the participants, with the exception of three, have lived in residential care (including group homes and foster care) either as children, as adults or both. As well, since several of the participants have been in conflict with the law, some of them have had to spend time in a correctional facility and/or on probation. In addition, many of the participants also struggle with substance abuse issues. Finally, it is important to note

that all of the participants are on Employment and Income Assistance and live well below the poverty line. Only a few of the participants are currently working sporadically or part-time to earn supplementary extra income. Due their level of income and rent restrictions imposed upon by Income Assistance, almost all the participants live in neighborhoods that are situated in the core area of Winnipeg, which generally have a high crime rate.

Methodology

Research Purpose

According to Jackson (1999) it is important for all researchers to articulate precisely what they wish to investigate. Only after the purpose has been clearly identified can the researcher move to the next stage of determining the "...conceptualization and operationalization of the concepts involved" (Wagenaar & Babbie, 2001, p.51). After careful consideration at the beginning of this project, the researcher determined that the purpose of this research was to:

- 1) Increase knowledge of the factors that positively contribute to the quality of life of participants in the S.A.L. program.
- 2) Elicit the perceptions of program clients and staff regarding the services being provided by the S.A.L. program to determine which ones are the most beneficial in contributing to and maintaining participants quality of life, as well as to identify what additional services they might like to see offered.

Design

The qualitative field researcher can utilize one of a variety of approaches for their project (Wagenaar & Babbie, 2001). A combination of a case study and participatory action research (P.A.R.) was used to elicit the perceptions of participants and staff regarding the services being provided by the S.A.L. program. The goal was to determine which services were the most beneficial in contributing to and maintaining participants quality of life, as well as to identify what additional services they might like to see offered.

The researcher placed a priority on ensuring that the research experience was an empowering, satisfying and enjoyable experience for the participants. They understood that the results would be disseminated and could be helpful to the S.A.L. program and to other programs providing services to people with disabilities. The researcher believed that she would elicit fuller answers and that the participants would put more thought into the process in a happy and relaxed atmosphere free of time or transportation restrictions. The researcher thought that driving around the city would trigger ideas for pictures. For example, in one instance we passed an ambulance and this evoked a memory of a positive experience with the health system for one participant.

Case Study

“Case studies yield both descriptive and explanatory insights. They can examine just one particular case or they can form the basis for developing more general theories” (Wagenaar & Babbie, 2001, p.68). Creswell (1998) describes a case study as having the following components:

Bounded System (bounded by time and place and the case being studied an event, program, activity, an individual or group of individuals). The research case studied for this project was the S.A.L. program and participants at New Directions and was conducted between the months of September to December in 2004.

Use of Multiple Sources of Information. This research project utilized observation, individual and focus group interviews, and visual material (photovoice). This research project utilized observation of nine S.A.L. participants in their homes, communities, and S.A.L. facilities. Photovoice is considered a document in qualitative research (Berg, 2001). Two focus group interviews were held in the S.A.L. lounge, one with four participants and one with eleven participants. The rationale for holding focus groups was to see if the focus group results would support the photovoice results and to see if any new themes emerged from the discussion.

Context of Case. The case for this research project was situated within a physical situation (New Directions Supported Apartment Living Program in Winnipeg, Manitoba) and a social setting (participants participation in programming, ongoing relationships, availability and use of social supports, housing and other interests).

Participatory Action Research

Many features of this project fulfill the requirements of a participatory action research project. These features include:

Participants Collecting Data. Participants took pictures to document factors in their environments that they valued as contributing positively to their quality of life.

Participants Analysis of Data. Participants sorted their pictures into quality of life domains and attached them to poster boards. The participants either wrote captions under the pictures themselves or told the researcher what to write.

Participants were Stakeholders not Research Subjects. Participants were important and involved in all aspects of the research process including: data collection, data analysis and the dissemination of results. The research outcomes will have a beneficent effect on the quality of life of the participants because they contributed data into which factors in their lives contributed to quality of life across the domains and identified the services most valuable in contributing to these factors. This information will preserve or expand the services they most value and contribute to the decision-making process on any future services.

Participant Inclusion in the Dissemination of Results. Participants and the researcher co-presented the results. As well, participants had input into the decision about which results are presented and to whom.

Research for the Purpose of Taking Action and Effecting Change. This research will contribute to social work knowledge in terms of participant feedback about program elements and aspects of their environment that they find most beneficial in contributing to and increasing their quality of life. Such information can be used to improve program delivery for individuals with disabilities living in a variety of community settings.

Informed Consent

Padgett (1998) states that five key elements need to be incorporated into a consent form when dealing with vulnerable populations, they are:

- 1) A brief description of the study and its procedures as they involve participants.
- 2) Full identification of the researcher's identity and of the sponsoring organization.
- 3) An assurance that participation is voluntary and the respondent has the right to withdraw at any time without penalty.
- 4) An assurance of confidentiality.
- 5) Any risks or benefits associated with participation in the study.

The researcher incorporated these elements into the consent forms. If a potential participant had been under an order of supervision from the public trustee, a consent form would have had to be signed by them on their client's behalf (Appendix A).

All participants were asked to sign an informed consent form before beginning their participation in the research process. Padgett (1998) suggests that threat of coercion is a concern when asking vulnerable individuals to participate in research. Potential research participants needed to be fully aware that they were free to decline from involvement in the research process. In addition, they were further informed that if they did agree to participate, they could withdraw from the study at anytime without fear of loss of supports or good will in the services provided by New Directions. The participants also needed to fully understand that if they were involved in photovoice, their pictures would be used in public presentations. The researcher solicited help from S.A.L. support staff to explain the consent forms to potential participants because they hopefully would have built rapport and trust with them.

Financial honorariums were provided to participants to compensate them for their time. How much to offer was an ethical question because too little an amount can be insulting and too large an amount can be seen as bribery or coercion (Padgett, 1998). It was

important to compensate the participants to make sure they felt valued and appreciated. Padgett (1998) also suggests that new researchers consult experienced researchers on an appropriate amount. The researcher consulted her advisor Dr. Brenda Bacon and they agreed that a \$20.00 honourarium to both photovoice and focus group participants was appropriate.

The research posed minimal risk to the participants. Since both the photovoice and focus group interviews focused on positive aspects of peoples' lives, it was anticipated that the experience would be enjoyable for them. In the unlikely event of emotional distress the researcher would have asked the participant for permission to contact their support staff or case manager for added support.

This proposal was submitted to the University of Manitoba Joint Faculty Research Ethics Board and was approved.

S.A.L. Staff Participation

The researcher started the data collection process by meeting with 10 support staff and management personnel from the S.A.L. program. During this meeting the researcher explained the research design and goals. The researcher provided those in attendance with an information package and a short questionnaire (Appendix B). Additional information packages and questionnaires for the S.A.L. staff not present at the meeting were given to the program coordinator. Completion of the questionnaires was voluntary and the questionnaire was anonymous and confidential. Staff members were asked to identify the five most and least important S.A.L. services in contributing to quality of life for the individuals they support. The questionnaire also asked staff to list services, if any, they

thought should be added to the S.A.L. program and to provide an explanation as to why they should be added. The researcher asked that the questionnaires be handed in to management and were then collected by the researcher at a later date. As only three questionnaires were returned to the researcher, the researcher did not include the staff questionnaires in the research results.

Photovoice

Sampling

The researcher asked staff to help select a purposeful sample of eight to ten participants from the S.A.L. program who they thought would be interested in participating in photovoice. Purposeful sampling is the process by which cases are selectively chosen in an effort to represent different perspectives on an event or problem (Creswell, 1998). Factors considered in client selection were age, gender, unique circumstances (marriage), employment, family involvement and ethnicity. The researcher encouraged the staff to attempt to select individuals who would be representative of all S.A.L. participants. The program coordinator explained that, to a considerable extent, the research participant selection would be impacted by the availability of the S.A.L. participants. For example, if a S.A.L. participant was experiencing a current mental health crisis or stressful personal issue during the research period, the person would not be able to participate.

The researcher, with the assistance of the program coordinator, discussed recruitment of photovoice participants with the staff. There was a general agreement among those in attendance at this meeting that posters inviting S.A.L. participants to attend an information session/lunch could be posted throughout the S.A.L. lounge. A date was

chosen and the posters and a sign-up sheet to attend the lunch were put up within a few days. Since not all of the S.A.L. participants use the lounge, staff members were asked to give other possible interested participants the information about the research project and the information session/lunch. Volunteers for this research project were then recruited from this information session. From the fifteen S.A.L. participants who attended the information session /lunch, nine were willing photovoice participants and two were willing focus group participants.

Due to confidentiality policies of the program, the researcher was not able to contact the interested participants directly by telephone. The S.A.L. program managers helped set up appointments for the researcher to meet with each individual and his/her staff to discuss and review the consent forms. These meetings took place from the end of August, 2004 to early December, 2004. The goals of these meetings were to ensure that the participants understood the process and what would be expected of them, that they wanted to participate in photovoice, and that they understood that they were able to withdraw from the research at any time.

When the researcher met with each participant, she took into consideration the amount of time between the information session/lunch and the actual meeting. At the start of each meeting with each participant the researcher again reviewed and clarified Schalock's eight quality of life domains (Appendix C), answered any questions and asked the participant to give some thought as to which pictures he/she wanted to take to depict each domain. The researcher noted that, in most cases, the participants had already decided on some of the photos they wished to take. It seemed to the researcher that the participants

were eager to do the photovoice and consequently the research was done either on the day of, or within a day or two, of the meetings.

Data Collection

The researcher met with the photovoice participants either in their homes or in the S.A.L. lounge to begin the photovoice session. The participants had given some thought to the domains and had made decisions or had ideas about pictures they wanted to take. The participants choice of pictures was relatively unrestricted by time or location as the researcher used her own car for transportation to any Winnipeg location and the research was conducted in mornings, afternoons and evenings to accommodate the different pictures the participants chose to take.

The researcher accompanied each participant into his/ her environment including homes, neighbourhoods, community resources, favorite locations frequented for recreation and relaxation, work sites, relatives' homes and any other place in their environment they chose to include. The participants took pictures (up to 24) of elements in their lives they felt were important. In some instances the participant wanted to take a picture that was not possible, for example, their participation in the Aboriginal group which was not meeting at that time. At the researcher's suggestion the participant agreed to take a picture to symbolize the subject he/she wanted included. As they took the pictures, the participants were asked by the researcher for an explanation of why each picture had meaning for them. As all the participants included pictures demonstrating their use of S.A.L. services the researcher took field notes of their comments about the services and the meaning their

pictures had for them. The researcher took field notes of their answers and read the notes back to the participants for clarification and accuracy.

The completed film was taken to a photolab and, in most instances the researcher and participant went out for lunch or dinner while the pictures were being developed. The pictures were picked up and the researcher and participant returned to either the participant's home or the S.A.L. lounge. The researcher interviewed each participant either during the meal, or while in their home or the lounge to ask them what services provided by the S.A.L. program they felt were the most valuable in contributing to a meaningful quality of life. Participants were prompted from a list of services provided by the S.A.L. program (Appendix D). Participants were then asked to talk about what services, if any, they would like to see added to the program and why. The researcher continued to take field notes and read the notes back to the participant to check for accuracy and clarification.

Data Analysis

The researcher, along with the research participants, sorted the pictures by themes according to Schalock's eight quality of life domains. These pictures were then organized by the participants on presentation boards according to the eight domains: rights, self-determination, emotional well-being, physical well-being, personal relationships, social inclusion, personal development and material well-being. The participants were asked by the researcher to either write themselves or tell the researcher a word or caption for each picture to express its meaning. Trustworthiness and credibility were increased by the involvement of the participants in the analysis.

Focus Group Process

As previously stated, one of the reasons for holding focus groups was to see if the focus group results would support the photovoice results and to see if any new themes emerged from the discussion. Another rationale for facilitating the focus groups was to provide S.A.L. participants with the opportunity to be included in the research. The researcher put up a poster with a sign up in the S.A.L lounge inviting participants to attend one of three focus groups. The poster included an explanation of the purpose of the focus group, the time and place of the groups and the honorarium provided. The intention was to have one focus group for Photovoice participants. The other two focus groups were for any other S.A.L. participants. The researcher also provided staff with a leaflet to give the information to the participants who would not see the poster because they did not frequent the S.A.L lounge (Appendix E). Two focus groups, one with four participants and the other with eleven participants, were facilitated. Facilitating a focus group composed of eleven participants was not what the researcher had intended. This focus group, intended for Photovoice participants only, increased to eleven participants. Three S.A.L. participants had been confused by the posters inviting the photovoice participants to the focus group and signed up for the group. The researcher did not want to discourage their participation and they were included in the focus group. One photovoice participant was not able to attend.

The researcher had requested and received permission/consent to videotape the focus groups for the purpose of transcribing them at a later date. The researcher's advisor was kind enough to videotape the focus groups.

Both focus groups began with a brief explanation of the goals and expectations of the focus group followed by the establishment of some group rules. The researcher

distributed and reviewed the consent forms and answered any questions. The participants signed the consent forms in the presence of staff and returned them to the researcher. All the presentation boards from each domain compiled by the photovoice participants were hung up on the walls around the room. The researcher introduced each domain by offering an explanation of the meaning of the domain and, using the photographs on each presentation board, gave examples of what could be included in each domain. The researcher used the presentation boards to initiate discussion by asking the participants to look at the pictures on the presentation boards before discussing what factors in *their* lives contributed to their quality of life in each domain. The ensuing discussion about the main themes attempted to get a degree of consensus as to which themes the participants considered most valuable to their quality of life.

Data Analysis

There are several forms of data analysis useful for case study research. In categorical aggregation, the researcher looks for multiple instances of relevant meanings within the data. In direct interpretation, the researcher draws meaning from single instances. Quite often patterns can also be established and correspondence can be found between two or more categories. Lastly, naturalistic generalizations can be formed. These are generalizations that interested parties can apply to the population that is the focus of the research (Creswell, 1998). The analysis undertaken in this research project utilized a combination of these four types of analysis.

Using the field notes and transcriptions from the taped focus group interviews, the researcher first used line by line coding as a process of identifying meaning units. The

researcher then entered the meaning units onto individual cards. Each card was put into categories and laid out on presentation boards so the researcher was able to identify themes as to what is important to the program participants' quality of life and which resources offered by the S.A.L. program they most valued. Finally, the researcher extrapolated naturalistic generalizations from the data analysis that New Directions and other agencies may find useful in supporting this population.

CHAPTER 4: RESULTS

This chapter focuses on the qualitative results of the individual participants and focus groups. Results have been categorized within each respondent section (individual participants, group and focus groups) by the themes that emerged from the data. The chapter begins with a description of the first level analysis conducted. Specifically, the photovoice process with each of the nine photovoice participants is provided including the participants' participation in the recruitment process, some background information on each participant and the participants' analysis of the pictures they took. The next section of this chapter focuses on the group photovoice results with emphasis on the dominant and unique themes that emerged. Chapter four concludes with a description of the results that emerged from the second level analysis conducted with two focus groups.

In accordance with the confidentiality aspect of the consent form the participants' names and the names of their pets have been changed to protect their identities.

Individual Photovoice Results

Each of the S.A.L. participants - Pete, Lucy, Julie, Jack, Zoe, Cam, Debbie, Holly and Larry - are individually listed with a description of their results. The results are categorized according to the eight domains - Rights, Self-Determination, Emotional Well-Being, Physical Well-Being, Personal Relationships, Social Inclusion, Personal Development and Material Well-Being (Schalock, 1997). A brief summary of the results are provided in two tables (Table 4.1 and 4.2) at the end of this section.

Pete

Background Information

Participant Description. Pete is a middle-aged white man in his late thirties who dresses with flair. He did not volunteer any information about involvement with his family.

Past and Current Living Arrangements. Pete recently moved into a newly renovated main floor duplex in an area that he described as quiet and relatively safe. Prior to his move Pete stated that he lived in "a dump in a bad area with gangs." Pete also said that he had some difficulty with managing stairs and it was important to him to live on a main floor. His prior accommodation was on an upper level.

S.A.L. Involvement. Pete receives individualized staff support a few times per week mainly for help with shopping and problem solving. He is involved in art classes, cooking classes and group outings such as barbecues and camping trips, and uses the S.A.L. lounge to socialize and play board games and do his laundry. Pete received housing support to find his new accommodations in the duplex.

Other Agency Involvement. Pete is involved with two programs in the provincial government department Family Services and Housing. He has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.).

Pete did not share information about any other past or current involvement with other agencies.

Recruitment and Participation in the Research Process

Pete did not attend the information session/lunch in the S.A.L. lounge because at that time he was temporarily suspended from the S.A.L. lounge. One of the S.A.L. case managers called the researcher one day following the information session to tell her that Pete was interested in participating in the photovoice research but agency regulations required that a male staff accompany Pete and the researcher at all times. The researcher met with Pete and his staff at his new home. Pete seemed to understand what was being explained to him and signed the consent form. Although the staff who accompanied Pete and the researcher throughout the photovoice tried to be as unobtrusive as possible, the researcher became aware that Pete did not share information about his family or his personal history and wondered if the presence of the staff contributed to his reticence. Pete began taking the pictures. There were a few instances when a picture Pete wanted to take was not available and the researcher suggested a picture be taken to symbolize the picture he wanted, explaining that he could write about what the photo symbolized on the board later. For example we set up a tent in Pete's yard and took a photo of the tent to represent Pete's enjoyment of the camping trip he participated in with the S.A.L. program the previous summer. As Pete's suspension from the S.A.L. lounge was still in effect and Pete wanted to have his artwork which was displayed in the lounge included in the photovoice, he gave the researcher permission to take pictures for him. The researcher took Pete and his staff to Pete's home, went to the lounge and photographed Pete's art work and took all the pictures to a one hour photo lab.

The researcher returned to Pete's home so he could make up the boards. Pete's staff observed but did not participate. The researcher reviewed each domain with Pete as

she spread the Bristol Boards out on the floor in the living room. Pete, with minimal assistance from the researcher, decided which domain each picture represented and taped the pictures on the boards. Although Pete did not want to write on the boards himself, he told the researcher which comments he wanted written and the researcher wrote the words for him. The researcher made suggestions for comments on the rare occasions when Pete said he did not know what to say about a picture. Pete sometimes wanted a picture included in more than one domain. For example Pete thought the picture of the cooking class could be on the physical well-being board because "it is important to eat healthy" but also on the personal development board because he learned new skills "I learned to make Chinese food".

Photovoice Session and Participant Analysis

Rights. Although Pete chose to include the picture of the duplex in the emotional well-being domain, he agreed that it could also be included in the rights domain as he has the right to live in a safe area.

Self-Determination. Pete did not initially choose to take a picture demonstrating self-determination. When the boards were completed the researcher commented that a picture could have been taken of Pete because he has a distinctive style of dress. The researcher commented that making the choice to have your own unique style is an example of self-determination. Pete agreed and gave the researcher permission to include this conversation in her write up of his photovoice session.

Emotional Well-Being. Pete took a picture of the outside of his duplex and commented that "I feel safer in this area," "I like being on the main floor," and "The apartment is clean, my last place was a dump."

Physical Well-Being. Pete took a picture of a tent to illustrate his enjoyment of camping and fishing. Pete stated that "Camping gives me a chance to get out of the city." Pete chose to take several pictures in Assiniboine Park because "I like hanging out, walking around and getting fresh air." Pictures taken included one at the Zoo with the comment that "I like animals." The next picture was of the picnic/barbecue area to express his enjoyment of the S.A.L. program's barbecues in the park. "I like the food and being there with my friends." Pictures of an open area and the pavilion were taken just because he enjoys the park. The pictures of the new S.A.L. lounge included one of the outside of the lounge and two of the inside. The latter two pictures include a chess set and a cribbage board to symbolize Pete's enjoyment of playing games and socializing with friends in the lounge.

