INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700  800/521-0600
SOCIAL SUPPORT AS A PREDICTOR OF WELL-BEING FOR ADULTS WITH MILD MENTAL RETARDATION

A Thesis
Presented in Partial Fulfilment of the Requirements for
the Degree Doctor of Philosophy in the Graduate School
of The Ohio State University

By
Yona Jennifer Lunsky, M.A.

*****

The Ohio State University
1999

Dissertation Committee:
Dr. Betsey Benson, Adviser
Dr. Steven Beck, Adviser
Dr. Charles Emery

Approved by

Betsey A. Benson
Adviser
Department of Psychology

Steven Beck
Adviser
Department of Psychology
ABSTRACT

Several advances have been made in the field of social support research in recent years in terms of conceptualization and methodology. Few of these advances, however, have influenced research with persons with cognitive impairments. The purpose of this study was to examine the prospective effects of perceived social support in adults with mild mental retardation. Social strain, reciprocity in relationships and extra-individual support sources (groups or places of support) were included as important aspects of support. The outcome variables of interest were perceived health, depressive symptoms and quality of life. Health as a predictor of depression and quality of life was also examined.

Eighty-four adults with mild mental retardation in supported living community placements were interviewed about their positive and negative interpersonal relationships, their health, their mood and their quality of life on two occasions, six months apart. Residential staff and family members provided supplemental information about reciprocity and the physical and mental health and quality of life of participants.

Conceptions of social support of adults with mental retardation mirrored those of the general population in several ways. Participants conceptualized their relationships according to function and structure, on both an individual and extra-individual level.
Many participants reported reciprocating in their relationships and their reports of reciprocity matched those of family members. Hierarchical multiple linear regression analyses revealed, controlling for effects of age, gender, and receptive vocabulary, that social support and health predicted quality of life six months later. Further, health and social strain predicted symptoms of depression six months later, whereas social support predicted symptoms of depression within the same time frame.

The results of the study indicate that adults with mild mental retardation conceptualize their social support in a similar manner to individuals without cognitive disabilities. Similar relationships can be found between social support and depression, health and quality of life for adults with mild mental retardation as in the general population. How individuals with mental retardation perceive their interpersonal relationships, both positive and negative, as well as their health, is important and cannot go unrecognized. Improving perceived social support while diminishing levels of social strain and fostering healthier lifestyles should be a focus of prevention efforts for this population in the future.
ACKNOWLEDGMENTS

Support for this study was provided jointly by a doctoral fellowship from Social Sciences and Humanities Research Council of Canada and a presidential dissertation fellowship from The Ohio State University. Funds for direct research costs were provided by an Ohio State University Alumni Research Grant.

I would like to thank my thesis examination committee, Betsey Benson, Steven Beck and Charles Emery, for their invaluable support and feedback. Steve's faith in the project and my abilities helped me to complete this task in my proposed time frame. Charles' interest in the health arena triggered some very important discoveries and some new areas of research for me. And Betsey's guidance and clear-thinking brought me to the level of becoming an independent researcher. I am grateful to her for all of the attention she gave to this project. I would also like to thank Steven Reiss for his encouragement to pursue this line of study, and Brian Lakey for inviting me into the broader social support research area.

This project could not have been completed without the assistance of Melissa Fiatal and Lynn Neely. I wish to thank them both for their enthusiasm and professionalism as my co-investigators.

I am grateful to my family for their support and patience over the last four years and my husband Ori, my light at the end of this tunnel, for his day to day support and editorial advice.

Most importantly, I wish to recognize the participants and their supports who allowed us into their lives and shared with us their thoughts and feelings on this vital topic.
VITA

December 31, 1971 ......................... Born - Toronto, Canada

1994 ....................................... B.A. Honors Psychology and Drama
University of Guelph

1994-1995 ................................ Graduate Research Associate
The Ohio State University

1995-1996 ................................ Fulbright Scholar
The Ohio State University

1996 ........................................ M.A. Clinical Psychology/Mental Retardation
The Ohio State University

1996-1997 ................................ Graduate Research Associate
The Ohio State University

1997-1998 ................................ Presidential Dissertation Fellow
The Ohio State University

1998-1999 ................................ Clinical Psychology Intern
Psychology Department, The Toronto Hospital

PUBLICATIONS


**FIELDS OF STUDY**

Major Field: Psychology
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Acknowledgments</th>
<th>iv</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vita</td>
<td>v</td>
</tr>
<tr>
<td>List of Tables</td>
<td>ix</td>
</tr>
</tbody>
</table>

## Chapters:

1. **Introduction**
   - A lifespan perspective of social support and mental retardation | 2
   - Traditional conceptions of social support | 5
   - Recent social support theory distinctions
     - Extra-individual support sources | 11
     - Social strain | 14
     - Reciprocity | 17
   - The relationship between social support and health | 20
     - Health of adults with mental retardation | 20
     - Models of social support and health | 23
   - Summary | 27
   - Purpose of present study | 28
     - Time 1: Conceptions of social support | 28
     - Time 2: Depression, quality of life and health | 29
     - Time 1 - Time 2: Relationships between social support, health, depression and quality of life | 30

2. **Method**
   - Participants | 32
   - Measures | 35
     - Self-report measures | 35
     - Staff measures | 40
     - Family member ratings | 42
   - Procedure | 43
3. Results .......................................................................................................... 47
   Time 1: Conceptions of social support ....................................................... 48
   Time 2: Depression, quality of life and health ......................................... 55
   Perceptions of health ............................................................................... 60
   Time 1 - Time 2: Relationships between social support, health,
   depression and quality of life................................................................ 63

4. Discussion .................................................................................................... 76
   Time 1: Conceptions of social support ....................................................... 76
   Time 2: Depression, quality of life and health ......................................... 82
   Time 1 - Time 2: Relationships between social support, health,
   depression and quality of life................................................................ 87
   Limitations .................................................................................................. 90
   Implications of the Study ...................................................................... 92
   Future Directions .................................................................................... 95
   Conclusion ............................................................................................... 97

List of References .......................................................................................... 98

Appendices:

A. Circles Task ................................................................................................ 113
B. Social Support Self Report (SSSR) ........................................................... 115
C. Functional Support Interview ................................................................... 117
D. Inventory of Negative Social Interactions for Adults with MR ............... 119
E. Reciprocity Measure ............................................................................... 122
F. Loneliness Questionnaire ........................................................................ 124
G. Birleson Depression Short Form Self-Rating Scale (BDS-S) ................. 126
H. Quality of Life Questionnaire ................................................................ 128
I. Healthy Behavior Screen ........................................................................ 132
J. Reiss Screen of Maladaptive Behavior .................................................... 134
K. Birleson Depression Scale - Informant version(BDS-I) ......................... 139
L. Family Reciprocity Scale ........................................................................ 141
M. Consent Form ......................................................................................... 143
N. Auxiliary Consent for Family Interview ................................................. 145
O. Debriefing Script .................................................................................... 147

viii
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>34</td>
</tr>
<tr>
<td>Demographic characteristics of participants with mental retardation</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>49</td>
</tr>
<tr>
<td>Number of individuals providing social support at Time 1 according to three social support measures</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Percentage of participants who listed roommates, family and staff as support sources on three social support measures at Time 1</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>51</td>
</tr>
<tr>
<td>Intercorrelations among Time 1 social support and social strain measures</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>53</td>
</tr>
<tr>
<td>Intercorrelations of family reciprocity ratings from participant and family member</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>55</td>
</tr>
<tr>
<td>Proportion of participants who named extra-individual sources of support at Time 1</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>56</td>
</tr>
<tr>
<td>Means, standard deviations, and Cronbach alphas for self-report and staff ratings at Time 2</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>58</td>
</tr>
<tr>
<td>Intercorrelations between staff and participant ratings of depression and psychopathology at Time 2</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>59</td>
</tr>
<tr>
<td>Staff-client agreement on Quality of Life Questionnaire</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>60</td>
</tr>
<tr>
<td>Healthy behaviors according to staff and participants at Times 1 and 2</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>62</td>
</tr>
<tr>
<td>Physical problems and occurrence of illness according to self-report and staff ratings at Time 2</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>63</td>
</tr>
<tr>
<td>Percentage of participants taking prescription and non-prescription medication at Time 2</td>
<td></td>
</tr>
<tr>
<td>Table</td>
<td>Page</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>13</td>
<td>Stability of self-report and staff ratings of social support, loneliness and depression from Time 1 to Time 2</td>
</tr>
<tr>
<td>14</td>
<td>Summary of hierarchical multiple linear regression of social support on perceptions of health at Time 2</td>
</tr>
<tr>
<td>15</td>
<td>Summary of hierarchical multiple linear regression of social support and health at Time 1 on change in depression scores at Time 2</td>
</tr>
<tr>
<td>16</td>
<td>Summary of hierarchical multiple linear regression of social support and health at Time 1 on depression scores at Time 2</td>
</tr>
<tr>
<td>17</td>
<td>Summary of hierarchical multiple linear regression of social support and health at Time 2 on depression scores at Time 2</td>
</tr>
<tr>
<td>18</td>
<td>Summary of hierarchical multiple linear regression of social support and health at Time 1 on quality of life scores at Time 2</td>
</tr>
<tr>
<td>19</td>
<td>Summary of hierarchical multiple linear regression of social support and health at Time 2 on quality of life scores at Time 2</td>
</tr>
<tr>
<td>20</td>
<td>Summary of hierarchical multiple linear regression of social support and social strain at Time 1 on depression scores at Time 2</td>
</tr>
</tbody>
</table>
CHAPTER 1

INTRODUCTION

This chapter will identify the major theoretical and measurement issues in social support research and consider their application to the field of mental retardation. Social support can be broadly defined as the interpersonal transactions or exchanges of resources between at least two people perceived by the provider or recipient to be intended to enhance the well-being of the recipient (Shumaker & Brownell, 1984). According to this definition, social support includes transactions and exchanges which can have positive or negative effects on the recipient; it does not depend entirely upon the recipient’s perceptions and it does not stipulate that the interaction be dyadic in nature. Most research on social support is based on findings from children and adults of average to above average intelligence.

In this study, the social support of adults with mild mental retardation was examined. Mental retardation (MR) is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. MR manifests before age 18 (Luckasson et al., 1992). The focus of
this study is on individuals with verbal ability in the mild range of delay (IQ = 56-70), although some issues considered here apply to individuals with more pervasive cognitive impairments as well as to individuals with other types of disabilities.

The characteristics of adults with MR challenge the limits of current social support theory. Specifically, their limited language, impairments of memory, impoverished social skills and structured work and home environments influence the way social support is received and perceived by them. Particular aspects of social support, such as reciprocity, are significantly affected by the cognitive and social limitations of persons with MR. Studying such aspects of social support in this population may therefore have ramifications for current social support theory.

A lifespan perspective of social support and mental retardation

Social support of individuals with MR can be best understood with reference to social support characteristics of the general population. Individuals with MR are first exposed to social support in infancy, as are most people, through attachment to caregivers. There is ample research comparing the manner in which infants with and without MR form attachments (see Blacher & Meyers, 1983). Some parents have trouble interacting with a disabled infant for which they either blame themselves, or blame the infant. Infants with developmental delays, because of communication difficulties and restricted eye contact, may be unresponsive to their parents.

Children with MR have greater difficulty than other children forming friendships with peers and maintaining these relationships (Stainback & Stainback, 1987). This may
be due in part to the current emphasis placed by learning institutions on academic and independence-skills training rather than social interaction (Strully & Strully, 1992). Some children with MR are placed in segregated classrooms while others are integrated, yet still isolated socially from their classmates. Guarlnick (1984) found that the mere presence of playmates without MR in an integrated classroom did not alter the play patterns of children with MR. Compared with their peers, children with MR show more solitary and parallel play as well as more negative play (Kopp, Baker & Brown, 1992; Taylor & Asher, 1984). Reasons for these differences include an expectancy of failure on the part of the children with MR, unusual expressive language difficulties, and social skill deficits that go beyond their cognitive impairments (Field, 1984).

As children with MR mature, they continue to receive aid from professionals and their families, unlike adolescents without disabilities who in adolescence gain further autonomy. While peers become an important support source for most adolescents (Licitra-Kleckler & Waas, 1993), adolescents with MR receive support primarily from their family. Wenz-Gross and Siperstein (1996) found that interactions between adolescents with MR and their peers were limited to school and that the phone was used less by individuals with mild MR than by other adolescents. Even those students with mild MR who are mainstreamed are not as well-integrated socially as was once thought (Guralnick, 1984).

Generally, adults with MR receive less support than individuals without MR (Rosen & Burchard, 1990). Like other adults, they may move away from their parents, interact with diverse circles of people at work, home, and in the community, and
develop intimate relationships with other adults. Unlike other adults, they continue to receive much of their support from professionals (Lunsky & Benson, in press), and are subject to environmental restrictions imposed on them that can deter them from developing traditional relationships. Many activities that typically occur in early adulthood, such as moving away from parents, are significantly delayed for individuals with MR. It is estimated that 85% of individuals with MR live with their parents (Fujiura & Braddock, 1992) and nearly 80,000 individuals are on waiting lists for residential services (Hayden, 1992 in Krauss & Seltzer, 1996). Many of them do not move from their parents' home until there is a parental death (Gordon, Seltzer & Krauss, 1996).