Pete said he did his laundry in the new S.A.L. lounge because "it's free and saves me money."

Personal Relationships. Pete chose to take pictures of staff saying that "I like talking to staff and like bugging them." He also said "They help me do the things I like to do." Pete commented that he considers some of the other individuals in the S.A.L. program to be friends but as he was temporarily suspended from the lounge he was unable to take pictures of them.

Social Inclusion. Pete took a picture of his favorite restaurant. Pete uses public transit and took pictures of buses to illustrate the importance of mobility. Pete said "I like talking to bus drivers and sometimes go on bus rides just for fun."

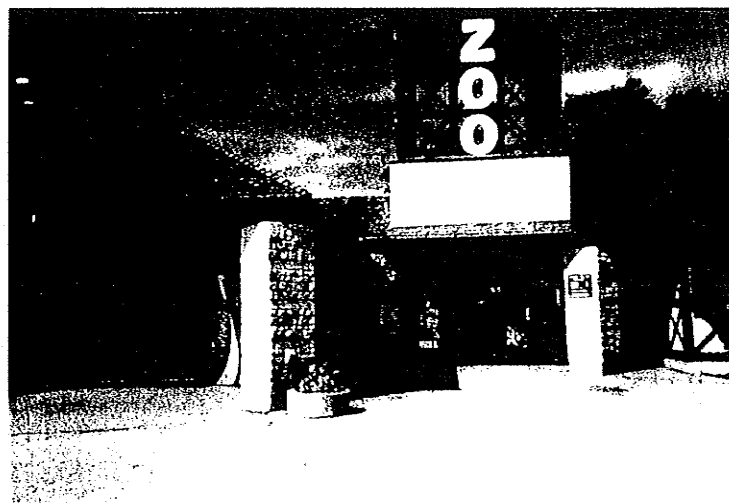
Personal Development. Pete talked about the pictures of his art work and the cooking class. He liked both of these classes because "I like to be with other people." In reference to the cooking class picture taken outside of a city of Winnipeg recreation centre, Pete said "It's important to cook good food, we learn to make new things like we made Chinese food." Pete verbalized that he goes to the art class because he really enjoys it and "I would not have the chance to make these things if I didn't go."

Material Well-Being. Pete chose to take a picture of the Employment and Income Assistance building (welfare). Pete said "I feel good because the rent gets paid and I know that I have money to buy groceries." Pete also told the researcher that he should have taken a picture of his jewelry. The researcher told Pete she would include his love of jewelry in her written report.

Comments Regarding S.A.L. Services. Pete said that New Directions staff helped him find his new residence. This assistance with finding better housing was important to him because he felt safer in this area and, as his new place is on the main floor, he did not have to climb so many stairs. The S.A.L. group outings were another favorite service as he enjoyed the camping trips, fishing trips and the barbecues. He liked the opportunity to make art work that he could keep and was aware that he would not have the opportunity to do this if the program did not exist. He enjoyed the cooking class and valued the lounge because he can do his laundry for free, play games and socialize with other

participants whom he considered to be friends. Pete liked the individualized staff support he receives a few times a week as he feels he can talk to staff and joke around with them.

Barbeques at Assiniboine Park (group outing at the Zoo)



Lucy

Background Information

Participant Description. Lucy is a friendly sociable Aboriginal woman in her thirties. She is currently unemployed but has a sporadic work history. Lucy is in frequent contact with members of her family. She commented that "I love my mother" and "My brothers look out for me but sometimes we don't see each other for a long time."

Past and Current Living Arrangements. Lucy did not share information with the researcher about her past living arrangements except to say that she spent some time

living with her mother. Lucy currently lives at the Salvation Army Residence. She stated that "I don't like it there" and "I am moving to Ontario with my boyfriend."

S.A.L. Involvement. Lucy receives individualized support from staff a few times per week, and commented that staff help her with laundry, cooking and accessing counseling. She participates in the art class and is involved in the Aboriginal group. She enjoys socializing in the lounge and accesses the light meal program. Lucy also participates in the group outings and specifically mentioned the camping trips and barbecues.

Other Agency Involvement. Lucy is involved with two programs in the provincial government department Family Services and Housing. She has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). Lucy did not speak of any other specific agency involvement but did mention that she had received counseling.

Recruitment and Participation in the Research Process

Lucy attended the information session/lunch and signed up to participate in the Photovoice research. The researcher met with Lucy and her staff in the S.A.L. lounge to explain the consent forms and obtain her signature. Lucy took some pictures in the lounge then accompanied the researcher into the community to take photographs. Lucy seemed to understand the quality of life domains and had given considerable thought about which pictures she wanted to take. For example, she had made prior arrangements to meet a friend at his work for the purpose of taking his picture. Lucy shared with the researcher that there were a few important components of her life that she wanted to

photograph but couldn't figure out how to do it. One example of this was her participation in the Aboriginal group as the group was not meeting the day we were doing the photovoice. Lucy liked the researcher's suggestion that we take a picture of an Aboriginal poster to symbolize the Aboriginal group. The researcher was struck by the enthusiasm Lucy showed throughout the photovoice session as demonstrated by her friendly and outgoing interactions with everybody she encountered during the day. Lucy suggested that we go for an ice cream sundae instead of having lunch. Lucy waited in the S.A.L. lounge while the pictures were being developed.

Lucy and the researcher made up the boards together. Lucy chose where the pictures should go on the boards, attached them to the boards herself and told the researcher which comments to write. During this process Lucy seemed somewhat pre-occupied with putting together her photo album. The researcher asked her if she could wait until the boards were finished. Although Lucy agreed to wait she appeared to rush through the process and appeared tired by the end.

Photovoice Session and Participant Analysis

Rights. Lucy took pictures of the Public Safety building. She requested that the researcher take a picture of Lucy with a female police officer to symbolize her right to live in a safe environment and have full protection under the law. Lucy said "My brothers hate the police but they (the police) helped me when my ex boyfriend was causing trouble." Lucy said she felt comfortable calling the police and described her experiences with them in a very positive way. Lucy shared with the researcher that she had been involved with the police a few times when she felt threatened or was being

physically hurt by a former boyfriend. Lucy said “the police were nice and helped me get an order for him.” Lucy felt confident that she could count on the police for assistance when she needed help. The female police officer was very friendly and generous with her time. Lucy asked the researcher if she could give a copy of the picture to the police officer so the next day we returned to the public safety building. The police officer responded by thanking Lucy, and, while hanging the picture on the office wall, commented that she really appreciated Lucy bringing the picture to her. Lucy seemed really happy with this brief contact with the police. The researcher thought it was a good example of Lucy’s ability to “give and take” in interactions with others in the community.

Lucy with Officer Shelly Glover of the Winnipeg Police Force



Self-Determination. No data provided by the participant.

Emotional Well-Being. Lucy chose to take a picture of her former work place although she had not worked there for several years. Lucy remembered it as being as being a very positive experience stating that “The other people who worked there were

good to me” and “Some of them were funny.” Lucy said she would like to work there again in the future.

Physical Well-Being. Lucy took a picture of the fridge in the S.A.L. lounge to symbolize her use of the light meal program. Lucy explained that at the Salvation Army residence the meals are served at set times. She appreciated knowing that she can have something to eat in the lounge when she misses a meal at the residence.

Personal Relationships. Lucy took a picture of staff. She stated that she “likes joking and bugging staff” and feels she has good relationships with them. Lucy also spoke of receiving help and support from staff when she needed it. The example she gave was “They helped me get counseling.” Lucy took a picture in the S.A.L. lounge of a friend of hers who is also involved with the S.A.L. program. Lucy commented that she has made good friends with individuals she has met through the program. The researcher took a picture of Lucy with her ex-boyfriend at his work site. Lucy described her relationship with him as “We went out for a long time but broke up.” Lucy wanted to take a picture of her two brothers at work but we could not find the construction site. She said “My brothers look out for me” and “Sometimes I don’t see them for a long time.” Lucy did not take a picture of her mother or children but she spoke lovingly of them.

Social Inclusion. Lucy told the researcher that she liked having coffee in local restaurants with friends. She asked to have a picture taken of herself with the researcher in an ice cream parlor to illustrate eating out or having coffee with friends.

Personal Development. Lucy took pictures of her artwork, her quilting and the sign for the art class to illustrate the importance she attaches to her participation in the art class. Lucy said that doing crafts made her “...feel good because I like learning new

things” and she feels “...proud of the art work.” Lucy took a picture of an Aboriginal poster hanging in the S.A.L. lounge to symbolize her participation in the Aboriginal group that meets weekly in the lounge. She described the group activities as including Aboriginal crafts and being important to her because “I can talk about being Aboriginal.” Lucy said that she enjoyed smudging and, in response to the researcher’s question about what smudging was, Lucy described it as “putting smoke on me to keep spirits away.”

Material Well-Being. No data provided by the participant.

Comments Regarding S.A.L. Services. Lucy stated that she values the individualized staff support because of the assistance they give her with laundry, cooking and problem solving. She also said she enjoys socializing in the S.A.L. lounge, “hanging around with my friends, playing shuffle board and bugging staff.” Lucy also accesses the light meal program in the lounge. Lucy enjoys the art program and the Aboriginal group. Lucy also said she loved the group outings especially the camping trip and barbecues because “It is my chance to go swimming” and “I love bonfires.”

Julie

Background Information

Participant Description. Julie is a white female in her late twenties. She presents as very assertive and confident.

Past and Current Living Arrangements. Julie shared with the researcher that she had spent part of her childhood living in the family home and also lived in a foster home.

She is now living in a room and board situation but hopes to move into her own apartment soon.

S.A.L. Involvement. Julie receives one/ one staff support and enjoys talking and doing fun activities with them like playing pool and having coffee. She participates in the cooking class, Aboriginal group, organized group outings and plans to start doing her laundry in the new S.A.L. lounge.

Other Agency Involvement. Julie is involved with two programs in the provincial government department Family Services and Housing. She has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). Julie did not share information about any other past or current involvement with other agencies.

Recruitment and Participation in the Research Process

Julie attended the information session/lunch and signed up to be a photovoice participant. Julie and her staff met with the researcher in the S.A.L. lounge to review and sign the consent forms. Julie had given considerable thought to which pictures she wanted to take prior to the meeting. Julie and the researcher spent the day taking pictures in the community. Julie had dinner at her residence then she went back out with the researcher in the evening to take a picture of her church group. Julie and the researcher met the next day at the S.A.L. lounge to make up the boards. Julie seemed pleased with the pictures. Julie enthusiastically began to write the captions and tape the pictures on the boards and continued doing this until she had completed most of the boards. At this point, Julie wanted to print a negative comment about a staff under his picture and the

researcher explained that the staff may be offended by the comment and encouraged her to ask his permission. The staff was working in the lounge that day and Julie explained to him what she wanted to write and said it was meant as a joke. The staff asked her not to write the comment. Julie appeared to become angry and accused the staff of not being able to take a joke. The staff then said he would withdraw his permission to use the picture if Julie wrote that caption. Julie reluctantly agreed to write a different caption. Julie's cooperation and enthusiasm in making up the boards deteriorated following this encounter. Her comments changed from phrases to single words and she appeared resentful towards the researcher for "taking the staffs' side."

Photovoice Session and Participant Analysis

Rights. Julie requested that the researcher take a picture of her with two sheriffs in front of the law courts building. Julie said that she has been to court several times to support friends at their court appearances. She felt able to do this because "The sheriffs protect people from gangs, guns and drugs." Julie also told the researcher that she has used the justice system to get a protection order and the police were "kind and helpful." Julie described being treated well in her contacts with the police. Julie also took a picture outside of the remand centre stating "It is my right to visit friends and acquaintances in there."

Self-Determination. Julie was not able to take a picture of her boyfriend because he was incarcerated at the time. Julie shared with the researcher that her friends, staff and family warned her against dating him but "I am going to go out with whoever I want."

Emotional Well-Being. Julie took a picture of her church group meeting in the church that she regularly attends. Julie made several comments about how important her participation in the church was to her. "I am able to talk about religion with them," "I find it a safe place when the world is stressful" and "It is good to be with people who agree and don't get resentful."

Physical Well-Being. The researcher took a picture of Julie playing pool in one of the common rooms at her residence. Julie chose to put this picture in the domain of social inclusion but agreed that it would fit in with the domains of physical or emotional well-being as well as she commented that "Playing pool is a stress reliever."

Personal Relationships. Julie shared with the researcher that she was disappointed because she could not take a picture of her boyfriend who was incarcerated at the time. Julie took several pictures staff at the S.A.L. lounge. Julie's comments about staff were for the most part positive stating that "They help me solve problems" and "I like to joke and hang around with them." She also commented that "Sometimes staff are naggy and they expect me to be perfect." Julie had made a similar comment during the picture taking part of the process. A song came on the radio with the line "I'm not a perfect person." while we were driving in the car. Julie told the researcher that "this is my song to the staff because they expect me to be perfect." Julie took separate pictures of two friends who are S.A.L. program participants stating that "We have been good friends for three years" and "We have good talks and joke around." Julie took pictures of her brother in law, niece and nephew and their family dog at her sister's home. Her sister could not be there because of work commitments. Julie said "My family know me better than the staff and they are always there for me." Julie also commented that the dog is an

important part of the family. "I watched her grow up, she is cuddly and playing with her feels good."

Social Inclusion. Julie put the picture of herself playing pool in the common room in her residence in this domain. She mentioned that some of the friends she had made in the residence were not involved in the S.A.L. program. Julie said that she enjoyed playing pool and eating with these friends in the cafeteria in the residence.

Personal Development. No data provided by the participant.

Material Well-Being. No data provided by the participant.

Comments Regarding S.A.L. Services. Julie participates in the cooking class. Her comments included "We get to chose what we make then we get to eat it after." Julie also stated that "When I get an apartment I'll probably use the food bank, not enough money from welfare." Julie also said that she likes hanging around the S.A.L. lounge, playing cards and joking around with staff and other participants. Julie told the researcher that she plans to start doing her laundry at the new lounge. Julie participates in the group outings and said "I like camping because it's a chance to get out of the city." Julie also said that on the last camping trip she enjoyed playing floor hockey. Julie stated that she likes having one to one staff because then "I don't have to share them with everyone in the lounge and have everyone jumping up at them." "I like having private time with staff so that I can talk about private stuff and have coffee with them." Julie's suggestions to improve existing S.A.L. services included giving people prior notice if the lounge is going to be closed early. Julie complained that on a few occasions "I have come to the lounge when it was supposed to be open and it wasn't. I was pissed off and I don't have a phone to call everyday and check." Julie also stated "More staff need to be

on in the lounge.” Julie’s suggestion for an additional service was to establish a weekly music class.

Jack

Background Information

Participant Description. Jack is a white man in his early forties. Jack has a positive attitude and presents as very friendly and approachable. The researcher and Jack live in the same area and she has seen him talking to people and letting them pat his dog (Buster) while he’s out walking him. Jack has a good sense of humour, gave good explanations for the pictures he chose to take and initiated several discussions on various topics with the researcher. He grew up in the family home with his mom, dad and sibling and has warm and positive memories of his upbringing.

Past and Current Living Arrangements. Jack grew up living in his family home. He is currently living in a self-contained suite in a multi- family home located in what he considers to be a well-kept up and safe area.

S.A.L. Involvement. Jack has individualized staff support a few shifts per week. Jack participates in the art class and the cooking class and enjoys spending time socializing and playing games in the lounge. Jack enjoys the group outings and takes advantage of the light meal program and the food bank when he needs to. He received housing support to locate his current suite.

Other Agency Involvement. Jack is involved with two programs in the provincial government department Family Services and Housing. He has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W). Jack

did not share information about any other past or current involvement with other agencies.

Recruitment and Participation in the Research Process

Jack attended the information session/lunch and signed up to participate in the photovoice. Jack and his staff met the researcher in the S.A.L. lounge to review and sign the consent form. The following day the researcher met Jack at the S.A.L. lounge then spent the morning and part of the afternoon taking pictures in the community. Jack had decided which pictures he wanted to take prior to our meeting. Jack asked the researcher to come with him while he took his dog (Buster) for a walk because he wanted pictures taken of him walking the dog in his neighborhood. Jack and the researcher dropped off the film to be developed then went to a restaurant for a late lunch.

Jack and the researcher picked up the pictures then went back to his apartment to make up the boards. Jack seemed to have a good understanding of the domains and taped the pictures on the boards himself. Jack did not want to write on the boards but told the researcher what captions to write.

Photovoice Session and Participant Analysis

Rights. Jack took a picture of the legislative grounds. He commented that "It is important to vote so you have a say in what's going on." He also said that "It's important to file income tax or you can get in trouble."

Self-Determination. No data provided by the participant.

Emotional Well-Being. Jack took a picture of the outside of his home. He commented that he feels very safe in his home because "There is an alarm in the building

and Buster would bark if there was trouble.” and “Buster is like a guard dog.” He took several pictures of Buster that could be included in this domain but Jack chose to place them on the Personal Relationships board. Jack also took a picture of flowers growing in a yard in his neighborhood to illustrate his opinion that “The neighborhood smells nice and is kept up.” Jack also talked about how much he likes his neighborhood and how he feels safe there.

Physical Well-Being. The researcher took a picture of Jack walking his dog. Jack commented that “Buster is my exercise partner.” Jack also said that “Buster helps me stay in shape, we go for long walks followed by long rests.” Jack took a picture of the kitchen area of the S.A.L. lounge commenting that “I like to eat there sometimes and it is always clean and tidy.” Jack took a picture of a movie theatre saying that “ Movies are relaxing and I like watching them. I like funny movies, I don’t like violent movies.”

Personal Relationships. Jack wanted to take a picture of his family but they were not available. Jack told the researcher to write the comment “My family always cares for me” on the personal relationships board. Jack also stated that “I am spending Christmas at my sister’s.” Jack took a picture of Buster describing him as “man’s best friend,” stating that “Buster always sticks by me.” Jack took a picture of his best friend who is also involved in the S.A.L. program. Jack took a picture of staff and commented that “Some staff are very funny, I make jokes about them and they make jokes about me but its all kidding and I like it.” Jack also said “I taught some staff how to play chess.” This comment sparked a conversation between Jack and the researcher about how he benefits by having staff but he has a lot to give back as well and staff have learned to play chess from him. Jack thought about this, looked pleased then said “That’s right.”

Pooch Smooch (Jack with “Man’s Best Friend” Buster)



Social Inclusion. Jack took a picture of himself shopping at a large mall. He describes himself as a “bargain hunter” and commented that “I like to own my own movies but I don’t buy them when they are expensive because they go on sale and prices go down.” Jack and the researcher agreed that his picture of the movie theatre could also have been included in this domain. His picture of himself walking Buster in the community could also have gone under this domain as he talked about getting to know his neighbors when they come out to pat Buster.

Personal Development. No data provided by the participant.

Material Well-Being. Jack took a picture of a display of D.V.D.’s in the window of a record store to symbolize his own collection. He likes to collect D.V.D.’s of old television series (Mr. Ed, The Munsters, Starsky and Hutch, Dukes of Hazzard, Xena and Hercules, etc.). Jack commented that “I like to own them instead of renting them because I can watch them whenever I want.” Jack also took a picture of a present he bought for Buster.

Comments Regarding S.A.L. Services. Jack stated that he likes the individualized support and uses staff to help him with budgeting, bill paying and grocery shopping so “I have enough money to feed my dog.” Jack likes the cooking class because “It’s good to learn how to make your own food.” He also commented that he enjoys creating art and feels happy when taking the art classes. Jack volunteered that “I use the food bank when I need it” and accesses the light meal program in the S.A.L. lounge. He enjoys “hanging out in the lounge” and loves the group outings but cannot always stay overnight on the camping trip because he “needs to look after Buster.” Jack received housing support to find his current residence.

Zoe

Background Information

Participant Description. Zoe is a white female in her thirties. Zoe was very friendly and talked easily with the researcher. Zoe is married and lives with her husband Cam and her cat Smoky. Cam is an S.A.L. participant and also volunteered for the photovoice research. The only comment Zoe made about her family of origin is that her mom lives in the city and she sees her infrequently. Zoe made several positive comments about her father in law stating that “He is a good man, he supported our marriage and he takes us out for coffee and ice cream.” “He used to have Cam and me over to his house and take us in the neighborhood but he’s in a nursing home now.” Zoe said that they visit him once in a while.

Past and Current Living Arrangements. Zoe did not share much about her past living arrangements except to say that she lived at home with her mother but also spent

some time in a foster placement. Zoe now lives with her husband Cam and cat Smoky in a duplex in downtown Winnipeg.

S.A.L. Involvement. Zoe receives individualized staff support a few shifts a week. Zoe commented that "They come to my house and help with cooking and cleaning." Zoe participates in the group outings, uses the food bank and enjoys spending time in the lounge. Zoe received housing support to find her current residence.

Other Agency Involvement. Zoe is involved with two programs in the provincial government department Family Services and Housing. She has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). Zoe also receives help with money management from the Public Trustee.

Recruitment and Participation in the Research Process

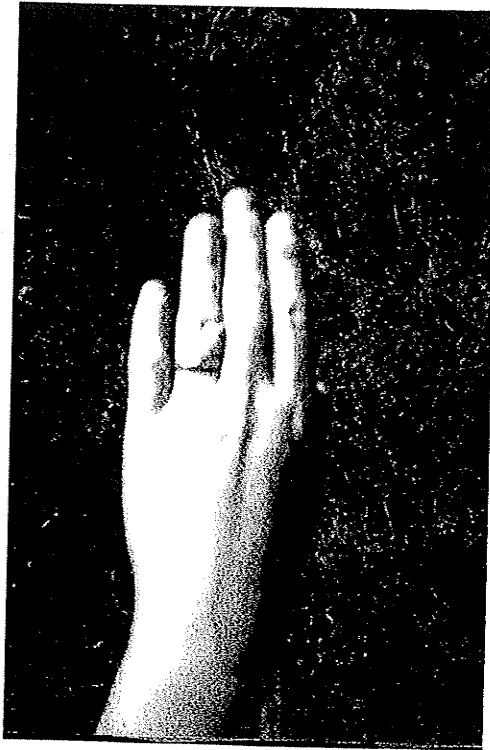
Zoe attended the information session/lunch and signed up for the photovoice research. The researcher accompanied Zoe and Cam to the Public Trustee to sign the consent forms. The Public Trustee told the researcher that she was only involved with Zoe and Cam on a financial level and they did not need her permission to participate in the research. Two days later the researcher picked up Zoe at her house and went to the S.A.L. lounge to meet with staff to review and sign the consent form. Zoe and the researcher went out in the community to take pictures. Zoe had decided that she wanted to take pictures of her home, husband and cat and really enjoyed taking these pictures but then seemed at a loss as to what else in her environment contributed to her quality of life. The researcher and Zoe reviewed and discussed the domains and the researcher also reminded Zoe that she would accompany her anywhere in the city to take pictures and had

lots of time to spend with her. Zoe responded by thinking up several other good ideas for pictures and we proceeded. Zoe and the researcher dropped the pictures off for developing, picked up Cam from their home and went to a restaurant for lunch. Zoe and the researcher picked up the pictures and went back to the lounge to make up the boards. Zoe taped the pictures on the boards and told the researcher which captions to write. The researcher found Zoe to be a friendly and enthusiastic participant in the research and was touched at her invitation to come back again to have coffee with her and Cam in their home at a later date.

Photovoice Session and Participant Analysis

Rights. Zoe took a picture of her wedding ring and the researcher took a picture of Zoe and Cam standing together to symbolize "The right to choose to be happily married." Zoe said the meaning of the ring is "I am not single anymore" and went on to explain that "I wanted to get married because I did not want to live common law anymore," and "I love being married, I love my husband." Zoe took a picture of the stairs at her duplex to symbolize her right to live in a safe home. Zoe commented "I am going to ask the landlord to put in better stairs with good grips so we don't fall down the stairs." Zoe told the researcher that she had recently fallen down the stairs and had to call the paramedics. Zoe stated that she enjoys her home with the exception of the stairs.

Zoe's wedding ring.



Self-Determination. No data provided by the participant.

Emotional Well-Being. Zoe took a picture of the outside of her duplex. Zoe described the area as “safe, better than my last area.” Zoe also commented that the duplex had been newly renovated right before they moved in.

Physical Well-Being. Zoe took a picture of the food bank commenting that “It is good food and keeps you healthy.” Zoe also stated that the food bank was important to her and other participants because “You can tell them what you need and they will bring the basket to you so you can have lots of food.”

Personal Relationships. Zoe took a picture of her husband and commenting that “He’s a great guy and a handsome man.” She also took a picture of her cat Smoky and shared with the researcher that “I rescued him, I got him at a giveaway.” She also

commented that she trained him to use his litter box and likes playing with him and taking care of him. Zoe took pictures of S.A.L. staff in the lounge and commented that "Staff are there for me and will help me if I need it." Zoe was unable to take a picture of her father in law so to symbolize his importance in her life she took a picture of his old house. Zoe said that he had always been kind to her and Cam and considered him a good support. Zoe took a picture of her chiropractor commenting that "He is my favourite doctor and he gives lots of good advice on sore backs." Zoe also said that they talk about other things as well.

Social Inclusion. Zoe took a picture of the chiropractor and his assistant because this is a service in the community outside of New Directions. Zoe and the researcher also agreed that this picture could have gone in the domain of physical well-being. Zoe took a picture of an ambulance to symbolize her use of paramedic services when she fell down the stairs. She said the paramedics treated her well.

Personal Development. No data provided by the participant.

Material Well-Being. Zoe took pictures of her wind chimes. She also took pictures of her candles and other knick-knacks on her coffee table.

Comments Regarding S.A.L. Services. Zoe commented that individualized staff was very important to her, "They come to my apartment to help me if I need it, like with cooking and cleaning." Zoe was grateful for the help she received from S.A.L. staff in planning and arranging for her wedding. Zoe stated "We got married in the lounge and staff were there and we had a night in a hotel for our honeymoon." Zoe uses the food bank and commented that it is an important service because they will bring the basket to her. She does not have to go to another food bank. Zoe also commented on how much

she enjoys the outings, "The barbecues are fun and I love camp, roasting marshmallows, sitting around the campfire." "I get to hang around with a lot of people and talk to them and laugh with them." Zoe really appreciated S.A.L. support in finding her new home.

Cam

Background Information

Participant Description. Cam is a white male in his late thirties. Cam was relatively quiet with the researcher during the photovoice and did not freely volunteer much personal information about himself but did respond openly when asked questions. Cam grew up in his family home and commented that he had a happy childhood. He has had regular frequent contact with his father, first visiting at the family home and, for the last year visiting him in his senior citizens home. Cam is married to Zoe who was also a participant in the photovoice research. Zoe usually accompanies Cam when he visits his father and both Cam and Zoe describe Cam's father as being supportive of their relationship and their decision to marry.

Past and Current Living Arrangements. Cam did not volunteer much information about his living arrangements in his early adult years. Cam described his childhood as a happy one and said he lived in the family home. Cam now lives in a recently renovated duplex with his wife Zoe and cat Smoky.

S.A.L. Involvement. Cam receives individualized support for household chores and medication management. Cam participates in the group outings and enjoys socializing in the lounge.

Other Agency Involvement. Cam is involved with two programs in the provincial government department Family Services and Housing. He has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). Cam receives help with money management from the public trustee.

Recruitment and Participation in the Research Process

Cam attended the information session/lunch and signed up to participate in the photovoice. The researcher accompanied Cam and Zoe to the Public Trustee to sign the consent forms. The Public Trustee told the researcher that her involvement with Cam and Zoe was limited to financial supervision and consequently they did not need her permission to participate in the research. Cam, Zoe, staff and the researcher met at New Directions to discuss and sign the consent forms. Cam told the researcher that he wanted Zoe to accompany him for his photovoice session. Throughout the photovoice session Cam frequently asked Zoe for her opinion on which photographs he should take. Zoe's response was "Whatever you want, it's your day honey." Zoe was very good company for Cam and the researcher but did not influence his decision making and was supportive of his choices. In the researcher's opinion Zoe's presence throughout the day increased Cam's comfort level and enabled him to be more talkative. We dropped the film off for developing, went to a restaurant for lunch, picked up the pictures and returned to the S.A.L. lounge to make up the boards. Although Cam asked Zoe for advice on placement of the pictures she continued to encourage Cam to make his own decisions. Cam told the researcher what to write on the boards the majority of the time, but the researcher did make a few suggestions when Cam seemed "stuck" and the researcher did the writing.

Cam seemed tired by the end of the day and seemed to want the process to come to an end. The last question the researcher asked Cam was what services he liked in the S.A.L. program. He named the services but would not elaborate on why he liked them.

Photovoice Session and Participant Analysis

Rights. Cam chose to have a picture taken of Zoe and himself with his arm around her to symbolize the right to be married. Cam stated that “I like being married” and described his wife as “beautiful.”

Self-Determination. No data provided by the participant.

Emotional Well-Being. Cam chose to place a picture of his former family home on this board to illustrate growing up in a safe neighbourhood. Cam commented that “I had a lot of fun “ and described the neighborhood as being a good and safe place to grow up in.

Physical Well-Being. Cam took several pictures of the new M.T.S. building. He lives in the same area as the M.T.S. building and described how he enjoyed frequent walks past the building site and seeing the daily progress on the construction of the building. He stated in an excited tone “I liked watching them build it,” and “If I have money I will go there for concerts and hockey.” Cam took pictures at the Forks because he likes walking around there. Cam took a picture of an ambulance after a discussion with the researcher and Zoe about the importance of proper medical care and services. Cam took a picture of a donut shop to symbolize eating good food.

Personal Relationships. Cam wanted to take a picture of the owner of the donut shop mentioned in the physical well-being domain but unfortunately the owner was not

available. The donut shop is located in his old neighbourhood close to his family's former home and the owner was a family friend. Cam and his father used to have coffee with the owner and Cam and Zoe have continued to go there to visit the owner and have coffee with him. Cam's picture of his family home also symbolized his relationship with his father. Cam commented "I have a good Dad" and "My dad helped with problems." Cam and Zoe visit his father in his senior's residence. Cam commented that "I have a beautiful wife" and "I have someone to talk to" when he had the researcher take a picture of the two of them together as a couple. Cam took a picture of his support staff in the lounge.

Social Inclusion. Cam took a picture of Robin's Donuts because he likes to eat in restaurants in the community. Cam included a picture of an ambulance at the Forks in this category as an example of using community resources, such as calling for an ambulance or frequenting the Forks. This picture was also included in the physical wellbeing category. Cam agreed that the pictures of the M.T.S. building that he put in the category of physical well-being could also be included in this category.

Personal Development. Cam took a picture of his old high school and commented that he had good and bad memories of his time there.

Material Well-Being. No data provided by the participant.

Comments Regarding S.A.L. Services. Cam stated that he enjoys the group outings and likes hanging out in the lounge. Cam also said he likes having his individualized support worker. Cam also stated he and his wife Zoe use the food bank. Cam and Zoe received housing support to find their current housing.

Cam and Zoe with their Case Manager at the office are pictured here.



Debbie

Background Information

Participant Description. Debbie is an Aboriginal woman in her mid twenties. The researcher found Debbie to be very intelligent and aware of her appearance with a definite personal style. Her hair, makeup and style of dress displayed her love of current fashion. Debbie talked about having contact with some extended family members including a niece and grand niece. Debbie also described an ex S.A.L. staff member as her guardian.

Past and Current Living Arrangements. Debbie spent some of her childhood in her family home. Debbie also mentioned a brief time in foster care. Debbie is currently living in a well furnished and comfortable one bedroom apartment in a room and board facility. She describes her current living situation as “a nice safe place to be in” and commented that “Rules keep the people safe but are annoying at times like no visitors after hours.”

S.A.L. Involvement. Debbie has had individualized staffing in the past but not at the present time. Debbie has had housing support, and regularly attends both the art classes and the Aboriginal group. She participates in the group outings such as the camping trip and enjoys socializing in the S.A.L. lounge.

Other Agency Involvement. Debbie is involved with two programs in the provincial government department Family Services and Housing. She has an Employment and Income Assistance (E.I.A.) worker and a Community Services Worker (C.S.W.). She did not share information about any other past or current involvement with other agencies.

Recruitment and Participation in the Research Process

Debbie attended the information session/lunch and signed up for the photovoice group. The researcher met Debbie at her apartment. The researcher told Debbie that she was the last person to participate in the photovoice. Debbie said her best friend Holly, (another S.A.L. participant) had also attended the information session/lunch and was very interested in being a photovoice participant. Debbie said that she and Holly had talked about the photovoice and wanted to do it together, so the researcher and Debbie went to Holly's apartment. Holly seemed very excited about participating and accompanied Debbie and the researcher to New Directions to review and sign the consent forms. Debbie, Holly and the researcher went into the community to take pictures. Debbie had not decided what pictures she wanted to take prior to our meeting but had thought about what factors contributed to her quality of life.

Holly and Debbie agreed that there were pictures that they both wanted to take including some pictures of the two of them together in different locations. Holly did not influence Debbie's decisions or choices for pictures. More than half of Debbie's pictures illustrated parts of her life in which Holly was not involved. The photovoice session ended at 9 p.m. so Debbie, Holly and the researcher agreed to go out for a late dinner and to meet at the S.A.L. lounge the following day to make up the boards. Debbie and Holly taped their own pictures to the boards and told the researcher what to write. The researcher made a few suggestions but the majority of the captions came from Debbie and Holly. The researcher felt that Debbie and Holly's close long time friendship had a positive effect on the research process because it enabled them to feel very comfortable in sharing information.

Photovoice Session and Participant Analysis

Rights. No data provided by the participant.

Self-Determination. No data provided by the participant.

Emotional Well-Being. Debbie included a picture of her stuffed animal collection on her bed commenting that she felt safe in her bedroom and her stuffed animals gave her emotional support. "I cuddle up with them when I'm sad and play with them when I'm happy." As previously stated, Debbie said she felt safe in the apartment building because of the rules.

Physical Well-Being. Debbie took a picture of her favourite radio station. Debbie told the researcher that she likes to relax around the house listening to the radio. She commented that "Music from the 80's brings back memories from my childhood, music

from the 90's brings back memories of being a teenager." The researcher took a picture of Debbie eating in one of her favourite restaurants, and Debbie talked about how eating properly was important to being healthy. Debbie took pictures of Assiniboine Park and the Forks. She stated that they were nice places to walk around and she enjoyed the atmosphere and the scenery. Debbie also included pictures of these places in the social inclusion domain.

Personal Relationships. Debbie took a picture of her niece and grand niece at their home. Debbie commented that "My niece is more like my friend, I became an auntie when I was four."

Debbie took a picture of a former S.A.L. staff member. Debbie described her relationship with this woman, "She is like my guardian." Debbie went on to say that she still keeps in contact with her and misses her at New Directions. The picture the researcher took of Debbie and Holly together was also included in this category. Debbie described her relationship with Holly as "We are so close we're more like sisters." "We have been best friends for a long time."

Social Inclusion. Debbie took pictures of Assiniboine Park, one of the Duck Pond and one the flower conservatory; she talked about skating on the Duck Pond and commented that "I like flowers." Debbie took a picture of a store at the Forks to symbolize her love of shopping. Debbie took a picture of one of her favourite restaurants because "I like going out for dinner with friends."

Debbie and best friend Holly, at the Olive Garden.



Personal Development. No data provided by the participant.

Material Well-Being. Debbie and the researcher talked about how her stuffed animal collection could have gone into this category. While the researcher was driving Debbie and Holly home after dinner they both commented on how they should have taken pictures of their game systems they each own because they really enjoy playing video games. The researcher agreed to add their game systems to their material well-being domains.

Comments Regarding S.A.L. Services. Debbie said that she has received individualized support staff in the past when she has needed it. She said that sometimes staff had been very helpful, "I like some of the staff but not all of them." Debbie appreciated the support she received to find suitable housing. Debbie also commented on the group outings stating that "I especially like the camping trip, swimming and relaxing by the river." Debbie also said she enjoyed spending time in the lounge using the computer, watching movies or doing arts and crafts "when I want to." Debbie explained

that she goes to the lounge for awhile then "I get bored and take a break." Debbie said she has also attended the Aboriginal group.

Holly

Background Information

Participant Description. Holly is an attractive Aboriginal woman in her early thirties. Holly presents as a very warm, caring and friendly person. She interacted easily and appropriately with people we met during the photovoice session. Holly has a positive relationship with her mother and sees her regularly. Holly also mentioned having infrequent contact with a former foster family.

Past and Current Living Arrangement. Holly shared with the researcher that she spent her childhood and part of her adolescence in the family home and part in foster homes. Holly shared that she had both positive and negative experiences in foster care. An example of a positive memory was Holly living with a financially well off foster mother and having a beautiful bedroom. A negative memory was of a different foster mother calling one of the other foster children in the home "fat." Holly said "I yelled at her and told her that was a mean thing to say." Holly now lives with her boyfriend in an apartment in downtown Winnipeg.

S.A.L. Involvement. Holly receives individualized staff support a few times per week. Holly participates in the art class and the Aboriginal group. Holly enjoys the group outings and hanging out in the S.A.L. lounge.

Other Agency Involvement. Holly is involved with two programs in the provincial government department Family Services and Housing. She has an Employment and

Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). No other agency involvement was reported.

Recruitment and Participation in the Research Process

Holly attended the information session/lunch. Holly's interest in participating in the photovoice was not officially communicated to the researcher by S.A.L. staff. The researcher found out about Holly's interest when she met with her best friend Debbie to take her out for her photovoice session. When the researcher shared with Debbie that she (Debbie) was her last photovoice participant Debbie told the researcher that her best friend Holly wanted to participate as well and they wanted to do it together. The researcher and Debbie went to Holly's apartment hoping to catch her in. Holly was arriving home with her individualized support staff and was excited and able to participate that evening. Holly commented that "I was hoping to do this. I'm glad you came to get me." Holly, Debbie and the researcher went to New Directions to review and sign the consent forms in the presence of an S.A.L. staff. Holly and Debbie share a close and long term friendship and have many interests in common. They chose to take several of the same pictures but about half of the pictures reflected Holly's individual decisions about what contributes to her own satisfaction and happiness in life. Holly had not had the opportunity to give much thought to the photovoice research and the domains in quality of life. However, she started talking about what made her life worth living and then came up with several ideas for pictures to illustrate these factors during the discussion with the researcher and Debbie. As the photovoice session did not end until 9:00 p.m., Holly, Debbie and the researcher had a late dinner and agreed to meet the

following day to make up the boards. Holly taped her pictures on the boards and, for the most part, dictated the captions while the researcher wrote them on the boards. The researcher is of the opinion that the joint participation of Holly and Debbie in the photovoice research not only added to the researcher's enjoyment but also added a dimension to the research as their friendship and support for each other and their enjoyment in being out in and participating in the community together was reflected in the pictures.