Many adults with MR who move away from their parents live in supervised settings and require staff assistance to participate in most social activities (Newton, Olson, & Horner, 1995). In one study, the individuals who lived most independently reported having the fewest friends (Burchard, Rosen, Gordon, Hasazi, Yoe, & Dietzel, 1993), suggesting that independence does not guarantee social interaction. Adults with MR do not tend to marry (see Koller, Richardson, & Katz, 1988) and thus may lack support not only from a partner, but also from children, who are an important source of support later in life (Seltzer, 1985). Older adults with MR tend to lose contact with their families unless they live with them, and also tend to have relatively few friends who call or visit (Ashman & Suttie, 1996).
Traditional conceptions of social support

Most categorizations of social support appear to rely upon at least one of two major distinctions. First, some definitions distinguish between a structural approach of network analysis versus a functional approach of what function the support serves. Second, some definitions state that support can be examined from a perceived (subjective) or a received (objective) perspective. There is overlap between these distinctions, as perceived support tends to be captured better by a functional perspective (Cohen & Wills, 1985) and actual or received support tends to be measured more often through a structural perspective.

Structural support or network analysis can be traced back to Jacob Moreno's research (1941) on small group relations in New York City. A structural perspective considers the layout of a group of persons who give and receive support. Structural characteristics include the size of the network, its density (how well members know each other), homogeneity (similarity among group members), multiplexity (the multiple roles served by each member), and the frequency of support provision. Size and frequency of support are most easily measured, but complex measures like density may have greater utility. For example, Hammer (1981) found, for example, that social networks of adults with schizophrenia were less likely to be severed if there were common connections between members or greater density.

To measure the support structures of children, simple structured measures are most popular. Children as young as four and a half can identify sources of support, but cannot yet indicate the frequency of support or the density of their networks (Zelkowitz,
Complex measures of social networks are rarely used with children, but may also be important (Wolchik, Beals, & Sandler, 1989). Through more open-ended and imaginative measures, children have identified sources of support not considered in the adult literature, such as pets and imaginary friends (Bryant, 1994).

Measures designed to rate social support structures may be modified to obtain accurate responses from individuals with chronic mental illness. One useful technique involves obtaining the individual's weekly schedule and then identifying the people that the individual sees at each place or time. A schedule of activities makes the concept of social support more concrete and facilitates easier recall (for comprehensive review of techniques see Beels, Gutwirth, Berkeley, & Struening, 1984). A more time intensive technique involves observing the individual and noting the people with whom she or he spends time so that social support questions can be tailored accordingly (Sokolovsky & Cohen, 1981).

Recent measures designed for adults with MR take into account considerations similar to those found in structural measures designed for children and for adults with schizophrenia. For example, several measures begin with names of individuals so that questions asked subsequently can refer to these names to be more concrete. Names can be recorded on cue cards (Wenz-Gross & Siperstein, 1996), or placed within a circle signifying the closeness of the relationship (McManus, 1997). Alternative network assessment methods include obtaining structural information from informants (Krauss, Seltzer & Goodman, 1992; Meins, 1993) or recording the social interaction patterns directly (Kennedy, Horner, & Newton, 1989, 1990).
Functional support, in contrast to structural support, considers what the support does for the individual. It has a much stronger association with well-being than do structural measures (see Cohen & Syme, 1985). Examples of functional divisions include: material aid, guidance, behavior assistance, feedback, intimate interaction and positive social interaction (Barrera & Ainlay, 1983). Certain functions of support have been identified as more influential on well-being than others. Emotional support is typically considered most important (House, 1981), with intimate support being the most valuable type of emotional support for adults. One reason emotional support may be of greater value than practical aid is because practical aid is often given begrudgingly (Heller, Swindle, & Dusenbury, 1986).

In the MR social support literature, a distinction is made between practical support (material or technical assistance with activities like banking, self care, and program planning), and emotional support (Krauss & Erickson, 1988; Nezu, Nezu, Rothenberg, DelliCarpini, & Groag, 1995). Greater research emphasis has been placed on practical support which is generally provided by staff or family depending on the subject's living situation. By comparison, less emphasis has been placed on emotional support by researchers as well as policy makers. Amado (1993) reported a systemic imbalance between personal and practical social support for adults with MR because of their dependency on practical services.

Other functions of support are less emphasized in research on adults with MR partly because support function is a difficult concept to define. Recent factor analyses of children's support have shown that children group their support more structurally
than functionally (Wolchik et al., 1989). Adults with MR may also conceptualize their supports by structure. One reason for structural categorization is that functional distinctions can be subtle and are often described using language with which individuals with MR are unfamiliar (Lieberman, 1986). Kultgen and Hawkins (1992) recommended that appropriate functional categories from the perspective of individuals with MR be adopted as an alternative to standard functions.

The second major distinction commonly made in the social support literature is between perceived and received support. Perceived support refers to a person’s perceptions or descriptions of support received. Perceived support is typically measured by asking people to describe to what extent they believe that social support is available to them (Helgeson, 1993). In comparison, received support is a more objective measure of the amount of support given as it can be assessed through direct observation. Typically, however, it is assessed by asking individuals to indicate whether specific supportive acts have occurred (Helgeson, 1993).

Early research did not distinguish between perceived and received support (Sarason, Sarason & Pierce, 1990). It was later recognized, however, that perceived support ratings were consistently found to more strongly correlate with well-being than received support ratings. Cohen and Wills (1985) interpreted this as evidence that the relationship between health and social support is cognitively mediated by one’s perceptions.

If a person’s perception of social support is a major correlate of well-being, then the social support perceptions of both children and adults with MR need to be studied.
Children's perceived social support has been considered important in its own right by developmental researchers (Berndt, 1984; Hymel, Franke, & Freigang, 1987; Zelkowitz, 1989) and accommodations have been made in the assessment process to increase the accuracy of its measurement. For example, visual cues have been given to children during interviews and parental aid has often been elicited (Wolchik et al., 1989). When this occurs, children offer considerable consistency in their reports (Berndt, 1984).

Several researchers have considered the perceived social support of adults with MR to be important (Burchard & Rosen, 1990; Edgerton, 1967; Kaufman, 1984; Legault, 1992; Llewellyn, 1995; Lunsky & Benson, 1997; Richardson, Katz, & Koller, 1993; Taylor, Bogdan & Lutfiiya, 1995). Support should be measured in terms that are meaningful to the individual (Kultgen & Hawkins, 1992; Taylor et al., 1995). When this has been done, researchers have found that the perceived social support of adults with mild MR correlates positively with well-being (Kaufman, 1984; Edgerton, 1967; Burchard & Rosen, 1990; Wenz-Gross & Siperstein, 1996). Shoultz (1995) concluded that researchers as well as service providers should acknowledge and adapt to the manner in which individuals with MR perceive both family and friend relationships. This would serve to give voice to the cultural perspective of people with MR (Keys, Balcazar, Bartunek, and Foster-Fishman, 1996).