Photovoice Session and Participant Analysis

Rights. No data provided by the participant.

Self-Determination. Holly took a picture of an eagle and a teepee to symbolize her participation in the Aboriginal group and her desire to learn about her culture.

Emotional Well-Being. Holly took a picture of her cat Muffin. Holly commented that "I love my cat, when my boyfriend isn't home he keeps me company." Holly and the researcher discussed how pets can help people feel safe and secure in their environments because "They know when you are down and they come to you."

Holly also included pictures of her cat in the Personal Relationships and Physical Well Being domains.

Physical Well-Being. Holly included a picture of her cat, Muffin, in this domain and commented that "I get exercise playing with my cat." Holly took a picture of her favourite radio station because she listens to music every day to relax. Holly took a picture of the conservatory at Assiniboine Park and commented that she likes walking

there. Holly took a picture of one of her favourite restaurants and commented that “The food is always fresh here.”

Personal Relationships. Holly included a picture of her cat, Muffin, in this category as well as the previous category and shared with researcher that “My family rescued Muffin when he was homeless and gave him to me, I’ve had him since he was a kitten.” The researcher took a picture of Holly and Debbie together. Holly commented that “We are best friends forever, I helped her when her mom died.” Holly and Debbie also told the researcher that they had been best friends for several years. Holly said that she wanted to take a picture of her favourite staff but she was not available. Holly took a picture of her favourite ex-staff member saying that she missed her a lot and had good memories of the time they worked together.

Social Inclusion. Holly took pictures of her favourite restaurant including a picture of the waiter. Holly had been joking with the waiter throughout dinner (this is the restaurant the researcher, Holly and Debbie went to). Holly commented “He is a good waiter and is kind of hot.” Holly said she enjoys eating in restaurants but rarely can because it is expensive. Holly took a picture of Assiniboine Park because it is one of her favourite places in the city.

Personal Development. Holly took a picture of decorated candles that she had made with art supplies from the S.A.L. lounge. Holly shared with the researcher that “I am giving them to my mom for Christmas.” Holly took pictures of a tepee and a mural of an eagle to symbolize her pride and interest in her culture.

Material Well-Being. When the researcher was driving Holly and Debbie home after dinner they both commented on how they should have taken pictures of their game systems they each own to symbolize their enjoyment of playing video games..

Comments Regarding S.A.L. Services. Holly stated that she liked the individualized staff support for grocery shopping, problem solving and making crafts at the S.A.L. lounge. Holly was very enthusiastic about the group outings saying that she loved the overnight camping and sitting by the fireplace. Holly sometimes liked hanging out in the S.A.L. lounge especially when they showed movies. Holly likes the Aboriginal group because she wants to learn more about her culture and enjoys the socialization component. Holly infrequently attends the art class.

Larry

Background Information

Participant Description. Larry is a white, physically fit male in his mid forties. Larry grew up with his brothers in a two-parent family in Winnipeg. Larry's father is deceased. Larry is in regular contact (weekly) either through personal visits or by telephone with his mother and a brother who lives in Winnipeg.

Past and Current Living Arrangements. Larry lived in the family home until he was in his early twenties, and since then has lived independently in the community with agency supports with the exception of a brief stay in a foster home. Larry was unhappy in the foster home stating "The foster care provider had stupid rules and was just in it for the money." Larry is currently living independently in a comfortable one-bedroom apartment in a high rise building in downtown Winnipeg.

S.A.L. Involvement. Larry receives individualized staff support a few times per week. Larry takes art classes in the S.A.L. lounge and occasionally socializes there. Larry participates in S.A.L. group outings such as the camping trip and the Christmas Feast. Larry received housing support to find his current apartment.

Other Agency Involvement. Larry is involved with two programs in the provincial government department Family Services and Housing. He has an Employment and Income Assistance (E.I.A.) Worker and a Community Services Worker (C.S.W.). Larry has had prior involvement with at least four other agencies that provide support for people with disabilities. Larry was dissatisfied with the supports he received from these other agencies and described them as being "unkind to people with disabilities", stating that "They tried to tell me what to do or they didn't respect my privacy and gave information about me to my mother and brother." Larry is currently involved with The Independent Resource Centre, Association for Community Living, People First, Community Care Incorporated, and the Y.M.C.A.

Recruitment and Participation in the Research Process

Larry did not attend the information session/lunch to learn about the research. The researcher had worked with him ten years ago while he was receiving services at another agency. The researcher re-introduced herself to him in the S.A.L. lounge. The researcher thought that Larry would enjoy participating in the research project and phoned the program coordinator to ask if Larry could be given the information about the project. The coordinator called back to say Larry was interested but needed more information and a time was arranged for the researcher to meet with Larry and his support staff. At the

conclusion of the meeting Larry volunteered to participate in the photovoice group and a time and date were set.

The researcher met Larry at his apartment. It seemed obvious to her that Larry had a very good understanding of what he was being asked to do in the photovoice process and had given considerable thought about which pictures he wanted to take to illustrate factors that contributed to his quality of life. Larry and the researcher spent the day taking pictures then dropped them off at a one-hour photolab and went to a restaurant for dinner. Larry and the researcher picked up the photos and went back to his apartment to sort them into quality of life domains and put them on boards. Larry was pleased with the quality of the pictures. The researcher spread the boards on Larry's living room floor. The researcher then asked Larry if he would like to tape pictures on to the boards and write comments under them. Larry helped the researcher sort the pictures into quality of life domains but was initially reluctant to make up the boards. Larry observed the researcher making the first board and told her what to write under the pictures. After the first board was completed he was confident about getting down on the floor and making the boards up himself. Larry seemed to enjoy the process. He explained very articulately the reasons for his choice of domains for each picture and the comments he wrote on the boards. Unfortunately Larry was not able to participate in the Focus Group.

Photovoice Session and Participant Analysis

Rights. Pictures taken included the Independent Living Resource Center, The Association for Community Living office building and staff, and the Community Care Incorporated office. Larry described the importance of the Independent Living Resource

Centre as "People who work there help explain my rights to me so I can be a better advocate." He described the people as "always friendly and willing to help me write advocacy letters." Pictures of the Association for Community Living (A.C.L) office building and staff were significant to Larry because "The staff are always there for me" and he meets with his People First group in the A.C.L. building. People First is a self advocacy group for people with disabilities. Membership is important to Larry because "This group stands up for people with disabilities." He commented that he has made friends in the group and that the staff at A.C.L are "always there for me." The Community Care Incorporated office picture was taken because Larry described their staff as "caring and understanding and this helps me to stand up for who I am."

Self-Determination. The pictures taken of the Independent Living Resource Center, the Association for Community Living building and the Community Care Incorporated office may also be included in the self-determination domain as Larry felt they all contributed to his sense of who he is and support his independent choices.

Larry chose to place pictures of his S.A.L. case manager and staff in the S.A.L. lounge on his self-determination board. Larry stressed that it is important to him that he chooses the agency that supports him. "It is my choice to be part of New Directions S.A.L. program." Other comments included "New directions is helpful to me in many ways. The staff never upset me, are open with me and this makes me happy. I like the way New Directions makes me feel. They treat me like I am somebody and they do not tell me what to do."

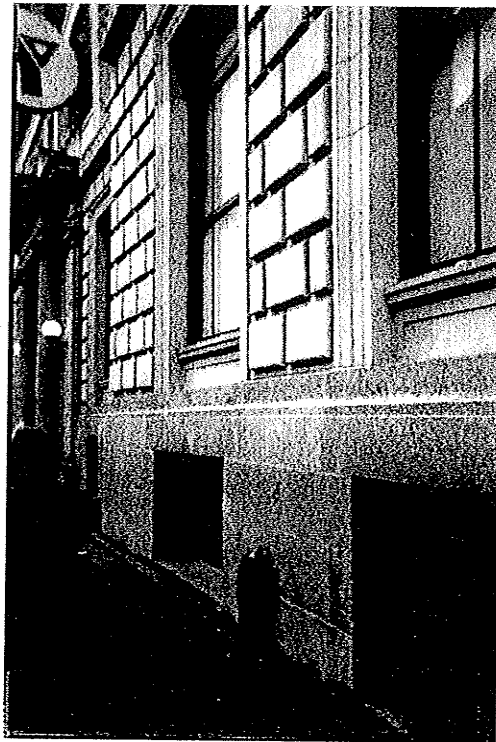
Emotional Well-Being. Larry took a picture of the outside of his apartment block because he said "I feel safe here and people keep to themselves and don't butt into

people's business.” Larry took pictures of the church he attends and made several comments about why the church was important to him. Larry said there are “kind people there, I meet with my brothers and sisters in the church, the priest is kind, and I like the singing and praying guides me.”

Physical Well-Being. Larry is a member at the downtown "Y" and attends frequently. He took a picture of the "Y" and commented that “It’s not a snobby place and is affordable because the fees are on a sliding scale.” He also said that exercise is good because it relaxes people, keeps them in good health and it “gets my mind off stressful things and I feel less anxious.” Larry said that he thought the researcher and his (Larry's) favourite S.A.L. manager should be going to the “Y” because it would be healthy and he was worried about their weight. The picture of bowling for Special Olympics was included in the physical well- being domain as well as in the social inclusion domain.

Larry spoke openly with the researcher about his mental health concerns and displayed a good understanding of the role of medication in managing his illness. He included a picture of his pharmacist because he understood the importance of having a pharmacist he could “trust to give me the information I need.” Larry and the researcher then discussed the importance of people receiving all information about the medication they are taking, possible side effects and negative interactions with other medications. Larry said that this pharmacist “gives lots of information about medication, he gives good advice and he answers questions.”

Larry keeps physically fit by 'working out' at the YMCA



Personal Relationships. Larry took a picture of his pharmacist and described him as “patient, helpful and a good listener.” Larry shared with the researcher that he has been on medications for a long time and he has had negative experiences with other pharmacists. Larry included his pictures of his case manager and his support staff in this domain because he felt the staff were good to him and were good listeners. The case manager “gives helpful advice but never pushes people to do things they do not want to do.” Larry was not able to include a picture of the People First group that he attends as they were not meeting at that time but he commented that he had made friends with people in the group.

Social Inclusion. Larry took a picture of bowling to represent his participation in Special Olympics which he described as a good social opportunity. He said “It gives me a chance to meet other disabled people” and “It is nice to practice and improve my score.”

Larry took a picture of the restaurant City Submarine in Portage Place because he said he likes to eat there after his workouts at the Y.M.C.A.

Other pictures illustrating Larry's use of community resources include the Y.M.C.A, the pharmacy and pharmacist, The Association for Community Living and the church he attends.

Personal Development. Larry chose to take pictures of certificates he has received for completing courses which he has displayed on the walls of his apartment. He commented that he likes school and likes taking courses. "Schooling helps me to succeed and have a better future [and] I like to learn new things and keep my mind busy." Larry took pictures of his art work (paintings) displayed in the S.A.L. lounge. He said that he participates in one to one art classes and commented that "Painting and drawing keep my mind busy and let me let out my emotions." Larry also stated that "Painting helps my mind succeed and is relaxing."

Material Well-Being. Larry took pictures of the inside and outside of his apartment building because he is proud of his clean and tidy apartment and of his possessions including furniture, artwork and certificates.

Comments Regarding S.A.L. Services. Larry values the individualized staff support because they assist him with grocery shopping, budgeting money and "they stand by what they say and are trustworthy." He also commented that if "they can't make it they phone and tell me." Larry said he likes to joke around with his staff and they are not rude. Most importantly "They are caring and gentle with disabled people, they never tell people what to do and they never badmouth people behind their backs." Larry also participates regularly in the art program. Larry states that "Painting lets me let out my

emotions like my pain and anger in my paintings.” Larry also participates in programmed group outings and commented that he especially liked the camping trip and the Christmas Feast. Larry said everyone who participated in the camping trip had some responsibilities and he “enjoyed pitching in and doing his share.” Larry described to the researcher why the Christmas Feast was so meaningful to him saying “My family does not celebrate Christmas and I would be very lonely if I had no one to share Christmas with.” Larry received housing support to find his current apartment.

Photovoice Group Results

The participants' categorization of experiences in Schalocks's (2000) quality of life domains are summarized in Table 4.1 and are followed by a discussion of the dominant and unique themes that emerged in each domain.

TABLE 4.1: Participants' Categorization of Experiences in Schalock's (2000) Domains

	Participants		
	Pete	Lucy	Julie
Rights	Home -I have the right to live in a safe area	Public Safety Building -Cops right to protection under the law	Law Courts Building -Sheriff protection and legal rights
Self Determination	Distinctive and unique appearance, hairstyle and dress		Boyfriend -I determine who I go out with -Warned against boyfriend by everyone
Emotional Well-Being	Home -I feel safer in this area -I like being on the main floor -clean apt	Former workplace	Church Group
Physical Well-Being	Group Outing -BBQs, Camping Assiniboine Park Zoo S.A.L. Lounge Laundry	Fridge-S.A.L Lounge Light Meal Prgm.	Playing Pool at her Residence
Personal Relationships	Staff Friends -Other S.A.L. participants	Staff Friends + Other S.A.L Participants Ex Boyfriend Brothers Mother + Children	Boyfriend Staff Friends – S.A.L. Participants Family + Family Dog
Social Inclusion	Restaurant Buses	Eating with Fiends in Restaurants	Playing Pool at the Residence with People
Personal Development	Artwork Class Cooking Class	Artwork(Quilting) Aboriginal Prgm.	
Material Well-Being	EIA Building -Ref checks coming in Jewellery Collection		

TABLE 4.1 Continued

	Participants		
	Jack	Zoe	Cam
Rights	Legislative Grounds -voting -file income tax	Wedding Ring -Right to be married Better Stairs at Duplex -Right to live at a safe place	Right to be Married
Self Determination			
Emotional Well-Being	Home Dog Flowers Neighbourhood Safe + Nice	Home -Safe, newly renovated	Old Family Home
Physical Well-Being	Walking Dog Light Meal Prgm. -Cleanliness in Kitchen at Lounge Movie Theatre	Food Bank Chiropractor	MTS Building -Walking, scenery Forks -Walking Ambulance -Healthcare Restaurant -Good food
Personal Relationships	Family Dog Friends Staff	Husband Smoky Cat Father-in-Law Chiropractor	Owner of Restaurant -Old family friend Wife Father Pet Smoky
Social Inclusion	Shopping at Mall Movie Theatre Walking Dog in Community Neighbours	Chiropractor + Assistant Ambulance Health Services	Restaurant with Friends Ambulance Health Services MTS Building Sporting Events
Personal Development			Old High School Education
Material Well-Being	DVDs -Own collection Present for Dog -Able to buy	Wind Chimes, Candles + Knickknacks -Favourite items decorative	

TABLE 4.1 Continued

	Participants		
	Debbie	Holly	Larry
Rights			Independent Living People First Community Care Office Self Adv. Rights for the Disabled
Self Determination		Eagle + Teepee -Learn about Aboriginal heritage	Ind. Living Rooms ACL CC Office Support Indpt. Choices
Emotional Well-Being	Stuffed Animal Collect. Bedroom Apt. Building	Cat	Apt. Safety Church
Physical Well-Being	Radio Station -music good for mood Restaurants -good food Forks -Walking, scenery Assiniboine Park -Walking, scenery	Cat -Exercise, playing with cat Radio Station -Music Assiniboine Park -Walking Restaurant -Healthy Food	YMCA -Exercise Special Olympics -How it Pharmacist -N.B. gives advice on medication, proper info Artwork
Personal Relationships	Family -Niece, grandniece Former Staff Member Best Friend	Cat Best Friend Favourite Staff/ Ex-Staff Mom	Pharmacist -Good relationship Staff ACL People -Friends made there
Social Inclusion	Forks Assiniboine Park Restaurant with Friends Store Shopping	Restaurant Waiter Assiniboine Park	Special Olympics Restaurant YMCA Pharmacy ACL Church
Personal Development		Artwork Candles Eagle + Teepee -Pride + interest in her culture	Educational Certificates -Education Artwork
Material Well-Being	Stuffed Animal Collection Game System	Game System	Apt. -Own Apt. possessions including furniture, artwork + certificates

Themes Within Each Domain

Rights

Seven participants provided data in this domain. Two participants provided no data for this category. Two participants took pictures to demonstrate that they understood and felt they had the right to use the legal system and law enforcement to provide safety. Both participants had exercised their right to protection under the law by obtaining protection orders against men that were a threat to them. They both expressed positive feelings about the response from and treatment by the police involved. Two participants took pictures of their housing units to demonstrate that they had the right to live in safe housing. One participant asked the landlord to improve the condition of the stairs for her safety. The other participant requested help from S.A.L. staff to find accommodations in a safe area. Two participants (married to each other) included pictures of themselves together as a couple to symbolize the right to be married. One participant shared with the researcher that she had moral reservations about living common law and was much more comfortable being married. One person took a picture of the legislature grounds to demonstrate his right to vote and the importance of filing income tax. One person took pictures of several agencies that both advocate on behalf of and teach self-advocacy skills to people with disabilities. He stated that the pictures illustrated his right to belong to these organizations and to use their services. He had a good understanding of the agency services and used staff to help with writing letters on his behalf and for advice.

Dominant Themes. The main theme that seems to emerge from these results is that the participants who had an understanding of and used their rights to safe housing, protection from the legal system, to marry, and to vote were pleased with the outcomes

and the treatment they received from the different systems. They had either self-advocated for these rights or had approached staff to advocate on their behalf. Knowledge of and the ability to use skills to advocate for themselves appears to have a positive impact on quality of life in the rights domain

Unique Themes. The unique theme was the strong interest in disability rights and the exercise of these rights of the one participant who was actively acquiring self-advocacy skills. He was involved with several agencies that advocated for individuals with disabilities, and attended People First meetings. People First is an international self-help organization whose membership is made up of people with disabilities who advocate for disability rights.

Self-Determination

Four participants provided data for this domain. The four participants who placed pictures in this domain seemed to have a clear understanding of this domain and why the pictures belonged in this domain. One participant described her choice of her partner as having "made up my own mind to date him even though friends, family and staff "disapproved of her involvement with this person and had tried to discourage her from becoming involved with him. One participant included her a picture illustrating Aboriginal culture as symbolic of her desire to learn more about her Aboriginal culture and her participation in the Aboriginal group. One participant said his prior experiences with several other agencies had contributed to his decision to be supported by New Directions because they delivered services in a respectful manner (S.A.L. staff had respected his privacy by refusing to release information about him to family members

without his consent). The other agencies had given information about him to family members against his wishes. One participant, with prompting from the researcher, agreed that his distinctive style of dress, his hairstyle and his choice to wear jewelry could be included in the self- determination domain. Five participants provided no data for this domain. The researcher attributes this low level to several possible factors, including the lack of a sufficiently clear explanation of this domain given by the researcher, and the overlapping of the domains. All the participants had taken several pictures they could have placed in this domain but they chose to place them in other domains. As the S.A.L. services the participants were using were not mandated services, all of the participants were making decisions and exercising choices on a daily basis. One example of the overlapping of domains was the decision by the one participant who wanted to be married rather than continue in a common-law relationship to include the picture of her husband and herself under the rights domain to illustrate their right to be married. This picture could also have been placed under the self- determination domain to symbolize her decision to marry rather than live common law.

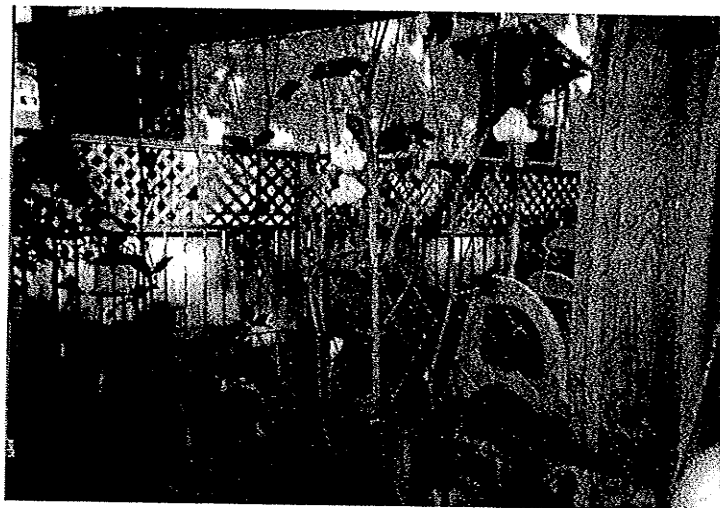
Dominant Themes. The theme common to all four examples is the exercise of personal choice, either in the face of opposition from others or not.

Emotional Well-Being

All nine participants provided data for this domain. Six participants put safe housing in safe neighborhoods in this category. Two participants included pictures of their pets in this domain. Two participants included involvement with the church and church groups in this category. One participant took a picture of her former work place.

Dominant Themes. The positive impact safe housing in safe areas has on emotional well-being was the dominant theme that emerged in this domain. Six of the nine participants took pictures of their residences. Participants' comments about the importance of safe housing included statements that they felt safer in their current housing than they did in their previous housing. This increased feeling of security was the result of either being relocated to safer neighbourhoods, or increased safety in the housing itself (security systems, improved locks, buzz up system) or both. One participant said the relocation from a second story apartment to a main floor apartment was important to him because he experienced physical difficulty managing stairs and felt safer in his new residence. Two of the three participants who did not include safe housing in this domain were in short term room and board facilities and perhaps did not attach emotional well being to a very temporary lodging situation.

A Safe Neighbourhood



The important contribution caring for pets can make to quality of life was a secondary theme in this domain as two participants included pictures of their pets. One

participant said that his pet gave him a feeling of safety and security because he would bark to warn him if there was any trouble in the apartment building. The other pet owner said that her pet was good company when she was home alone. One participant included a picture of her stuffed animal collection and commented that she likes to cuddle with them when she is feeling sad. This participant was not allowed to have a live pet because of restrictions in her room and board facility.

Unique Themes. Participation in church groups and services emerged as a unique theme in this domain. Although only two participants took pictures to symbolize their participation in church activities, their comments indicated that it was very important for them to have a welcoming and safe place for them to meet, pray and talk with other people who shared their spiritual beliefs.

The participant who included a picture of her former work place chose to do so because of the positive memories she has of working there with co-workers who were good to her. She expressed a desire to work there again in the future. Her memories of her past employment and of her co-workers were very positive. The theme of positive employment experiences is a unique theme as she was the only participant to mention this. Few of the S.A.L. participants have regular employment.

Physical Well-Being

All nine participants provided data for this domain. Five individuals stated that walking outside in the fresh air was important to their physical well-being. Favourite places to walk in the community included the Forks and Assiniboine Park. Three individuals commented on the importance of being able to access healthcare: one

example was the availability of emergency services (calling an ambulance when necessary) Another example was visiting medical professionals (pharmacist, chiropractor) to receive advice and assistance. Three individuals talked about eating healthy food in restaurants. Three participants included the availability of food from the light meal program and food bank at S.A.L. lounge. Comments included reference to money from E.I.A. being inadequate and the security of knowing that if you are hungry there is always food available in the lounge. Two participants included listening to music as being important for relaxation. One participant played pool. One participant enjoyed going to the theatre. One participant worked out regularly at the Y.M.C.A. and participated in Special Olympics. One participant mentioned the S.A.L. group outings. All the participants included at least one picture and seven participants more than one picture in this domain, and they all seemed to have a good understanding of components in their lives that contributed to their physical well-being.

Dominant Themes. A dominant theme was the use of free or low cost community resources, facilities and establishments while they were engaged in healthy activities. For example, favourite places to walk in the fresh air included the Forks and Assiniboine Park, services essential to health included ambulances, healthy food included eating in local restaurants occasionally, one participant was a member of the Y.M.C.A. and one participant enjoyed going to movie theatres. All of these pictures could have been included in the social inclusion domain as these choices reflect the choices made by people in the general population.

The significance of healthy and adequate food to physical well-being is reflected in that three individuals took pictures to illustrate the light meal program or the food bank and three different participants took pictures of restaurants.

Unique Themes. The unique theme in this domain is the insight shown by the one participant into the role played by medication in managing his mental health concern. He wanted to stay informed about the benefits and side effects of his medication and had found a pharmacist with whom he felt comfortable asking questions and seeking advice.

Personal Relationships

All nine participants provided data for this domain. Eight of the nine participants included pictures of S.A.L. staff in this category. Eight of the nine participants included other S.A.L. participants as friends.

Seven of the participants took or wanted to take pictures of their family or extended family members. In a few cases family members were not available. Five participants took pictures of their pets. Two participants took pictures of medical professionals. The two participants who are married to each other took pictures of their spouses.

All the participants demonstrated a clear understanding of this domain and the importance they attach to personal relationships is reflected by the fact that all but one of them of them had a minimum of three pictures in this domain and that participant had one.

Dominant Themes. In addition to the concrete assistance participants received from staff (budgeting, grocery shopping, cooking, cleaning, etc.) the participants also

attached importance to the relationships they formed with staff. The participants commented on the comfort level and fun they felt while joking around with staff, the trust they had in talking over personal issues with staff and the assistance staff gave them with problem solving. Participants seemed to need and want the concrete services but highly valued the emotional and social support they received from staff.

Friendships formed between program participants emerged strongly as a dominant theme. A few of the participants were acquainted with each other before entering the S.A.L. program but most of them met and made friends with the others through outings, group activities, attending scheduled activities in the lounge or “hanging out” in the lounge. The opportunities and encouragement the S.A.L. program gave participants to develop individual friendships and networks of friends appeared to be helpful in preventing and alleviating loneliness, boredom and isolation.

The theme of the importance of family relationships was reflected in the choice of the seven participants who included pictures of family or extended family in this domain.

The theme of the importance of pets is reflected by the comments the five participants used as captions over the pictures of their pets. Pets were described as good sources of companionship and it appeared that pet ownership contributed to a sense of pride and competence.

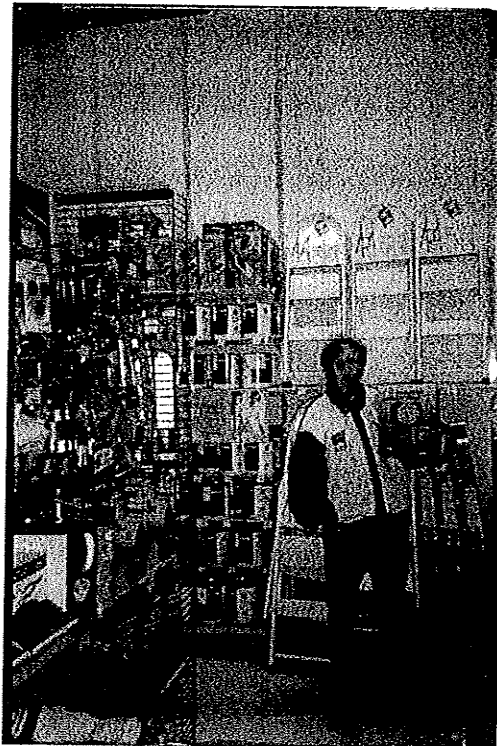
Unique Themes. Two participants took pictures of medical professionals. One individual said he had had negative experiences with other pharmacists who did not give him the information he wanted. The pharmacist he was currently using took all the time needed to answer his questions and gave him good advice. Another participant described her relationship with her chiropractor as important because he took the time to talk with

her about a variety of topics as well as her health and she felt comfortable talking with him. The common theme from these participants was that both these professionals took the time to ensure that the participants had their questions and concerns addressed and treated them with friendly respect.

The two married participants included the pictures of their spouses and pictures of the two of them together as a married couple. This is unique theme as they are the only two participants who are married.

Social Inclusion

All nine participants included data in this domain. Six participants included pictures of restaurants to symbolize socializing while having coffee or eating out with friends. Three participants included pictures to symbolize their use of healthcare services. Two participants took pictures of stores to symbolize shopping.



Two participants took pictures to symbolize being a spectator at movies or sporting events. One participant took a picture of bowling to symbolize his participation in Special Olympics bowling. One participant included a picture of herself playing pool in a common room at her room and board facility. The researcher found that an explanation of this domain was necessary early in and throughout the photovoice research. The first few participants thought that S.A.L. program activities would be included in this category, but, when the researcher explained, were able understood the distinction between participating in S.A.L. programming and general use of community resources and inclusion in community activities.

Dominant Themes. It appeared that socializing with friends was an important component of social inclusion. The pictures the participants chose were illustrative of activities chosen by members of the general population with the one exception of the participant who included his Special Olympics bowling.

Unique Themes. Participation in Special Olympics is unique because it is a program outside of New Directions for individuals with disabilities. Special Olympics is an international program with local groups in communities. The community activities at the local level are run by volunteers from the community.

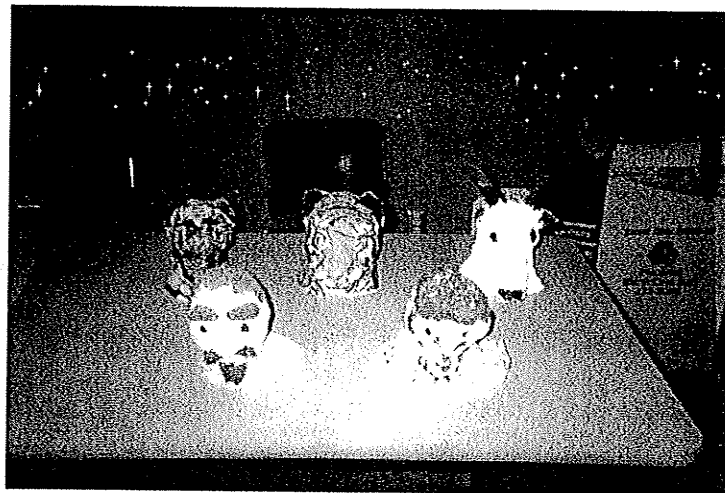
Personal Development

Five participants included data in this domain. Four participants included pictures of their art. Two participants included pictures to symbolize formal education. One participant's picture was of his former high school but he was not involved in any formal education at present. The second participant was actively involved in taking a variety of

courses. Two participants included pictures to symbolize their involvement in the Aboriginal group. One participant took a picture to symbolize the cooking class. Four participants provided no data for this domain. The pictures taken by the five participants for this domain demonstrated a good understanding of the concept of self- development. Pictures included in other domains could have been included in this domain. For example the picture symbolizing belonging to a group in the church could have been included in this domain.

Dominant Themes. The participants' appreciation of the opportunity to do art in the art class as well as with their individual support staff and of the availability of art supplies in the lounge was a common theme. They were proud of their art work and one participant said that she would be giving some of her art work to her mother for Christmas. Participants' comments indicated that they were aware that they might not have had the opportunity to make art if the S.A.L. program was not available due to the expense of buying art materials and the fact that the individual assistance would not be available.

An Example of the Many Different Types of Art created in the Art Class.



Unique Themes. The two participants who included participation in the Aboriginal group talked about the importance of learning about their Aboriginal culture and the comfort they experienced spending time with people in the Aboriginal group.

One of the participant's pride in completing courses was evidenced by having the certificates he had received framed and hung on the walls of his home. He spoke about the positive role new learning played in keeping his mind busy and how this helped him manage his mental health concern and he planned to keep taking courses. The theme of continued education and the contribution it makes to positive self esteem and growth and the insight he has about the role it can play in helping manage the symptoms of mental illness was unique.

Material Well-Being

Six participants provided data for this domain. Six participants took pictures of their favorite personal possessions including D.V.D. collections, game systems, jewelry and knickknacks. One participant took a picture of the E.I.A. building to symbolize the importance of having a guaranteed income. One participant took a picture of a present he had purchased for his dog. Three participants provided no data for this category. One possible explanation for not having pictures in this domain is that two of the three live in very small rooms in temporary room and board facilities. The rooms offer very little space to display material possessions.

Dominant Themes. All six participants that gave data took pictures of their favourite personal possessions including d.v.d. systems, a jewelry collection and

decorative items including wind chimes and candles. The importance of these personal possessions is reflected in their comments about being able to watch this video whenever they wish or the pleasure they remember in making the work of art.

Unique Themes. In addition to his pictures of personal possessions, the participant who included the picture of the E.I.A. building indicated that he felt good and it was important to know that he had the money to pay bills and buy groceries and that his rent will be paid.

One participant was proud of managing his money well and demonstrated that by taking a picture of the present he was able to buy his pet. One participant commented that having his own clean and tidy apartment illustrated material well-being. This was unique.

Use of S.A.L. Services

All nine participants enjoyed the organized group outings especially the camping trip, and BBQs. All nine participants described the individual staff support hours they received as very important to them. All nine participants commented that they enjoyed spending time and socializing in the S.A.L. lounge.

Eight participants had received support finding a place to live by either their case manager or their individualized support staff. Six participants attended the art class. Four participants used the food bank. Three participants attended the cooking class. Three participants attended the Aboriginal group. Three participants used the light meal program. Two participants used the laundry facilities in the S.A.L. lounge.

Light Meal Program



TABLE 4.2: The Use of Services by S.A.L. Participants

		Categories									
		Housing Support	Group Outings	Art Class	Cooking Class	S.A.L. Hanging Out	Laundry	Indiv. Staff Support	Light Meal Prgm.	Aboriginal Group	Food Bank
Participants	Pete	X	X	X	X	X	X	X			
	Lucy	X	X	X		X		X	X	X	
	Julie*	X	X		X	X	X	X			X
	Jack	X	X	X	X	X		X	X		X
	Zoe	X	X		X	X		X			X
	Cam	X	X			X		X			X
	Debbie	X	X	X		X		X		X	
	Holly		X	X		X		X		X	
	Larry	X	X	X		X		X			
TOTAL		8	9	6	3	9	2	9	2	3	4

Suggestions for Improvements in Existing Services and for Services

One participant suggested that notices be posted in the lounge several days in advance of any planned early closure of the lounge This will prevent the frustration

experienced when a participant makes a trip to the lounge and finds it closed. One participant suggested that a weekly music class be added to S.A.L. services.

Dominant Themes. All participants enjoyed at least some of the group outings with some comments that there should be more of them. The camping trip received the highest number of comments. The theme running through the comments was that camping gave them a chance to get out of the city overnight to experience a little holiday, enjoy bonfires, roasting marshmallows, swimming, socializing with others in a different environment. Camping afforded the participants the opportunity to participate in a variety of activities that were not available to them in the city and their enjoyment of the experience was reflected in the enthusiasm of their comments. One participant commented that he liked the chance to participate in the work on the camping trip as he said everybody has a job and it feels good to pitch in. Several participants mentioned the barbecues at Assiniboine Park and the good food and fun this outing provided. One participant who had joined a Christian church but whose family did not celebrate Christmas specifically mentioned that the Christmas Feast was important to him as it gave him the opportunity to celebrate with others.

The group outings give the participants the opportunity to socialize with staff and other participants, share fun times and develop friendships and give them a steady supply of activities to look forward to with anticipation. The friendships formed and the memories of good times shared with others seems to be an effective method of alleviating the sense of isolation and loneliness which can be a problem with independent living. The group outings were seen as contributing to their quality of life in several domains, especially in personal relationships and physical well-being domains. The reality of living

on E.I.A. would preclude the majority of the participants from being able to finance even a brief holiday. Some type of holiday is common to most members of society and the camping trip gives the participants an opportunity to have a holiday.

All nine participants attached significant value to the individualized staff hours they received on a regular basis with one participant commenting that it was important to her that staff would call if they were unable to come. The participants used their staff hours in a variety of ways with some participants relying on assistance with concrete tasks such as cooking, cleaning, grocery shopping and budgeting. All participants enjoyed the sense of camaraderie they felt with staff and this appeared to be an important source of social support to them. Most participants reported feeling a good comfort level with staff and this enabled them to turn to staff for advice and assistance with problem-solving. The individualized staff support provided a valuable source of social support. One of the participants took a picture of a former staff with whom she had formed a bond and included it in the personal relationships domain.

All nine participants make good use of the S.A.L. lounge. Comments indicated they valued the chance to have fun interacting with staff and other program participants. The main theme that emerged was that the lounge gave them a safe, comfortable place to go to hang out, play games, talk with other people, get something to eat, do their laundry and get assistance with personal issues. Almost all of the participants had made friendships with other participants in the lounge. Use of the lounge seems to give the participants a sense of belonging and connection to a group. The lounge and the activities available there are provided at no cost to the participants. All of the participants are on E.I.A. and would not have been able to afford a very active social life in the community

Eight participants had used housing support from the S.A.L. program. Several of the participants commented on how unsafe they had felt in the areas from which they formerly lived. The researcher noted that all six of the participants who had been moved into their own homes invited her in and appeared to be proud of their living arrangements, wanting to take pictures both inside and outside of their space. Several had their possessions and art work displayed and one participant had his certificates framed and hanging on the wall. The one participant who lived in a nicely furnished separate suite in a long- term board and room facility also invited the researcher into her home, but the two participants who lived in short term board and room facilities did not invite the researcher into their homes. All four of the participants who were pet owners lived in their own housing. One participant who was very fond of her family's dog commented that she was not allowed to have a pet in her board and room facility. The importance of safe housing in safe areas and the contribution it makes to quality of life in several domains and the valuable part played by the housing support program was evident.

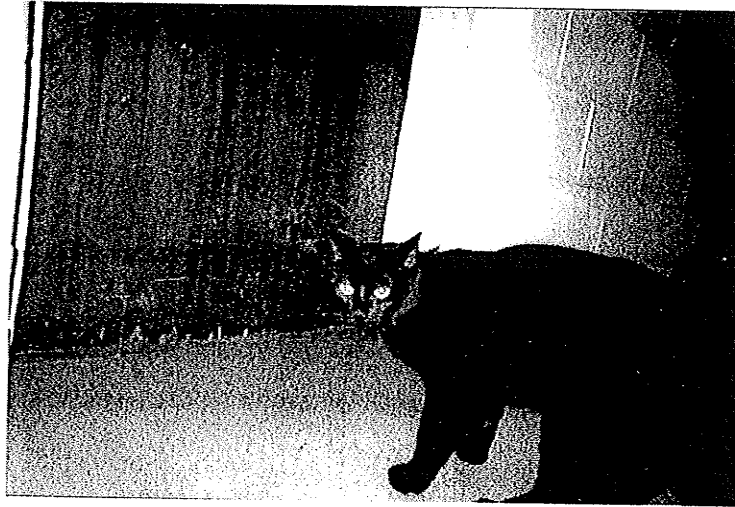
Important Themes That Overlap Domains

Safe housing in safe areas was a dominant theme in the domains of emotional well-being, rights, and a unique theme in the material well- being domain. The value the participants placed on safe housing in safe areas is reflected in the statistic that eight of the nine photovoice participants had used the housing support service.