In summary, perceptions of support and the functional aspects of support have been emphasized in the adult literature on social support, as both have been found to correlate positively with measures of well-being. For individuals with MR, as with children, measures have been primarily structural and less emphasis has been placed on
perceived support. Measures that assess support using more “reliable” sources than the self ignore the importance of these perceptions. If the function of support and the perceptions of support are as important as some researchers suggest (i.e., Cohen & Wills, 1985; Sarason, Sarason, & Pierce, 1990), then they should be thoroughly studied in individuals with MR. There are no studies that consider both structural and functional social support from the perspective of the individual with MR. In order to gain a complete picture of the social support of individuals with MR, the interrelations among structural and functional support measures from the self perspective should be studied.

Recent social support theory distinctions

Three additional social support research topics will now be reviewed. These topics have significantly influenced social support research generally, but have yet to be applied to persons with MR. The first topic addresses the question: Who provides the support? Traditionally, it has been thought that only individual people should be considered as sources of support. Recent writings suggest, however, that there are other larger support sources besides individual persons, termed “extra-individual support sources.” The second research topic addresses the question: What is being provided? Past research has focused primarily on the positive assistance provided through social interaction. “Social strain,” in contrast, considers how social interactions can be stressful, as well as supportive. The final topic addresses the question: What support does the individual provide to others as opposed to what support does the
individual receive? There is a growing awareness that it is not only the provision of support that helps the individual, but also the opportunity to reciprocate or be a support provider oneself (Heller, 1979).

**Extra-individual support sources**

In 1992, Felton and Shinn criticized social support research for defining and measuring social support only at an individual level when social support, by definition, is based on a system of relations. They proposed that extra-individual variables like place (i.e., work), and organized activities or groups (i.e., bowling leagues) be considered important aspects of social support.

Concerning place, Heller (1990) noted that we all belong to multiple communities: where we live and work, the institutions and organizations we belong to, and the activities that we share. How does the concept of locality or place as social support apply to adults with MR? Walker's recent chapter on social geography (1995b) found that adults with MR tend to spend their time at home in homogeneous groups. Time spent in places other than the home tend to be in large, public, and anonymous places like the mall or restaurant. Such places may have heightened significance for individuals who are less able to use the phone or travel independently and who have limited budgets for travel (Walker, 1995b). In Ashman and Suttie's study (1996) seventy percent of the individuals depended on their agencies for transportation and only fifteen percent of them used the phone to speak to friends. The neighborhood market, a place where people with cars and good communication skills take for granted,
may be the only place an individual with MR can get to independently. Furthermore, if such people lack other social opportunities, the market may become a primary place to socialize. Post-hoc analysis of social support interviews with 50 adults with mild MR found that 10% of individuals, when asked “who are your friends,” responded with names of places (Neely & Lunsky, 1998).

Another extra-individual type of support can be derived from organized activities like a bowling league, church, or a support group. Felton and Berry (1992) found that when elderly adults were asked to identify supportive individuals, they often identified undifferentiated entities such as family groups or the bridge club. Standard social support measures generally dismiss such responses. Felton and Berry’s results suggest that group support should not be dismissed as a “default response.” Forcing respondents to divide group support into separate units of individual support transforms a system of support into a disconnected set of links.

The functions served by group support may be different from the functions of individual support. Group support provides a reassurance of worth and a sense of belonging, while intimacy may be a function limited to individual support. Group support may serve as a buffer when there are losses within the group because groups survive losses of individual members (Felton & Berry, 1992).

Felton and Shinn (1992) identified several aspects of groups that can be empirically evaluated. These include stability, longevity and the ability to integrate new group members. If a person identifies a group as a source of support, the interviewer can assess whether the person perceives the group or specific group members as supportive.
Assessing how the various groups are connected to each other is an important variable to include in studies of people who receive support from several agencies or groups (Ashman & Suttie, 1996).

Group support appears to play an important role for adults with MR. While many adults with MR lack the skills to maintain one-to-one relationships in their spare time (Schalock & Lilley, 1986), they are frequently involved in organized groups. Many of them work in groups, such as workshops teams or group enclaves and many of them live in group homes or intermediate care facilities. Several chapters have been written recently that discuss the support that groups such as a community choir (Bogdan, 1995b), the Thomas Hughes Public Speaking Course (Fisher, 1995), and a bakery (Luftiyaa, 1995) provide. One disadvantage to group support is that when the group disbands, people with MR often lack the social skills necessary to maintain ties with other group members (Fisher, 1995).

For research purposes, there are advantages to recognizing groups as a form of support. In a prior study, Neely and Lunsky (1998) reported that some adults with MR had difficulty naming their friends, but had no problem discussing the groups with which they were involved such as ARC industries, Special Olympics, or church organizations. Twenty-four percent of them listed groups of individuals as supports when asked “who are your friends?” It would be useful to test whether in fact the groups as whole provide the support or the individual group members. It may be that the cognitive impairments of persons with MR make individual names difficult to retrieve. If the naming of groups is not a default type of response, a proposition supported by
Felton and Berry (1992), then social support intervention might best be provided to individuals with MR at a group level. Future research on this topic could help determine whether greater emphasis should be placed on personal relationships or on increased community group involvement.

**Social strain**

The social strain construct proposes that some forms of interpersonal interaction can cause distress rather than enhance well-being. This idea arose from the recognition that social interactions are not always positive and that they do not necessarily constitute social support. Shinn, Lehmann, and Wong (1984) outlined four ways in which social support can be straining. First, some social support may be intended as positive, but perceived as negative. Second, social support, which may be perceived as helpful, can foster dependency and lead to deterioration. Third, support that is initially perceived as positive may no longer be perceived as such, as support needs change over time. Finally, support that serves one function well may interfere with another support function.

Shinn et al. (1984) noted that support as strain had been discussed only in terms of family therapy, and they concluded that “deleterious social interactions” were worthy of future study.

Rook’s research on widows (1984) was one of the first empirical papers to compare the effects of negative to positive social interactions on well-being. Her two main findings on social strain have been replicated in various populations since then. The first of these findings states that negative support or social strain occurs at a lower
frequency than positive support. The second states that negative strain is more
influential on well-being than is social support and should therefore not be
overshadowed by positive support measures. Lakey, Tardiff, and Drew (1994)
demonstrated that negative support is independent of positive support and also
conceptually separate from daily hassles.

Negative support or social strain has been considered explicitly in a small
number of studies dealing with adults with MR (Bramston, Bostock, & Tehan, 1993;
Lunsky & Havercamp, under review; Nezu, Nezu, Rothenberg, DelliCarpini & Groag,
negative support was positively correlated with depression while positive social support
and depression were uncorrelated. In another study, it was noted that most daily hassles
reported by individuals with mild MR were of an interpersonal nature (Bramston et al.,
1993). Finally, in a recent study based on staff report, symptoms of psychopathology in
adults with MR correlated positively with social strain (Lunsky & Havercamp, under
review) but showed no correlation with ratings of “positive” social support.