Five of the nine participants owned pets and pet ownership was a dominant theme in the domains of emotional well-being and personal relationships, and a unique theme in the material well-being domain. Additionally, getting exercise by walking the dog or by

playing with the cat were mentioned by participants in the physical well-being domain, and one participant mentioned meeting neighbours when he was walking the dog which could be included in the social inclusion domain.

Pet Ownership



Physical exercise, recreational activities and socializing in the community with friends were included in the domains of physical well-being and social inclusion. Examples included participation in Special Olympics and going to the Y.M.C.A., walking around and hanging out at the forks and Assiniboine Park and eating and having coffee in restaurants.

Participation with church was included under the domains of emotional well-being and social inclusion.

Researcher's Influence on Photovoice Results

The researcher explained to the participants that they would have ample time and transportation to take pictures as she would use her car and was available to accompany

them into the community at different times of the day. In a few instances the photovoice took place over two days. The participants understood that they would be given a copy of their pictures with an album and this generated some excitement which could have contributed to the participants giving extra thought and care about their choice of pictures. Some of the participants had arranged a meeting time with a friend or relative to take a picture. The researcher was impressed and pleased that the participants had carefully considered the choice of pictures.

It was important to the researcher to ensure that participation in photovoice research was a positive experience for the participants. For example, the researcher suggested the participant accompany her to have a meal in one of his/her favourite restaurants while the pictures were being developed. In a few instances the participant suggested a fast food restaurant and the researcher asked if the participant would like to try a different restaurant. One participant really wanted to go to a fast food restaurant and enjoyed his meal there but the other participants opted for slightly more upscale restaurants. Overall, the participants appeared to have an enjoyable day. They were treated well and this resulted in participants responding in a positive and upbeat perspective.

The researcher and each participant were together for several hours, and inevitably some negative topics of conversation came up, for example one participant was upset because her boyfriend was incarcerated. The researcher redirected the person back to a positive frame of mind by asking about subjects the participant enjoyed, for example asking for more information about the camping trip. On a few occasions participants told the researcher that he/she wanted to take a photo that was not available and the researcher

suggested taking a picture to symbolize the picture the/she wanted to take. Thus, the researcher deliberately attempted to keep participants focused on positive aspects of their lives. This was done to meet the overall objectives of the research (i.e. positive quality of life, to meet the personal objectives of the researcher and to provide a positive experience for the participants).

Results

Focus Group One

Group 1 consisted of four participants, three men and one woman. The woman and one of the men were in the foster care program but also used the lounge and participated in S.A.L. programming. The other two participants were in the S.A.L. program. One support staff attended the group. The participants were engaged in the discussion and were respectful of each other, taking turns talking and listening when others were speaking. Unfortunately they were tired near the end of the two hours and consequently they did not contribute much data to the S.A.L. services section.

Focus Group Two

The focus group was composed of eleven participants. Eight of the nine photovoice participants attended. Three other S.A.L. program participants had been confused by the posters inviting the photovoice participants to the focus group and signed up for the group. The researcher did not want to discourage their participation and they were included in the focus group. One of the three S.A.L. participants arrived quite late and

missed the discussion on the rights, self determination, personal development and physical well being domains. One of the photovoice participants was ill but wanted to attend. She participated in as much of the discussion as she was able, but, unfortunately, she frequently had to leave the room for short periods of time.

The video recorder stopped functioning during the discussion of the physical well-being domain and although the video camera operator took notes of the discussion this may have resulted in less data for this domain.

As previously discussed in the section on group photovoice results the researcher thought that her explanation of the self-determination domain had not been sufficiently clear and the lack of data from a significant number (five) of the participants was the result. A number of participants had placed data in the rights domain that could also have been included in the self determination domain. The researcher decided to combine the rights and self- determination domains because of the overlapping of the data in these two domains in the photovoice group results. An additional consideration was the time limit of two hours to complete the objective of discussing all the domains and the favourite S.A.L. services. As in focus group one the participants appeared tired during the discussion about S.A.L. services and this may have contributed to receiving less data.

Focus Group Results

The focus groups one and two results have been combined under each of the domains. These results reinforced, and, in some instances, strengthened photovoice results and contributed three additional dominant themes.

Rights/Self-Determination

The researcher was impressed with the participants' understanding of the meaning of rights and self determination. One participant described his understanding of rights as "Everybody has rights. I have rights and you have rights and my rights are equal to your rights. You have to appreciate every ones right's."

Focus group results reinforced and added to the positive perceptions of the health care and justice systems noted in the photovoice results as several participants gave examples of exercising these rights and being pleased with the outcomes. Comments included "People have the right to stay in a safe place to get well." "Police were helpful and respectful." "The Police took me to the hospital, made sure I got food and had a place to sleep" and "If you are being followed all you have to do is call the police and they will help you."

A dominant theme from the large focus group was the importance of having control over one's own life. The clear consensus was that they wanted to make their own decisions without being told what to do by others, including their families and staff.

Emotional Well-Being

The focus group participants reinforced the photovoice results about the contributions made by safe housing in safe areas and pet ownership to the domain of emotional well-being. Comments included "Friends come to visit you when you live in a safe place." and "I feel safe because I live in a locked building with locks on the doors."

The importance of feeling physically and emotionally safe was expanded in the first focus group to include environments other than their homes. All four participants in this focus group agreed that they felt safe attending the S.A.L. lounge, and liked the security guard presence in the building, specifically the security guard posted at the entrance to the building. One participant added that she liked the rules about respecting the rights of others in the lounge and felt safe knowing that there were rules. Two participants stated that they felt safe due to visible security guard or police presence in downtown Winnipeg and at Portage Place. One participant said that he felt safe in his church as he knew his jacket would not be stolen. He added that praying makes him feel good and at peace. The topic of physical safety in environments other than their homes did not come up in the second focus group or in the photovoice results.

Physical Well-Being

The dominant themes from photovoice including getting regular exercise and eating healthy food were supported by the focus group results. The unique theme of medication management in the photovoice group emerged as a dominant theme in the focus groups. The majority of participants commented on the importance of medication and having a good relationship with your doctor. Some participants were on long term

medication monitored by a doctor. One participant shared that his doctor had explained to him side effects of his medication. Another participant described his doctor giving everyday good advice about washing hands after you use the bathroom and before you eat. One participant took over the counter medication when she had a cold. Three participants took vitamins regularly. At least three participants volunteered that they had had a flu shot.

Focus group participants shared more information than photovoice participants about the activities they did to relax. Activities included listening to music, watching television, going to movies, playing cards, taking long bus ride, reading and going out for coffee with friends (the two friends he named were part of the focus group). One person commented that attending the Aboriginal group helped her to relax.

Personal Relationships

The dominant themes from the focus groups of relationships with family, pets, friends and S.A.L. staff reinforced the photovoice results. The depth and quality of friendships formed between S.A.L. participants and the importance the participants attached to the relationships formed with staff were striking. At least two of the friendships are between men and women and several of the friendships had endured for years.

Social Inclusion

The dominant themes of socializing with friends including shopping, having coffee and meals in restaurants and going to public parks and malls and accessing medical care mentioned in the photovoice results were also dominant themes in the focus groups. The use of public transportation emerged as a dominant theme in the focus groups and had not emerged in the photovoice. All participants used public transit (bus) as their main form of transportation. Comments included "The bus takes me anywhere I want to go," and "I know all the bus routes." One participant shared that he sometimes takes the bus for fun and enjoys talking to the bus drivers. One participant shared that he had a bus pass. All the participants seemed to know their bus routes well and felt comfortable using the system. They used the bus to visit friends, get to work, to shop, go out for coffee. The existence of an adequate bus system is important for social inclusion but had not emerged as a dominant theme in the photovoice group. The researcher used her own car for photovoice and the subject of transportation did not come up.

Participants mentioned doing their grocery and personal shopping in local stores and malls located in their community including Portage Place and a Christian Bookstore. Dancing at socials or church functions emerged as a theme in the focus groups.

Personal Development

Participation in the art classes, the Aboriginal group and the cooking classes were dominant themes in the focus groups with increased emphasis on the importance of the cooking class and the Aboriginal group. The art class was a dominant theme in the photovoice results and the Aboriginal group and cooking classes were discussed but were

not dominant themes. Comments about the Aboriginal group included "'I lost my dad and my brother and my mother will be next, going to the group helps deal with losses" and "Smudging helps keep bad spirits away" and "Smudging cleanses the soul."

A large majority of the participants had acquired some knowledge of computer usage. The degree of expertise ranged from awareness that information and pictures can be found on the internet to using the computer to play games, searching the internet and burning compact discs. Many of the participants used the computer in the lounge and received help from S.A.L. staff and/ or other participants. One participant mentioned looking up information on the internet with staff. The acquisition of computer knowledge and skills emerged as a dominant theme in the focus groups but had not been a factor in the photovoice results.

Use of the public library to access information and to borrow books for self-teaching or for pleasure reading emerged as a unique theme in the focus groups. One participant shared information about the variety of jobs he had worked at in the past few years including snow shoveling, working on a moving van and delivering frozen food. He appeared to be proud of his work ethic and that he was making money. This enthusiasm for work was a unique theme.

Material Well-Being

The dominant theme of ownership of personal possessions (an angel card) with the emphasis on electronic equipment (compact discs, stereos, televisions, video games and game systems)as discussed in the photovoice results was also a dominant theme in the focus groups. The only participant who did not mention having electronic equipment

lived in a hotel room and mentioned that the police were in regular attendance to settle disputes between the residents. He did not feel safe in his environment and perhaps thought his possessions would be stolen if he kept them in his room. He did mention that he owns some caps and sports pictures as he likes hockey.

One participant mentioned that she had her own home with a lawn. One participant mentioned that he owned a dog.

Comments Regarding S.A.L. Services

The most valued S.A.L. services were the individualized staff support, the group activities, the well- equipped and staffed lounge and the housing support.

The positive comments made by the participants about the individualized staff support demonstrated the importance of the contribution it made to their quality of life. One of the participants commented that "I have been with this charming gentleman for a long time" referring to the support staff who was in the focus group with us. He said they went out shopping and did other activities together

The focus group participants were also enthusiastic about the art and cooking classes and the Aboriginal Group.

Discussion of Focus Group Results

The group results from the focus groups reinforced the themes from the photovoice group results in all the domains with the additional dominant themes of the importance of public transportation to their quality of life and their computer use. All the focus group participants used the bus as their main mode of transportation and were familiar with the routes they needed to know. The participants felt comfortable taking the bus and a few participants mentioned taking the bus just to see the city. Public transportation emerged as a dominant theme in the domain of social inclusion but had a positive impact on emotional well being, physical well being and personal relationships.

All participants in the second focus group had acquired a degree of computer knowledge and skill. The researcher had not asked the photovoice participants about their computer use and computer use was not mentioned in the first focus group. During the discussion of the personal development domain in the second focus group, one participant said he used the computer in the lounge and all of the other participants joined in to discuss their computer use. There was a computer in the S.A.L. lounge and the participants had all acquired some degree of skill and knowledge from self- teaching, experimenting, and/ or receiving help from other participants and staff.

The Aboriginal group was discussed as making a positive contribution to quality of life in the emotional well-being and personal development domains in the individual and group photovoice results but emerged as a dominant theme in the focus group results. The six participants who attended the group were very expressive and passionate in their descriptions of the meaning this group had for them.

The two participants who were married to each other had included the right to be married in the rights/self determination domains but the role of the S.A.L. program and staff emerged again in the second focus group. The participants wedding was held in the S.A.L. lounge and S.A.L. staff had been very helpful in helping with the planning and arrangements but also in supporting the decision to be married. The S.A.L. participants both had memories of their wedding as being very special and gave the staff a lot of credit for making the day wonderful.

CHAPTER 5: DISCUSSION AND CONCLUSION

The final chapter focuses on assessing the factors identified in the literature review that negatively impacted on individuals in supported apartment living programs. These factors include isolation and loneliness, inadequate housing, lack of activities, poverty, and difficulties with problem-solving and other community living skills. In the following discussion the S.A.L. services will be reviewed as to their effectiveness in addressing these problems, the domains of quality of life the services affect, and the research results from the photovoice and focus groups as to the participants use of the service. Participants' recommendations for additional services and improvements to current services are included. The chapter then examines the possible impact this research could have on social work, including realistic actions that can improve S.A.L. programs by organizations and individuals on the front lines. Chapter five ends with concluding remarks from the researcher.

Assessing the S.A.L. Factors

Isolation and Loneliness

Isolation, loneliness, the need for social relationships, social support, recreation, safe housing and the negative effects of poverty were identified in the literature review as concerns in supported apartment living programs (Parkinson, et. al., 1999; Schalock et. al., 1981; Vandergriff & Chubon, 1994). Social supports have a positive effect on all

domains but are especially important to emotional well-being, social inclusion and personal relationships.

All the S.A.L. services, directly or indirectly, identified the reduction of isolation and loneliness and the alleviation of poverty as anticipated outcomes. The following services are viewed by the participants as the most effective in contributing to the domains of emotional well-being, social inclusion, and personal relationships.

The Two Lounges

With the exception of one individual all the participants rated the lounge as one of the four most important S.A.L. services. The lounge was perceived as a physically and emotionally safe place to go to socialize with friends and staff, have a light lunch, get help with personal or relationship issues, relax, play games, create art, use the computer, and participate in organized classes to develop skills and enhance self development. A few of the participants welcomed the presence of security personnel in the building housing the New Directions offices including the S.A.L. lounge. One participant commented that she felt safe in the lounge because there are rules about respecting others and staff are always present. The security guard and the rules of the lounge enhanced individuals feelings of positive emotional and physical wellbeing as well, the presence of staff, food and other participants in the lounge foster a sense of inclusion and belonging. The lounge contributes positively to the domain of personal development by promoting competence as they learn new skills in the classes and at the computer. Emotional well-being is supported as they know there will be staff there to assist with problems if needed and friends and staff with whom to socialize and play games. The availability of healthy

food if they are hungry contributes to the physical well-being domain. The use of the lounge contributes to the personal relationships domain as using the lounge gives the participants the opportunity to develop or strengthen friendships with other participants.

Friendships formed in the lounge and in the group activities frequently extend to sharing activities in the community outside of the S.A.L. program. Many of the friendships have lasted for years and some of the participants expressed satisfaction in having helped other participants through difficult times. This social support from peers positively contributes to the domains of emotional well-being and social inclusion, as loneliness and isolation are decreased and options for leisure activities are increased. Some participants included their art work in the domain of material well-being. Self-Determination is respected as participants choose whether or not to go to the lounge All the S.A.L. services are voluntary. The participants were pleased with the opening of the new lounge and with the extended hours which now include weekends.

Opening of the new S. A. L. Lounge



Organized Group Activities

All the participants except one said they had attended some of the organized group activities. They were especially enthusiastic about the camping trips, the barbecues, and the Christmas feast. The organized group activities help reduce the effects of poverty by enabling the participants to have a holiday outside of the city at no cost to themselves.

This might not be otherwise possible as their income from E.I.A. is severely restricted.

All the organized group activities are free to the participants. In addition to alleviating the effects of poverty the organized group activities contribute to physical well-being because they offer healthy, fun activities such as fishing and swimming and an abundance of food. The group outings contribute to emotional well-being as the participants feel included as part of a group sharing a good time together and staff and other participants are present and available for support. Two of the participants commented that they liked being able to contribute to the outings as everyone has a job on the camping trip and it feels good to do your job. The group outings foster personal relationships affording the participants the opportunity to spend time with old friends but also form new contacts with other S.A.L. participants. Several participants mentioned the chance to tease and joke with staff was a big part of the fun on the group outings. The group outings contribute to social inclusion as community facilities are often used for the group activities.

Individualized Staff Support

This service and the staff hours involved are adjusted according to the participant's needs. All the participants involved in the photovoice research had individualized staff support. The individualized staff support made a positive contribution

to all domains. The staff will assist participants with advocacy within different systems and teach them to self-advocate. Staff will accompany participants to ask for services from the police (restraining orders, information) This contributes to the rights domain. The staff contribute to the self-determination domain by giving the participants information about their options, reminding and explaining to them that they have choices, and supporting them in making their own decisions, identifying the steps and supporting them to achieve their goals. Perhaps the domain that is most effected by the individual staff support is that of emotional well-being. The awareness that one can count on regular hours with a support person when you need help with stressful areas of life is comforting and reassuring. The assistance ranges from basic survival skills (cooking and cleaning) to relationship building and problem-solving assistance. The help with cooking, shopping, cleaning, getting to doctor's appointments and connecting to needed services all contribute to the physical well-being domain.

The rapport and trust in the relationship that develops between the support staff and the participant may contribute to their willingness to expand their network of personal relationships by connecting with other participants and staff.

The social inclusion domain is positively impacted by the staff connecting the participants with resources outside of the S.A.L. program. Examples of this include joining the Y.M.C.A. or bowling through the Special Olympics. Support staff can also support the participants to use the bus routes and feel comfortable on the bus. A few participants discussed how individualized support staff also contributed positively to the domains of personal development and material well-being. Several participants commented that they had received support using the computer at the S.A.L. lounge. This

enabled them to increase their knowledge of computer usage and access information from the internet themselves. The participants can say they were self taught through experimenting on the computer. One participant reported that her staff had taught her how to make candle holders in the S.A.L. lounge. This enabled her to learn a new skill and give a family member a Christmas present. The participant commented that she did not have enough money to buy Christmas presents and she felt good about giving her step mother an attractive present she had made herself. Individualized support workers also help participants with budgeting (if they need support). One participant commented that because of staff assistance with budgeting he had enough money each month to buy toys for his dog and D.V.D.'s for himself.

Poverty Issues

All the participants are on E.I.A. which allows a subsistence level of living that is well below the poverty line. The S.A.L. program alleviates poverty through several services available in the lounges. The food bank and the light meal program ensure that the participants have healthy food available to them at all times. The cooking class held nearby contributes to the self- development domain as the participants learn to cook nourishing food. The participants now have free laundry facilities available to them in the new lounge. The cost of using commercial laundry facilities is relatively expensive on an E.I.A. budget. Negative reactions from members of the general population to an unclean appearance diminish self esteem and impede social inclusion. Clean clothes contribute to the emotional and physical well-being domains and foster social inclusion. The food bank, light meal program and laundry facilities all help alleviate poverty. The art class

and availability of art supplies in the lounge contributed to the domain of personal development and material well-being while alleviating poverty. Participants' enthusiasm for the art program was demonstrated by the display of their art in their apartments and in the lounges and through their comments.

Poverty Diminishes Choice in Housing Options.

S.A.L. participants whose only income is E.I.A. have had difficulty finding and affording safe housing in safe areas. Housing support is essential in alleviating the effects of poverty and contributing to social inclusion and emotional well-being. The literature review revealed that unsafe housing in unsafe areas had a strongly negative effect on quality of life in the domains of emotional well-being and social inclusion. Frequent moves necessitated by poor housing were disruptive as they impeded the development of a feeling of belonging in the area or of forming positive connections with other area residents. The sense of being physically and emotionally unsafe exacerbated mental health issues.