These results suggest that it is not only the absence of support that causes
distress for individuals with MR, but also the presence of stressful support. Many
individuals with MR lack social support (Ashman & Suttie, 1996; Rosen & Burchard,
1990; Sands & Kozleski, 1994) but not all of those individuals show typical signs of
depression (Laman & Reiss, 1987). It is possible that negative or stressful support, be it
from stressed parents, disinterested staff, or demanding teachers, is what distinguishes
those who present with problem behaviors from those who do not.
Individuals with MR may be more likely to receive negative support than individuals without MR because they are less able to escape it. Individuals with schizophrenia display similar difficulties (Hammer, 1981) which is why part of their treatment may involve the removal of individuals (i.e. family) who cause stress from the environment. Adults with MR, who are highly dependent on others and reinforced for their passivity, may be more likely to receive a higher percentage of support that distresses them than other people. They may be less able to prevent or eliminate this type of support because of their inability to articulate their desire to be left alone.

Why would the individuals with MR who do have the skills and freedom to escape negative interactions continue being with people who do not give them positive, self-enhancing support? One explanation is that they do not perceive the negative support as negative because of socio-cognitive deficits (Lunsky & Benson, under review). A second explanation is that they lack alternative positive forms of support (Sands & Kozleski, 1994). A third possibility is that, even if the support providers are not very supportive, calling them “friends” reinforces that they have friends, which could boost their self-esteem (Gibbons, 1987). A final explanation is that negative support does not enhance their self-concepts at all. Instead, it confirms the negative “disabled” image that they have of themselves. Swann and Brown (1990) have proposed that such confirmatory information can bolster one’s sense of control, even if it does not flatter the individual.

Thus, there is some preliminary evidence linking negative social support and depression in individuals with MR, although this has yet to be thoroughly studied. A
next step should involve more elaborate study of the differential effects of positive and negative support in adults with MR, to better understand the effects of negative support on them.

Reciprocity

One fundamental aspect of social support that has not been adequately addressed in the MR literature is reciprocity, defined here as the normative obligation of a help recipient to assist people who have provided help to him or her (Gouldner, 1960). Mutual obligation and interdependence develop from reciprocity (Youniss, 1994) making reciprocity a prerequisite to any friendship (Kultgen & Hawkins, 1992). There are several types of reciprocity. Young children learn to reciprocate on a specific exchange basis (Youniss, 1994). With age, reciprocity can become less literal and immediate. Adults can also learn to return favors to each other in different ways (generalized reciprocity) and sometimes do so indirectly through other people (network balancing).

There are numerous benefits to reciprocal exchanges and some negative consequences from failing to do so. Reciprocity can lead to improved self-efficacy and self-confidence on the part of the reciprocator, and give rise to feelings of gratitude on the part of the other party (Horwitz, Reinhardt, & Howell-White, 1996). According to Rook (1990), this sense of symmetry is the defining characteristic of companionship, in contrast to support which can be one-sided. Some researchers have argued that if a focal person receives aid but does not return it, then disequilibrium occurs followed by
resentment on the part of the help-giver, and ending potentially in the destruction of the relationship (Shumaker & Brownell, 1984). Thus, both the receiver and provider of support suffer from the failure of the recipient to reciprocate with the result that neither is likely to support the other in the future.

Studies have shown that individuals with MR tend to reciprocate less than they receive support (Green et al., 1995; Newton, Olson, Horner, & Ard, 1996; Rosen & Burchard, 1990). In Green et al.'s study (1995), most of the friendships formed between university volunteers and adults with MR as part of a friendship project ended shortly after the completion of the project. One explanation given for the abrupt endings was that the volunteers felt an absence of reciprocity in their friendships, i.e., "I am doing most of the talking." In Rosen and Burchard's study (1990), individuals with MR self-reported less reciprocity than individuals without MR, with most individuals with MR reporting having no reciprocal relationships at all.

Reciprocity and many social skills are influenced by perceptual, cognitive, behavioral and linguistic deficits, the defining characteristics of MR (Edgerton & Kernan, 1983). Recently, Moffatt, Hanley-Maxwell, and Donnellan (1995) found that adults with mild MR have significant impairments in affective perspective taking. They argued that the cognitive perceptual deficits that prevent adults with MR from interpreting behavior and emotions of others make reciprocity especially challenging. Lack of reciprocity may also be a learned behavior for individuals with MR which corresponds to the expectations that people place on them. Children with MR are often "patronized" and are rarely expected to contribute in their relationships (Gibbons,
Many of the relationships of adults with MR are with their staff. These types of relationships are defined by their asymmetry (Heller, 1979) and do not foster reciprocity.

Two emerging views seek to promote reciprocity among adults with MR. The first, a more popular view, is that all individuals can reciprocate so long as reciprocity is defined broadly, as with Horwitz, Reinhard and Howell-White's definition (1996): Reciprocity is each side perceiving that the other is doing the best s/he can to maintain a balanced relationship within the constraints of their abilities (p. 150). Some authors have discussed how individuals with special needs reciprocate through “their gifts,” or “their being,” or in “what they can teach us about ourselves.” (e.g. Andrews, 1995; Strully & Strully, 1992). One problem with this view is that it suggests that individuals reciprocate with their families or communities by having a disability and not through their actions. According to this view, there is no need to teach individuals with MR more standard reciprocity or social skills. Defining reciprocity as simply contributing by having a disability is inadequate as it does not give the individual with disability any responsibility as a support provider.

The other emerging view about reciprocity, which may have greater utility, is that some individuals with MR reciprocate in their relationships through their actions and not just by virtue of their handicap. Such a view has two advantages over the former view. First, it encourages researchers to look more carefully before dismissing individuals with MR as incapable of reciprocating. Second, it suggests that with skills training, other individuals could learn to reciprocate in their relationships. Reciprocal
relationships have been reported to exist both with other people with MR (Llewellyn, 1995; Mest, 1987) and with people without MR (Bogdan, 1995; Kaufman, 1984; Luftiyya, 1993; Schwier, 1993; Shoultz, 1995). When studying social support it is important to examine how individuals with MR reciprocate support to individuals with MR, to family, to individuals without MR, and to the community at large.

No empirical research on social support and MR has included reciprocity measures except for the research of Rosen and Burchard (1990). Their study gave no indication of how reciprocity impacted on the quality of the relationships and their quality of life more generally. It is important to measure how reciprocity affects one’s well-being as perceived by individuals with MR.

The relationship between social support and health

Social support is relevant to psychology researchers because of its established relationship to health, defined by the World Health Organization as physical, mental and social well-being. While health is not the primary focus of this paper, a basic familiarity with the research on the mental and physical health of adults with MR is necessary.