The focus of the S.A.L. housing support program is to find safe housing in safe areas for the participants. The importance to mental health consumers of living close to the services and resources they need was discussed in the literature review. S.A.L. staff assist the participants to locate adequate housing in the downtown/west end area relatively close to the S.A.L. lounge. This area has a wide range of housing, shopping, small businesses, professional services, a community centre and several parks and is close to major bus routes. All the participants in the second focus group said that they rely on public transit to get around the city, they know the bus routes they need and they feel confident and comfortable taking the bus.

One of the successful results of the housing support initiative was the formation of a partnership with Westminster Housing to provide safe and secure long term housing in this west end area. The participants' feeling of safety in their environments allows them to go for walks in the district, become acquainted with neighbours and use local services all of which contribute to social inclusion, physical well-being and emotional well-being. One participant expressed his awareness of the importance of safe housing by volunteering the information that people visit him now that he lives in a safe place. The participants proximity to the S.A.L. services ensures that they are also living relatively close to each other and this has contributed to the development and fostering of personal relationships between the S.A.L. participants.

Safe Housing in Safe Area (originally a "Westminster Housing Project, now owned and operated by New Directions.)



Many of the participants spend time in the community with friends they made in the S.A.L. program. All the photovoice and focus group participants mentioned

friendships with other S.A.L. participants in the domain of personal relationships. The participants sense of pride in their homes was illustrated in their positive comments and two of the participants included their homes in the material well-being domain. All the photovoice participants, with the exception of two participants who lived in room and board facilities, invited the researcher into their homes. The researcher noticed that their apartments were clean, decent and in good repair, and that the participants seemed "house proud." Their possessions (televisions, d.v.d collections etc) were displayed and most of them had added personal touches such as their art work or certificates that made the place their own. Perhaps the participants who relocated to good housing believed that their possessions were now safe and so had more interest in accumulating possessions and displaying them.

Lack of Recreational and Leisure Activities

The lack of recreational opportunities identified as a problem in the literature review is addressed by the facilities in the lounge, organized group outings, the organized classes, the Aboriginal group, and the individualized staff support. The Aboriginal group received special mention by the participants who attended as being important to them because the group enabled them to spend time with Aboriginal people while they learned about their culture and participated in their cultural traditions. Several participants included the Aboriginal group as contributing to their quality of life in the emotional well-being domain but the group also fosters the development of personal relationships. S.A.L. participants are encouraged to join in organized activities outside of the S.A.L. program and several have joined Special Olympics and belong to Church groups, and a

few go to the Y.M.C.A. The participants use the lounge for recreation as they play board games, watch movies and socialize with other participants and staff. All of the S.A.L. programming promotes positive use of leisure time and contributes to the self-development, social inclusion, personal relationship or emotional and physical well-being domains.

The most used S.A.L. services are the lounges and the resources available within the lounges, the group activities, the individual staff support and the housing support. All of these services contribute to quality of life across all domains but are especially effective in addressing the problems identified in the literature review including loneliness, isolation, poverty, lack of recreation and the effects of living in unsafe housing in unsafe areas. The S.A.L. program has designed the services to provide for enhancement of quality of life across all domains either by reducing the effects of poverty or by building in the supports needed. The success of the program is reflected by the participants' use of the available services, by their improved quality of life across the domains and by their comments about the services.

Participants' Recommendations

The S.A.L. participants expressed a high level of satisfaction with the S.A.L. services and had few suggestions for improved services. A few participants mentioned that they wanted more group activities and one participant wanted to see a weekly music class added to the services. One participant wanted notices posted a few days in advance if the lounge was going to be closed early.

One focus group participant commented that he liked to work and wanted help finding work and one photovoice participant included good memories of working in the emotional well-being domain while commenting that she would like to work there again. Perhaps the S.A.L. program could add a service that provides assistance in finding paid employment for participants who are interested. The S.A.L. program has been successful in forming partnerships with other services and agencies (Winnipeg Harvest food bank, Westminister Housing) and in promoting social inclusion through the use of community resources. Perhaps an arrangement could be made with E.I.A. for help with finding paid employment.

The pleasure the participants gained from caring for their pets clearly illustrated the role pets play in increasing quality of life in several domains but the cost of veterinary services and pet food is difficult to manage on a limited budget. Perhaps the S.A.L. program could negotiate a reduced rate for veterinary services and/or buy pet food in bulk to distribute to participants to assist with expenses.

Social Work Values and Practice

The core value of respect for the dignity and worth of individuals and their individual right to self-determination is incorporated in the policies and practices of the S.A.L. program. Each of the participants chooses to belong to the program and then chooses whether or not to participate/use each service offered in the program.

Individualized staff support is flexible and focused on providing assistance with developing competence in community living and problem solving skills and with setting and achieving goals. The principle of respect for diversity and cultural sensitivity is

observed by the inclusion of the Aboriginal Group in the services offered and in the wide range of services available to the participants. The S.A.L. program is flexible and offers considerable choice of services to participants.

Pursuit of social justice is a core social work value as noted in the Code of Ethics adopted by The Canadian Association of Social Workers (C.A.S.W.) in 2005. The code of ethics states that "Social workers ... act to reduce barriers and expand choice for all persons, with special regard for those who are marginalized, disadvantaged, vulnerable and/or have exceptional needs" (Canadian Association of Social Workers, 2005, p.5). The S.A.L. program services alleviate the effects of poverty and provide for basic human needs with the provision of groceries through the food bank and light meals and free laundry facilities available in the lounge. The provision of housing support with a choice of housing located either in a community co-operative housing project or in the general community meet the basic human need for safe and affordable housing. Use of the lounge and the facilities and groups available in the lounge, the organized group outings, and the individualized staff alleviate the effects of poverty and address the problem of isolation and loneliness.

Service to humanity is another core social work value and supports the encouragement and pursuit of individual goals and development. The cooking and art classes, the informal support in the lounge to learn computer skills, and the voluntary participation in the Aboriginal Group incorporate this value.

One of the participants commented that he has remained in the S.A.L. program for several years because S.A.L. staff respected his privacy and did not release information about him to his family without his consent. He said other agencies had not protected his

privacy in the past. Respect for the participant's right to confidentiality is a social work principle. The researcher obtained informed consent from all participants involved in the research by ensuring that a staff member was present to explain the participants right to choose not to participate and their right to withdraw at any time.

Retention of Staff

The effectiveness of agency programs relies to large degree on the quality of staff. The staff support available in the lounge and on an individualized basis is key to the success of the program and the use of the lounge. The participants' relationship with staff is critical to the development of trust and comfort in the program. Careful consideration given to preventing high staff turnover by ensuring that staff feel valued contributes to positive outcomes for the participants (Karan & Bothwell, 1997). One of the principles of social work practice derived from the code of ethics advocates that social workers promote the provision of training, adequate resources and professional support for staff. Adherence to this principle assists in the retention of staff (Canadian Association of Social Workers, 2005).

Partnerships with Other Agencies

In accordance with the C.A.S.W. guidelines for ethical practice which advocates collaboration with other professionals and service agencies the S.A.L. program has formed partnerships with other agencies and services to provide benefits to the participants (Canadian Association of Social Workers, 2005). The partnership with Westminster Housing Initiative and Harvest Food Bank are two examples of successful

teaming. The importance of teaming and networking with other agencies and services is reflected in the benefits the participants receive. Teaming reduces duplication of services and frees staff to attend to other needed areas. Additional benefits include the exchange of information about available resources, identifying gaps in available services, the exchange of ideas about problem solving and the possibility of forming coalitions to advocate for the needs and rights of disabled people in the community. Social work principles encourage participation in social action focused on gaining access to resources for disadvantaged /marginalized persons. One example of advocacy could be to approach the transit system to reduce fares, or to at least stop the annual increases in fares. The participants in the S.A.L. program were all dependent on public transit.

Utilizing Community Resources to Increase Awareness of Individual Rights

Several of the participants had a positive perception of the police and the justice system. Several of the participants who had used the police and ambulance services were pleased with the treatment they received. Increasing participants' knowledge of and confidence in their own ability to access community resources meets the social work value of increasing participants competence. The introduction of a monthly information session with a guest speaker from a community agency is recommended to give the participants information about their rights to use the service, how to access the service and the benefits to them of participating in the service. For example, a community police officer could attend a meeting to give information and answer questions about the participants' rights in the community. All the participants agreed that the right to vote was

important but very few exercised the right. Perhaps they would choose to vote if they received information about the policies the candidates espouse that would affect them.

Forming Community Connections

Fostering connections in the community outside of the S.A.L. program has enriched participants' lives. Participants attended the local Y.M.C.A., Special Olympics, churches, and one participant attended an advocacy group for people with disabilities. Community participation contributes to all domains but especially to social inclusion, personal development and personal relationships. As discussed in the literature review, the expansion of social support networks is a goal of case managers (Walsh, 2000) and respects the social work principle of promoting social development for the participants (Canadian Association of Social Workers, 2005).

Comparing the Results to Others

Due to the uniqueness of this study it is difficult to compare the results found with previous studies. Specifically, many studies were concerned with the deinstitutionalization of individuals with developmental disabilities into the community. However, the researcher's results would support the findings in Kim, Larson and Lakin (1989) that supporting people in the community is a better alternative provided adequate supports are in place. The results also support the Schalock and Carver (1979) and the Schalock, Harper and Carver (1981) findings that a supported living environment provides increased autonomy and independence for people with intellectual disabilities. In addition, all of the participants in this study reported feeling positively about having

their own apartments, the freedom to "do their own thing", their participation in normalized activities in the community and use of community resources; a finding that Schalock, Harper and Carver (1981) found in their study. All photovoice participants with the exception of two individuals, who were under order of supervision from the public trustee (financial involvement only), and most focus group participants, two who were in foster care, had total autonomy over all decision making in all aspects of their lives, including if they wanted to voluntarily participate in New Directions programming.

Schalock (1997) identifies eight domains – Emotional Well-Being, Interpersonal Relationships, Material Well-Being, Personal Development, Physical Well-Being, Self-Determination, Social Inclusion and Rights – that he believes are capable of viewing the enhancement of quality of life because they reflect a person's desired conditions of living. Although this researcher attempted to utilize these domains in this research project, it was not possible. Changes to the domains were required by combining the Rights domain with the Self-Determination domain to accommodate the participants intellectual level of understanding these terms. This is deemed acceptable since Taylor and Bognan (1990) view the concept of quality of life as sensitizing us to listen, observe, learn and care about how the intellectually disabled have experienced their lives and how they feel about it. In this instance, by combining the two domains it facilitated the ability of the researcher to listen, observe and learn from the participants.

As mentioned, the researcher utilized a unique method to collect data. Specifically, she utilized a methodology that combined Participant Action Research with Photovoice. Wagenaar and Babbie state that:

“participant action research, which sees the researcher’s function as serving as a resource to those being studied as an opportunity to act effectively in their own interest. Typically, this approach involves disadvantaged groups, who help define their own problems, identify desired remedies, and take the lead in designing research that will help them attain their goals” (Wagenaar & Babbie, 2001, p. 168).

One result of participant action research is that it allowed the researcher to utilize photovoice to collect data. Photovoice facilitated the ability of the participants to fully participate in the research project by allowing them to take an active lead in deciding what pictures should be taken to reflect the quality of life domains and developing recommendations. The successful use of photovoice with this group would suggest that it could also be successful with other groups that lack a proper education or possess less verbal communication skills. This innovative research method of combining P.A.R. and photovoice probably generated more in-depth data. The participants were excited about the picture taking and probably put in a lot more effort than they would have for a questionnaire or a formal sit down interview in a closed room. Also when working with marginalized individuals who may not have had access to education and have difficulties with speech sometimes a picture gives more information than words.

Another result of conducting research in such a manner is the researcher was able to collect data that was previously not collected or found by other researchers. For instance the importance of pets and public transit to the S.A.L. participants and the interest in computer usage. Inadequate public transit would impede on individuals with disabilities ability to commute to where community resources and social opportunities are, which could increase social isolation and loneliness. As stated in the results section the importance of pets as a source of companionship overlapped several domains, including personal relationships, emotional well-being and physical well-being.

Individuals with disabilities who live in community group homes, institutions or room and board facilities would most likely not be allowed to own and care for a pet, which might explain why the importance of pets has been overlooked by many researchers. Having the choice to care for a pet fits with the principle of normalization (discussed in the literature review) as increased autonomy and ability to make choices increases as a more normalized living environment increases.

Strengths and Limitations of the Study

The primary focus of the study was to establish what factors contribute to a positive quality of life for individuals with developmental disabilities. The research results demonstrated there exists a variety of factors, which fall within the eight domains (rights, self determination, emotional wellbeing, physical wellbeing, personal relationships, material wellbeing, social inclusion and personal development), that contribute to individuals with developmental disabilities quality of life. Another finding was that the research participants valued the same quality of life factors (pets, independence, etc.) as the non-disabled population. A final strength regards the manner in which the data was collected. As mentioned in the previous section, the researcher utilized a unique method to collect data - participant action research with photovoice. A number of strengths of utilizing this methodology have previously been outlined, however, a further strength that can be identified regards the fact the methodology allowed the participants' voices to be purely reflected in the results.

There are several limitations of this study. First, the researcher did not ask the participants about negative factors in their environment which had an impact on their

quality of life or what services offered by the S.A.L. program they least valued. This information would have been useful to New Directions and the disability field but because there needed to be parameters to limit the scope of the research the researcher made a decision to focus on positive contributing factors to fit in with the researcher's personal goal of providing a positive experience for participants. Another limitation of this study is that the effect of the amount of time the researcher and the photovoice participants spent together and the force of the researcher's personality probably had an impact on the results. It is impossible to measure the effects of these two variables. A further limitation was the results were really affected by the variety and quality of the services provided by the New Directions S.A.L. program. Finally, due to the uniqueness of this study it is difficult to compare the results found with previous studies and to future studies conducted with other programs.

Recommendations for Future Research

There have been few studies that have tackled the multidimensional issue of quality of life for individuals with developmental disabilities utilizing a unique methodology that allowed purely participants' voices to be heard. As previously discussed, it is important when conducting research with this population to give participants a sufficient amount of time to share their ideas and perceptions. The success of this approach suggests that utilizing P.A.R. and photovoice with this population in future research would be beneficial. For instance, to find out what barriers hinder a good quality of life for individuals with disabilities. Also research that incorporates a negative aspect can only enhance the findings of this study. Research into these areas would be

beneficial to the disability field because agencies could set up supports and programs to counter or eliminate barriers as the S.A.L. program has done in the areas of poverty, social isolation and inadequate housing.

Conclusion

Communication and action is an important element of P.A.R. It is inadequate to write a research report and fail to have the results properly disseminated. This results in a lack of any action to improve the situation of the participants (Morris, 2002). Due to time constraints related to university regulations about the time limits to complete degrees the researcher felt it would be most appropriate not to include dissemination as part of this thesis. However the researcher would like to co-present to the Board of New Directions and to the S.A.L. program staff with photovoice participants if they are willing to be involved.

The benefits from this research included: the empowerment of the participants through their participation in the research, the opportunity to share their personal experiential knowledge and have it valued and validated, the chance to express their opinions on services, and to advocate for themselves for any added services. It is the belief of the researcher that this project provided the participants with a positive introduction to participation in research and fostered the development of public speaking and self- advocacy skills. The researcher has been given no indication to contradict her perception that participation in the research was an enjoyable experience for the participants and that they feel they have contributed to a positive outcome through sharing their opinions.

The client feedback about program elements they find helpful in improving their quality of life can be useful in improving and delivering programs in a variety of community settings. This is the first evaluation of the New Directions S.A.L. program. The increased knowledge of which services are most valued by program participants will, hopefully, be both affirming and helpful to S.A.L. program management and support staff. This knowledge of consumer preference can be used when considering program additions and changes. The knowledge of the services this S.A.L. program is delivering which have been highly effective in contributing to participants' quality of life and alleviating or reducing the identified difficulties encountered in other S.A.L. programs can be useful for other agencies that are planning to develop S.A.L. programs. This research has also contributed to disability research through the use of the innovative technique of photovoice to elicit participants' views and perceptions about elements in their lives that contribute to satisfaction and happiness.

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APPENDIX A: CONSENT FORMS

Informed Consent Agreement (S.A.L. Program Participants - Photovoice) Quality of Life Project

You are being asked to participate in a research study. Before you decide whether or not you agree to participate, it is important that you fully understand the following information. Please feel free to ask your support staff as many questions as you need in order to fully understand what will be asked of you if you agree to participate.

What is the purpose of this study?

The reason I am doing this study is to find out from you and other S.A.L. program participants what contributes positively to your quality of life (what are the best parts of your life?) and which services offered by the S.A.L. program you like the most and least and why. I would also like to ask you if there are any other services you would like to see offered in the future.

Who is doing the study?

Heather Milton, who is a university student, under the supervision of Dr. Brenda Bacon, a professor in the Faculty of Social Work at the University of Manitoba, will be doing this study together with New Directions for Children, Youth, Adults and Families.

What will I be asked to do if I consent to participate in this study?

You will be asked to take me with you on a photography tour of your living, working and recreational environments. You will be given a disposable camera and asked to take pictures of anything that contributes to your quality of life by giving you pleasure and/or satisfaction, and explain why it is important to you. Next I will ask you a few questions about what services offered by the S.A.L. program you like most and least and why. I will also ask you if there are any other services you would like to see offered. **You do not have to answer any questions you do not want to answer. You will still receive twenty dollars for your participation.** Taking the pictures and answering the questions should take about two to three hours of your time.

When I get the pictures developed I will make two copies. I will give one set to you and keep the other set to be used with other pictures taken by other program participants. All the pictures will be arranged on big boards so that other S.A.L. program participants and New Directions staff will be able to see and understand what in your environment gives you happiness and satisfaction. **The pictures will be used in presentations at New Directions and possibly at other agencies with similar programs.**

What will the information be used for?

The information will be used in a report so I can finish my university degree. **The report and pictures may also be used by the S.A.L. Program at New Directions to improve and continue services for you and other participants in the program, and may be shared with other agencies that provide similar programs.**

What are the benefits of participating in this study?

Participation in the study will give you the opportunity to take pictures of your environment and describe what gives you satisfaction and enjoyment. You will be given a copy of all the pictures for you to keep.

Participating in this study will give you a chance to share what services offered by S.A.L. you like most and least and any services you would like to see added. **You will also receive twenty dollars for volunteering your time.**

Can I stop participating?

Yes. If you agree to participate in the study and change your mind later you can stop participating at anytime by telling either your support staff or me that you want to stop. If you don't want some of the pictures you took used on the big boards for other people to see you can say so at anytime and the pictures will either be destroyed or returned to you.

What steps will be taken to keep information confidential and anonymous?

If you do agree to participate your name will not be used in any presentations or reports about the study. Any information that could lead to your identification will not be included in the study.

All notes, audiotapes, videotapes and computer discs will be kept locked up and only Dr. Brenda Bacon and I will be able see them. All notes, audiotapes, videotapes and computer discs will be destroyed after the final report is completed.

What should I do if I want to participate in the study?

Signing your name below means that you agree to be in the study. Your signature also means that you understand the information in this agreement, have had the opportunity to ask questions about the study, and understand that you may stop participating at any time. You will be given a copy of this agreement. The researcher, Heather Milton, can be reached by calling 510-1656. Her thesis advisor, Dr. Brenda Bacon at the Faculty of Social Work can be reached at 474-8454.

Name of Research Participant (please print)

Signature of Research Participant

Date

The staff signature below indicates that the staff has fully explained the research study to the participant, answered any questions and is confident that the participant fully understands their rights in agreeing to participate in this study.