Health of adults with mental retardation

Individuals with MR are as susceptible to the same physical health problems as other individuals if not more so because of factors specific to this population. These factors include: (1) a sedentary lifestyle with excessive sleep and limited exercise, as well as high rates of obesity (Beange, McElduff, & Baker, 1995; Rimmer, Braddock, &
Fujiura, 1993); (2) a difficulty detecting and reporting symptoms, possibly because of communication and sensory deficits (Crocker et al., 1987); (3) chronic health conditions associated with the etiology of the MR; (4) caregivers who under report problems to physicians in stages where prevention is still possible; and (5) the tendency of physicians to overlook health problems in individuals with MR because of insufficient funds and limited training with this population (Lennox & Chaplin, 1997). Physicians might also ignore minor health problems and health risk factors because of commonly held assumptions that adults with MR do not drink, smoke, or work hard and that they are immune to stress (Bond, Kerr, Dunstan, & Thapar, 1997).

While information on health of people with MR is limited and confounded by other factors, some studies have been published on the prevalence of physical disease in this population. In one study of 151 adults in a vocational center in Wales, 72% of the sample had inadequate contact with physicians. Health problems unmanaged prior to the study included: hypertension, chronic bronchitis, arthritis, gross obesity, and hearing and vision problems (Howells, 1986). In a similar study by Martin, Roy and Wells (1997) 84% of a sample of adults with MR were found to have previously undiagnosed medical conditions including endocrine problems, cardiovascular problems, and problems requiring minor surgery. In two random samples of Australians with MR, Beange and Bauman noted that two thirds of the first sample (1990), and 42% of a more recent sample (Beange et al., 1995) had undetected medical conditions, including diabetes, deafness, hepatitis B carrier status, hypertension, and florid skin diseases. In the latter study, 58% of the sample was taking prescribed medications. Tests of 61
individuals revealed that 50% of them had drug levels above the therapeutic range. In an epidemiological study in Maine, Minihan and Dean (1990) noted that two thirds of 333 community members with MR had chronic conditions that required medical attention. While these findings are far from conclusive, they appear to show that adults with MR have a high susceptibility to physical illness and disease and they may not always receive adequate medical attention for these conditions.

As with physical illnesses, clinicians may also be more likely to fail to diagnose or misdiagnose mental disorders in individuals with MR. Clinicians may find it particularly difficult to assess whether individuals with limited receptive and expressive verbal ability and tendencies to acquiesce meet criteria for particular DSM-IV disorders. Some research has looked at the prevalence of mood, psychotic and anxiety disorders in persons with MR, suggesting that prevalence of such disorders is as high as in the general population (Reiss, 1994). The most common treatment for mental disorders in adults with MR is medication. In one survey, physicians reported over-medicating adults with MR with antipsychotics and choosing to pursue other forms of therapy to only a limited extent (Lennox and Chaplin, 1996).

Thus, adults with MR are as susceptible, if not more susceptible, to mental and physical illness as are other individuals. Research reviewed suggests that their disabilities, as well as their home and work environments, can lessen the likelihood that their disorders will be accurately diagnosed in a timely manner and treated effectively. It is therefore very important to investigate risk factors for health problems in this population. Social support has been identified as one risk factor in the general
population and it may be relevant to this population as well. The following section will examine how social support can be an important influence on physical and mental health.

**Models of social support and health**

Several models of social support and health have been proposed in the research literature on the general population. Two in particular have received the most attention: the Direct Effect hypothesis or Main Effect model and the Buffering hypothesis or Moderator Effect model. The Main Effect model stipulates that social support enhances health and well-being irrespective of stress level (Cohen & Syme, 1985). According to this model, effects of stress are independent of effects of social support. Stress and social support, therefore, make additive contributions to health and well-being. The Buffering hypothesis, in contrast, states that social support buffers or protects people from the pathogenic effects of stressful life events (Cohen & Syme, 1985). Two other models that have been proposed to explain these relationships are the Mediator model and the Artifact model (for a more extensive review, see Barrera, 1988).

All four of these models have received some empirical support from studies within the general population (see Barrera, 1986). Cohen and Syme (1985) have cautioned, however, that consistent patterns of results can be found using virtually any social support hypothesis. One factor to consider when interpreting these results is the manner in which social support is conceptualized in the research. A structural viewpoint may be more powerful when testing the Main Effect model and a functional perspective
may be better at identifying buffering effects (Cohen & Syme, 1985; Murrell, Norris, & Chipley, 1992). The Main Effect model may be more relevant when explaining long-term consequences of social support, like socialization, while the Moderator Effect model may be more appropriate for explaining the short-term consequences of coping (Gibbons, 1987).

None of the models of social support and health have been explicitly applied to individuals with MR. The reason for this may be twofold. Firstly, social support research as it applies to both the MR and general populations has been heavily criticized on theoretical grounds for its conceptual ambiguity and lack of construct validity (e.g., Coyne & DeLongis, 1986; Shumaker & Brownell, 1984; Vaux & Harrison, 1985). Sarason, Sarason and Pierce (1990) noted that most of the social support instruments still used today were developed with little theoretical basis, based on face validity only. Cohen and Syme (1985) warned that social support measures should not be selected simply on the basis that they were used in previous studies. A researcher needs to conceptualize the construct and its hypothesized correlates first and then select measures accordingly.

There has been only limited research on the correlates of social support within the MR population. As such, the relationships proposed in this research between social support and mental or physical health are speculative at best. Instrument selection for social support research has yet to be theory guided, being that the area is still in its infancy. Future research on MR and social support will require theories that specify
predictors of social support and consequences or outcomes, as well as measures that are theory based.

Secondly, social support research as it applies to both the MR and general populations suffers from methodological shortcomings. (For a thorough review of methodological issues see Depner, Wethington, & Ingersoll-Dayton, 1984.) Methodological problems common in research with the general population include confounds of measures of support, health and well-being and stressors (see Dohrenwend & Shrout, 1985; Shumaker & Brownell, 1984; Zelkowitz, 1989 re: children) as well as method variance. (In most studies, all measures are self-report; Depner et al., 1984).

Other problems include biases and halo effects (Shumaker & Brownell, 1984), an individualistic emphasis (Felton & Shinn, 1992), lack of correlation between measures (Barrera, 1986), inappropriate research designs (cross sectional as opposed to longitudinal; Murrell et al., 1992) and poorly matched control groups (Monroe, Bromet, Connell, & Steiner, 1986). In studies in which these measurement issues are addressed, results vary significantly from more commonly reported findings (e.g. Monroe et al., 1986; Turner & Moreno, 1994). An additional methodological limitation found in most social support research is its exclusive reliance on quantitative data. Depner et al. (1984) outlined several ways to successfully incorporate qualitative data into quantitative research on social support, although their recommendations have not been that influential thus far.

Methodological problems are most apparent in MR social support research. Confounding measures are as much of a problem in research with individuals with MR
as they are with the general population. Researchers often make use of data from individuals with mild MR as they are the only ones able to provide self-reported information. As such, self-report findings are not generalizable to the greater population of individuals with MR. Individuals with MR when asked to self-report are prone to acquiescence (see Heal & Siegelman, 1995). There are few existing longitudinal research studies involving social support and individuals with MR, with the exception of early ethnographic studies like that of Edgerton (1967). Although it is known that individuals with MR have difficulty recalling events retrospectively (Naradajah et al., 1995), few studies are prospective. Finally, the division between qualitative and quantitative research is glaring in the MR field. Rarely do researchers from one group refer to findings or methods from the other group.

Researchers in the MR field face the further difficulty of measuring health and well-being in this population. In the past, researchers resorted to using nominal ratings of well-being such as living in the community or back in the institution (Edgerton & Kernan, 1983). The current trend is to measure one’s “quality of life.” This new construct is more operationally defined than prior measures (see Renwick, Brown, & Nagler, 1996; Schalock, 1996) but still criticized by some researchers as subjective (Taylor & Bogdan, 1996).

Health outcome research for persons with MR is scarce and primarily descriptive. Many of the findings from these studies are based on chart reviews from large, institutional settings. Psychopathology research also has its problems. Standard diagnostic criteria for mental illness may not always be appropriate for adults with MR.
(see Singh, Sood, Sonenklar, & Ellis, 1991). The relationship between social support and mental health has received cursory examination in this population and any relationships between social support and physical health have yet to be studied. Even the relationships between physical health, mental health, and quality of life are not clear.

Summary

Past research on social support and MR can be criticized on both theoretical and methodological grounds. In order for findings to be more reliable and valid, research requires a stronger theoretical foundation with more appropriate research designs. A strong research study requires that a model of social support and health and well-being be tested, with conceptualizations of social support, health and well-being. The research reviewed here suggests that both the structure and function of support should be measured, combining qualitative and quantitative methods. Other important considerations include a broader definition of social support that takes a broader range of support sources and social interactions into consideration. The act of reciprocity, not commonly considered in the MR literature as a major support component, should also be included. The literature reviewed also suggests that the relationships between social support, health and well-being are mediated by the individual’s perceptions. Therefore, perceptions of support, rather than informants’ ratings of support need to be measured. In measuring perceptions of individuals with MR, the limitations of self-reports must be taken into consideration. Because of problems associated with self-reports, it is important that the people conducting the research must take the time to get to know the
individual (Taylor & Bogdan, 1996). Integrating qualitative research methods is also necessary (See Depner et al. for explanation on how to integrate two methods in social support research.) Finally, in order to study the causal relationship between social support, health and well-being, a prospective research design is required.

**Purpose of Present Study**

The purpose of this study is to examine the relationship between perceived social support, health and well-being in individuals with mild MR. Social support is operationalized broadly as having both functional and structural aspects, as making positive and negative contributions, and as coming from a wide array of sources, including groups. Health and well-being is operationalized in terms of perceived physical health, the absence of depressive symptoms, and good quality of life. The primary research question is: Does social support at Time 1 predict quality of life and symptoms of depression six months later? A secondary interest is to examine how perceived physical health is related to social support, depression and quality of life. Does perceived health at Time 1 predict quality of life and depressive symptoms six months later? Furthermore, does social support influence perceived physical health?

**Time 1: conceptions of social support**

Several predictions can be made about how the social support measures correlate with each other at Time 1, strengthening the validity of the social support construct for individuals with mild MR:
**Hypothesis 1: Relationship between functional and structural support measures**

Structural and functional social support measures will be significantly positively correlated, but less so than structural measures with each other. This prediction is based on non-MR findings that structural and functional support measures are not significantly correlated (Barrera, 1986; Cohen & Syme, 1985).

**Hypothesis 2: Relationship between social support and social strain**

Social strain will not be significantly correlated with measures of perceived positive support as the two are distinct independent constructs in the non-MR literature (Lakey et al., 1994).

**Hypothesis 3: Relationship between self-report and family report of reciprocity**

Reciprocity ratings of individuals with MR will be positively correlated with ratings of support by family members and reciprocity ratings by family members, based on findings by Horwitz et al. with individuals with chronic mental illness (1996).

**Hypothesis 4: Incidence of extra-individual sources of social support**

In their listing of support sources, individuals with MR will list alternative sources of support including group support, supportive places, and other non-traditional support sources.

**Time 2: depression, quality of life and perceptions of health**

Several predictions can be made about loneliness, depression, quality of life, and health at Time 2, strengthening the validity of the outcome variables as measures of health and well-being for individuals with mild MR:

**Hypothesis 5: Relationship between loneliness and depression**

Loneliness will be positively correlated with depression. This is an index of construct validity.
Hypothesis 6: Relationship between self-report and staff ratings of depression
Informant and self-reports of depression will be positively correlated, as an index of staff-client agreement and validity.

Hypothesis 7: Relationship between self-report and staff ratings of quality of life
Informant and self-reports of quality of life will be positively correlated as an index of staff-client agreement and validity.

Hypothesis 8: Relationship between quality of life and depression/psychopathology
Quality of life will be negatively correlated with psychopathology and depression (self and informant measures) based on the suggestion that individuals with mental health problems experience impoverished quality of life (Schalock & Keith, 1993).

Time 1 - Time 2:

Relationships between social support, health, depression and quality of life

Several predictions can be made about the relationship between social support, perceived health, quality of life and symptoms of depression for adults with mild MR:

Hypothesis 9: Time 1 social support predictors of health at Time 2
Social support and loneliness at Time 1 will predict perceived health at Time 2.

Hypothesis 10: Time 1 social support and health predictors of depression at Time 2
Social support and loneliness at Time 1 will predict change in depressive symptoms at Time 2. Health at Time 1 will predict change in depressive symptoms at Time 2 above and beyond social support and loneliness at Time 1.

Hypothesis 11: Time 1 social support and health predictors of quality of life at Time 2
Social support and loneliness at Time 1 will predict quality of life at Time 2. Health at Time 1 will predict quality of life at Time 2 above and beyond social support and loneliness at Time 1.
Hypothesis 12: Additional Time 1 predictors of depression and quality of life at Time 2

Negative support, reciprocity and extra-individual measures of support combined with positive support measures and loneliness will predict symptoms of depression and quality of life at Time 2 more strongly than positive support measures alone.
CHAPTER 2

METHOD

Participants

Adults in the mildly delayed range of intellectual functioning (Luckasson et al., 1994) living in "supported living" environments and their staff were recruited to participate in this study. To qualify as “supported living,” the living arrangement had to be a house or apartment as opposed to a large institutional facility and staff practical support (either by phone or in person) was to be provided on at least a weekly basis. Practical support can involve assistance with daily or weekly activities like food preparation, shopping and banking. Typically, family members do not live in the same dwelling and residences are made up of no more than three or four people. Potential participants were nominated by 11 residential providers in Central Ohio and 3 residential providers in Southern Ontario out of a total of 18 agencies approached. Non-participating agencies explained that they either did not have appropriate candidates for the study or were not interested in supporting research efforts.