Name of Support Staff (please print)

Signature of Support Staff

Date

This research has been approved by the University of Manitoba Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons, or the Human Ethics Secretariat at 474-7122.

**Informed Consent Agreement
(S.A.L. Program Participants – Focus Group)
Quality of Life Project**

You are being asked to participate in a research study. Before you decide whether or not you agree to participate, it is important that you fully understand the following information. Please feel free to ask your support staff as many questions as you need in order to fully understand what will be asked of you if you agree to participate.

What is the purpose of this study?

The reason I am doing this study is to find out from you and other S.A.L. program participants what contributes positively to your quality of life (what are the best parts of your life?) and which services offered by the S.A.L. program you like the most and least and why. I would also like to ask you if there are any other services you would like to see offered in the future.

Who is doing the study?

Heather Milton, who is a university student, under the supervision of Dr. Brenda Bacon, a professor in the Faculty of Social Work at the University of Manitoba, will be doing this study together with New Directions for Children, Youth, Adults and Families.

What will I be asked to do if I consent to participate in this study?

You will attend a 1.5 – 2 hour meeting at New Directions with three or four other S.A.L. participants to look at pictures that others in the S.A.L. Program have taken. You will then be asked to discuss your ideas about the pictures and what you feel are important factors in *your* quality of life. **You do not have to answer any questions that you do not want to answer. You will still receive twenty dollars for volunteering your time.**

What will the information be used for?

The information will be used in a report so I can finish my university degree. The report may also be used by the S.A.L. Program at New Directions to improve and continue services for you and other participants in the program, and may be shared with other agencies that provide similar programs.

What are the benefits of participating in this study?

Participating in this study will give you a chance to share your opinions about what contributes to your quality of life and why?

Participating in this study will give you a chance to share what services offered by S.A.L. you like most and least and any services you would like to see added. You will also receive twenty dollars for volunteering your time.

Can I stop participating?

Yes. If you agree to participate in the study and change your mind later you can stop participating at anytime by telling your support staff or me that you want to stop.

What steps will be taken to keep information confidential and anonymous?

If you do agree to participate your name will not be used in any presentations or reports about the study. Any information that could lead to your identification will not be included in the study.

All notes, audiotapes, videotapes and computer discs will be kept locked up and only Dr. Brenda Bacon and I will be able to see them. All notes, audiotapes, videotapes and computer discs will be destroyed after the final report is completed.

What should I do if I want to participate in the study?

Signing your name below means that you agree to be in the study. Your signature also means that you understand the information in this agreement, have had the opportunity to ask questions about the study, and understand that you may stop participating at any time. You will be given a copy of this agreement. The researcher, Heather Milton, can be reached by calling 510-1656. Her thesis advisor, Dr. Brenda Bacon at the Faculty of Social Work can be reached at 474-8454.

Name of Research Participant (please print)

Signature of Research Participant

Date

The staff signature below indicates that the staff has fully explained the research study to the participant, answered any questions and is confident that the participant fully understands their rights in agreeing to participate in this study.

Name of Support Staff (please print)

Signature of Support Staff

Date

This research has been approved by the University of Manitoba Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons, or the Human Ethics Secretariat at 474-7122.

**Informed Consent Agreement
(Public Trustee)
Quality of Life Project**

Your client, _____, has volunteered to participate in a research study. Below is an explanation of the purpose of the study and provisions for confidentiality. This project was explained to your client with the assistance of their staff support person from the S.A.L. Program at New Directions in order to ensure that they fully understood the research project. A consent form signed by your client is attached.

What is the purpose of this study?

The purpose of this study is to determine from the S.A.L. program participants which factors contribute positively to their quality of life and which services offered by the S.A.L. program they feel are the most and least beneficial to their quality of life. The researcher is also interested in the participants' opinions about which additional services (if any) they would like to see offered in the future.

Who is doing the study?

Heather Milton, who is a university student, under the supervision of Dr. Brenda Bacon, a professor in the Faculty of Social Work at the University of Manitoba, will be doing this study together with New Directions for Children, Youth, Adults and Families.

What will clients be asked to do if they consent to participate in this study?

Photovoice participants will each be asked to take Heather Milton with them on a photography tour of their living, working and recreational environments. Participants will be given a disposable camera and asked to take pictures of anything in their environment that contributes to their quality of life by giving them pleasure and/or satisfaction, and explain why it is important to them. Participants will be asked to answer a few questions about what services offered by the S.A.L. program they feel are most and least valuable to them and what services (if any) they would like to see offered in the future.

Focus group participants will be asked to participate in a 1.5 to 2 hour group discussion about factors that contribute to their quality of life, and what services offered by the S.A.L. program they feel are most and least valuable to them and what services (if any) they would like to see offered in the future.

What will the information be used for?

The information will be used in a thesis report to complete the student's requirements for a Master of Social Work degree. The report may also be used by the S.A.L. Program at New Directions to improve or maintain services for clients in that program, and may be shared with other agencies who provide similar programs.

What are the benefits of participating in this study?

Participation in the study will give clients the opportunity to take pictures of their environment and/or to describe which factors give them satisfaction and enjoyment and contribute to their quality of life.

Participating in this study will give clients a chance to make their opinions known about what services offered by S.A.L. you most value and any services they would like to see added. To compensate clients for their time they will receive twenty dollars.

Can clients stop participating?

Yes. If clients change their mind at any time, they can stop participating by telling their support staff or myself that they wish to withdraw their consent.

What steps will be taken to keep information confidential and anonymous?

Clients' names will not be used in any presentations or reports about the study. Any unique characteristics that could lead to client identification will not be included in the study.

All notes, audiotapes, videotapes and computer discs will be kept locked up and only Dr. Brenda Bacon and myself will have access to them. All notes, audiotapes, videotapes and computer discs will be destroyed after the final report is completed.

What should I do to approve client participation in this study?

Signing your name below indicates that you approve of [client's name] in the study. Your signature also indicates that you understand the information in this agreement, have had the opportunity to ask questions about the study, and can withdraw your approval of your client's participation at any time. You will be given a copy of this agreement. The researcher, Heather Milton, can be reached by calling 510-1656. Her thesis advisor, Dr. Brenda Bacon at the Faculty of Social Work can be reached at 474-8454.

Name of Research Participant (please print)

Signature of Public Trustee

Date

This research has been approved by the University of Manitoba Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons, or the Human Ethics Secretariat at 474-7122.

**Informed Consent Agreement
Persons Identified in Research Photographs
Quality of Life Project**

You are being asked to give consent for your picture to be used in a research project. Before you decide whether or not to give this consent, it is important that you fully understand the following information. Please feel free to ask the researcher as many questions as you need in order to fully understand the repercussions of your consent.

What is the purpose of this study?

The purpose of this study is to determine from the S.A.L. program participants which factors contribute positively to their quality of life and which services offered by the S.A.L. program they feel are the most and least beneficial to their quality of life. The researcher is also interested in the participants' opinions about which additional services (if any) they would like to see offered in the future.

Who is doing the study?

Heather Milton, who is a university student, under the supervision of Dr. Brenda Bacon, a professor in the Faculty of Social Work at the University of Manitoba, will be doing this study together with New Directions for Children, Youth, Adults and Families.

What will the pictures be used for?

The picture with you in it may be used to aid discussion with other participants of the S.A.L Program about quality of life matters, and may be used in presentations to clients, staff and/or board members of the S.A.L Program, and New Directions.

What steps will be taken to keep information confidential and anonymous?

If you do agree to allow your picture to be used, your name will not be used in any presentations or reports about the study. It is possible that your picture may be included in future presentations or displays at New Directions for Children, Youth, Adults and Families.

What should I do if I want to participate in the study?

Signing your name below indicates that you agree to let your picture be used in this research. Your signature also indicates that you understand the information in this agreement, have had the opportunity to ask questions about the study, and understand that you may withdraw your consent to participate at any time. You will be given a copy of this agreement. The researcher, Heather Milton, can be reached by calling 510-1656. Her thesis advisor, Dr. Brenda Bacon at the Faculty of Social Work can be reached at 474-8454.

Name of Research Participant (please print)

Signature of Research Participant

Date

This research has been approved by the University of Manitoba Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons, or the Human Ethics Secretariat at 474-7122.

**Informed Consent Agreement
S.A.L. Program Staff
Quality of Life Project**

You are being asked to participate in a research study. Before you decide whether or not you agree to participate, it is important that you fully understand the following information. Please feel free to ask as many questions as you need in order to fully understand what will be asked of you if you agree to participate.

What is the purpose of this study?

The purpose of this study is to determine from the S.A.L. program participants which factors contribute positively to their quality of life. A second purpose is to find out which services offered by the S.A.L. program participants and support staff feel are the most and least beneficial to clients' quality of life. The researcher is also interested in the participants' and staffs' opinions about which additional services (if any) they would like to see offered in the future.

Who is doing the study?

Heather Milton, who is a university student, under the supervision of Dr. Brenda Bacon, a professor in the Faculty of Social Work at the University of Manitoba, will be doing this study together with New Directions for Children, Youth, Adults and Families.

What will I be asked to do if I consent to participate in this study?

Participants will each be asked to complete a brief written questionnaire about what services provided by the S.A.L. program they believe contribute most positively to clients' quality of life, and what (if any) additions should be made to the S.A.L. program to further improve clients' quality of life.

What will the information be used for?

The information will be used in a thesis report to complete the student's requirements for a Master of Social Work degree. The report may also be used by the S.A.L. Program at New Directions to improve or maintain services for clients in that program, and may be shared with other agencies that provide similar programs.

What are the benefits of participating in this study?

Participating in this study will give you a chance to make your opinions known about what services offered by S.A.L. you feel are most valued by clients, and any services you would like to see added.

Can I stop participating?

Yes. If you consent to participate in the study and change your mind later you can stop participating at anytime by telling Heather Milton that you wish to withdraw your consent.

What steps will be taken to keep information confidential and anonymous?

If you do agree to participate your name will not be used in any presentations or reports about the study.

All notes, audiotapes, videotapes and computer discs will be kept locked up and only Heather Milton and Dr. Brenda Bacon will have access to them. All notes, audiotapes, videotapes and computer discs will be destroyed after the final report is completed.

What should I do if I want to participate in the study?

Signing your name below indicates that you agree to be in the study. Your signature also indicates that you understand the information in this agreement, have had the opportunity to ask questions about the study, and understand that you may withdraw your consent to participate at any time. You will be given a copy of this agreement. The researcher, Heather Milton, can be reached by calling 510-1656. Her thesis advisor, Dr. Brenda Bacon at the Faculty of Social Work can be reached at 474-8454.

Name of Research Participant (please print)

Signature of Research Participant

Date

This research has been approved by the University of Manitoba Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons, or the Human Ethics Secretariat at 474-7122.

APPENDIX B: INFORMATION PACKAGE FOR STAFF

Staff Hand Out

Quality of Life for Developmentally Delayed Adults in Supported Living

Summary of Project

There has been increasing recognition that intellectually disabled individuals' perspectives on their quality of life takes precedence over other more objective criteria in measuring and assessing quality of life. However, gaining knowledge of individual values and preferences has been problematic because of difficulties with speech and language, acquiescence and the desire to present as socially acceptable. This research will use a combination of photovoice (letting participants "speak" through the use of photographs), interviews, staff perspectives, and researcher observation to gather information about intellectually disabled people's quality of life in a supported independent living program. The researcher has eight years experience in working with individuals who are intellectually disabled and those who have mental health concerns, and this experience has lead to her interest in this thesis topic.

This study has two goals. The first is to increase knowledge of factors that positively contribute to the quality of life of clients of the Supported Apartment Living program (S.A.L.) at New Directions. The second goal is to elicit from program clients and staff their perceptions of the services offered by the S.A.L. program that are most and least beneficial in contributing to "clients" quality of life, and what additional services they might like to see offered.

This study will employ multiple sources of data and multiple methods of collection. First, support staff from the S.A.L. program will be asked to list the five S.A.L. services they consider most valuable and the five S.A.L. services they consider least valuable in contributing to their clients' quality of life. Second, the researcher will meet individually with a sample of program participants while they use disposable cameras to photograph aspects of their environments that are most important to them (photovoice). The researcher will use field notes to record their explanations of the value they attach to each picture. The researcher will also briefly interview these individuals about the services they receive through the S.A.L. program. The researcher will record their answers and ask for clarification throughout the interview by reading the recorded answers back to them to overcome the barrier of language and reading difficulties. The final steps in the methodology involve the researcher and individual clients involved in photovoice analyzing the photographs and sorting them into domains of quality of life. The selected pictures that are representative of each primary life domain will then be mounted on poster board and will provide the focus for discussion with the other program clients about their perceptions of quality of life in the supported apartment living program. The researcher will facilitate focus groups (four to five individuals in each) in which the participants will be asked to look at the pictures and discuss their perceptions of quality of life in regard to the main life domains. These interviews will be videotaped and transcribed.

Data from the photovoice technique, questionnaires, observation notes from individual interviews, and transcripts from the client focus groups will be analyzed to determine factors contributing to quality of life for clients in supported apartment living. A meeting will be held for all program participants to decide who will be participating in the dissemination of research results. Clients will be asked to volunteer to co-present the results of this study to New Directions staff and board.

This research will make a contribution to social work knowledge in terms of client feedback about program elements that they find most helpful. Such information can be used to improve program delivery for disabled people living in a variety of community settings. This research will also make a contribution in its use of an innovative technique (photovoice) to elicit disabled individuals' perceptions directly rather than relying on proxy opinions.

Informed Consent

All participants will be asked to sign a consent form before beginning their participation in the research process. The researcher will emphasize that participation is voluntary and that clients are free to decline involvement in the research process, and that participants can withdraw from the study at anytime without fear of losing supports provided by New Directions. The researcher will be assisted by S.A.L. support staff to explain the consent form to potential participants because they will have rapport and trust with them. If a potential participant is under an order of supervision from the public trustee, a consent form will also have to be signed by them on their client's behalf. Focus group participants will be informed that the discussion will be videotaped. Should objections to videotaping arise during the focus groups, the recorder will be turned off, and the researcher will rely on field notes.

A consent form will be provided to S.A.L. staff who agree to participate in the study as well.

If the photovoice participants take pictures of important people in their environments, a consent form will need to be signed by those individuals. If consent cannot be obtained due to lack of availability of the individuals (e.g. a bus driver with unknown identity), the faces of these individuals will be blurred in the photographs, or will not be used in subsequent steps in the research (client focus groups and dissemination of results).

Deception

No deception will take place at any time during this study.

Feedback/Debriefing

The researcher along with selected S.A.L. program participants will co-present the results to all S.A.L. program staff and participants, and may present to the Board of New Directions as well. The researcher will provide New Directions with a copy of the written report to be made available to participants and staff at their request.

Risks and Benefits

The research poses minimal risk to the participants. Since the photovoice and interviews focus on positive aspects of peoples' lives, it is anticipated that the experience will be enjoyable. In the unlikely event of emotional distress the researcher will ask the participant for permission to contact their support staff or case manager for added support.

The benefits from this research include empowerment of the participants through participation, and having their personal knowledge valued and validated. Ideally participation in the research will be an enjoyable experience and they will feel they have contributed to a positive outcome through sharing their opinions about what they value in the S.A.L. program. S.A.L. program staff will benefit from increased knowledge of which services are most and least valued by program participants.

Anonymity and Confidentiality

All data will be kept in locked files in the researcher's private home. The researcher will use pseudonyms for clients in the written report. A master list of clients' real names and assigned pseudonyms will be stored separately from the field notes, tapes and transcriptions. At no time in the written report will staff members or participants be named. All notes, audiotapes and videotapes will be destroyed following the completion of the research. No personal information that could identify any of the participants will be included in the report.

Compensation

All program participants will receive twenty dollars to compensate them for volunteering their time. The participants involved in Photovoice will receive a copy of their pictures. Food and beverages will be provided at the focus groups. The program staff involved in the research will not be compensated.

APPENDIX C: REVIEW OF SCHALLOCK'S DOMAINS

I know you are anxious to go out to take pictures and I am really looking forward to that too. Remember, the pictures are for you to keep but to also show others what things and activities in your life make you feel good, safe, satisfied and happy with yourself and with your life. While you are telling me about these things I will be making a list of pictures to take so that when we go out we won't miss taking pictures of anything that is important to you.

When others have done research on what gives people enjoyment in their lives they have come up with these ideas.

Well-Being - This means anything that helps you feel stable, safe and positive in your surroundings (home, work place, place of worship (such as church, synagogue etc.) access to proper medical care and medication support.

Relationships - Any connections you share with people that make you happy (family, friends, staff, others).

Material Well-Being - What you have that yours that makes you feel happy (furniture, clothes, pictures, sports equipment, own apartment, anything else, money in the bank, regular checks coming-in).

Personal Development - Any activities that you are doing that help you learn new skills or find out about things you wanted to know about (any type of group classes, or activity with another person or on your own).

Physical Well-Being - Any activities that help you feel physically healthy (eating good food, getting exercise, taking medication properly, opportunities to have fun and enjoy recreation and leisure activities, any adjustments made to an apartment to maximize mobility).

Self-Determination - The freedom and opportunities you have to make your own decisions and your own choices (what time to get up, what to wear, what t.v. programs to watch, where to live, what to eat for dinner, what activities to do and many other choices).

Social Inclusion - Involvement with people and activities in the community outside of New Directions - (work, volunteer work, eating in restaurants, visiting friends, activities with friends in the community, contacts with people in your apartment block, using community resources, (doctor, transportation)).

Rights - Laws in Canada say that everyone has the right to free health care, to vote in elections, to meet with a lawyer if you need one, to not be discriminated against on the basis of race, gender, religion, sexual preference or physical or cognitive disability. All Canadians have the right to privacy, medical records, a lock on your door, etc.

APPENDIX D: LIST OF SERVICES

S.A.L Program

This includes access to the Resource Lounge located on the 8th floor at 491 Portage Avenue, the evening/weekend centre located at 559 Portage Avenue, S.A.L.'s Place, and in the community where the following services are offered:

- ♦ Cooking classes
- ♦ Music classes
- ♦ Arts and crafts classes
- ♦ Movies and video games
- ♦ Outings to various community activities/outings
- ♦ Annual camping trip
- ♦ Holiday celebrations
- ♦ Games and activities in the lounges
- ♦ Socialization and networking in the lounges
- ♦ Receipt of Food Bank donations
- ♦ Light meals and snacks while utilizing the lounges
- ♦ Assisting with problem-solving and the development/enhancement of social skills and daily living skills
- ♦ Access to housing supports, projects, and supplements where applicable
- ♦ Free laundry facilities (at S.A.L.'s Place)

APPENDIX E: FOCUS GROUP INFORMATION LEAFLET

ALL S.A.L. Participants

You are invited to attend a group discussion about:

What brings you happiness, joy and satisfaction?

What are the best parts of your life?

What services offered by the S.A.L. program do you like the best and find the most helpful in contributing to a healthy, happy life?

The groups will be held at the S.A.L. lounge at the Rice Building

December 9, 2004 9:30 a.m. – 1:00 p.m.

December 15, 2004 9:30 a.m. – 1:00 p.m.

December 15, 2004 1:00 p.m. – 4:00 p.m.

You will receive \$\$\$\$\$20.00 for volunteering your time and snacks will be provided.

If interested please sign up at the S.A.L. lounge.

If you require further information please call Heather at 510-1656 or ask your staff.