Eighty-four adults with mild mental retardation (MR) were recruited to participate in the study, 41 males and 43 females, ranging in age from 20 to 65 (see Table 1 for detailed summary). Inclusion criteria for individuals were: adequate
communication skills, and an ability to respond to Likert scale measures. Specifically, individuals were required to understand the consent form and reach a basal score above age five on the PPVT-III to satisfy communication skills requirements, and were required to respond to the example item on each questionnaire appropriately to show that they understood Likert scale measures. Residential agencies were informed that they could recommend any adults with mild MR whom they thought would be able to participate in a 90-minute interview, even those individuals with comorbid mental health issues.

Staff who knew the individuals well (for at least three months) were asked to complete written questionnaires about those individuals. These informants were typically selected by the agencies who referred the individuals with MR to the study. On three occasions, participants requested a different staff person during the interview than the one recommended by the agency and so their requests were met. At Time 1, 76 of 84 staff questionnaires were returned and at Time 2, 74 of 80 questionnaires were returned. Two questionnaires were returned by one staff three months following the participant interview and were not included in the analyses. Eleven staff completed Time 2 questionnaires who did not complete Time 1 questionnaires, due to staff changes. At the time of the second rating, staff knew the individuals rated between 4 months and 17 years with a mean of 3.3 years. They had worked in the field of developmental disabilities between 0 and 20 years (mean=9.2 years), and ranged in age from 22 to 55 (mean=37.2 years). They had on average 21.1 contact hours with the individuals with MR per week.
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Range 20-65 yr., $M=38.0$ yr., $sd=10.4$ yr.</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>85% Caucasian</td>
</tr>
<tr>
<td></td>
<td>14% African American</td>
</tr>
<tr>
<td></td>
<td>1% Asian American</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>51% female</td>
</tr>
<tr>
<td></td>
<td>49% male</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
<td>79% American</td>
</tr>
<tr>
<td></td>
<td>21% Canadian</td>
</tr>
<tr>
<td><strong>PPVT-III raw score</strong></td>
<td>Range (63-164) $M=120.6$, $sd=26.0$, $MA=8-10$ yr.</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td>28% live alone</td>
</tr>
<tr>
<td></td>
<td>30% one house mate</td>
</tr>
<tr>
<td></td>
<td>31% two house mates</td>
</tr>
<tr>
<td></td>
<td>11% three or more house mates</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td>45% community / supported employment</td>
</tr>
<tr>
<td></td>
<td>43% sheltered workshop</td>
</tr>
<tr>
<td></td>
<td>12% unemployed</td>
</tr>
</tbody>
</table>

*Table 1* Demographic characteristics of participants with mental retardation ($N=84$)
In addition, 31 family members selected by the participants as the “person in your family most supportive of you” were interviewed over the phone about social support and their family member with MR. The sample consisted mainly of mothers (45%), sisters (29%) and fathers (10%), with one cousin, one in-law and one step-parent. Family members of the remaining 53 individuals were not contacted because participants either reported no contact with family and were therefore not asked to nominate a family member, or they reported some contact with family but preferred not to give out phone numbers. Typical reasons for not giving phone numbers included maintaining confidentiality or the belief that the family member would not be interested or would be disturbed by the information request. The family members interviewed ranged in age from 31 to 79 (mean=52.1 years). They reported seeing the individual with MR once a month on average and reported speaking with him or her on the telephone on average three times per week.

Measures

**Self-report measures.** The following measures were administered at Time 1 and Time 2 in this order.

**Time 1:**
- Peabody Picture Vocabulary Test-III
- Circle technique (CT)
- Social Support Self Report for mentally retarded adults (SSSR)
- Functional support measure (FSM)
- Inventory of Negative Social Interactions (INSI)
- Reciprocity Measure
- Loneliness Questionnaire (LQ-W, LQ-R)
- Birleson Depression short form self-rating scale (BSD-S)
- Healthy Behaviors Screen (HBS)
The Peabody Picture Vocabulary Test-Third Edition (PPVT-III; Dunn, Dunn, & Williams, 1997) is a measure of single word receptive vocabulary, and takes approximately 15 to 30 minutes to administer to adults with MR. The respondent is required to point to one of four pictures that best illustrates a word. Earlier versions of the PPVT-III have very good reliability and validity and have been used by many researchers working with adults with MR.

Social support structure was measured through respondents’ reports of people in their lives, assessed through Antonucci and Akiyama’s “circle” technique (1987). Respondents are shown a page with a circle labeled “you” surrounded by three concentric circles, then told to think of these circles as representing “all the people who are important in your life right now”, and asked first to identify those people “who you feel so close to that it is hard to imagine life without them.” After these people’s names are recorded in the innermost circle, individuals are asked to identify the people “who you don’t feel AS close to but who are still very important to you,” and finally to identify the people “who you didn’t mention yet but who are close enough and important enough to be in your circle.” This scale was adopted successfully by McManus (1997) in his doctoral dissertation with adults with mild MR (See Appendix A).
The Social Support Self-Report for Mentally Retarded adults (SSSR) is a perceived support self-report instrument in two parts. Part one is a structured interview where the individual identifies the number of supportive people in his/her life. While the original scale only considers family, friends and romantic partner (Reiss & Benson, 1985), the modified scale also explicitly considers staff (see Lunsky & Benson, 1997). Part two evaluates the quality of perceived support provided by each source, with five questions: 1. How often do you see ________? 2. How often do you talk to ________ about your feelings? 3. How much do you like ________? 4. How much does ________ help you with your problems? and 5. How much do you help ________ with his/her problems? The person can respond "a lot" (2 points) "a little" (1 point) or "not at all" (0 points). This scale permits a total perceived support score as well as subscale scores for each support source and a reciprocity score. It has adequate internal consistency and correlates significantly with other self-report instruments and with residential staff ratings (Lunsky & Benson, 1997; See Appendix B).

The Functional support measure (FSM), developed by Felton and Berry (1992), based on Weiss’s description of six social provisions critical for mental health, was also used. Six questions, one for each social provision, are asked to determine whether or not respondents have anyone who makes these provisions. The six questions ask if there is someone they can count on for sympathy and understanding (attachment), for pleasant companionship (social integration), for help with household or personal tasks (reliable alliance), or for advice if needed (guidance); if there is someone they know who recognizes special abilities they have (reassurance of worth); and if there is someone
who relies on them for their care or part of their care (opportunity for nurturance). Up to three providers are coded for each provision (See Appendix C).

Negative social interactions were measured by the Inventory of Negative Social Interactions (INSI; Lakey et al., 1994). This instrument focuses on stressful interpersonal transactions and is structured identically to the Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler, & Ramsey, 1981). There are 40 items for which the respondent rates the frequency of specific types of interactions that have occurred over the past four weeks. The original response choices are on a five-point Likert scale of "not at all" to "about every day." The internal consistency of the scale with undergraduates was reported to have a Cronbach’s alpha of .93. For individuals with MR, the instrument is presented verbally, rather than in written form and there are only 3 response options (not at all, sometimes, and a lot). For the purposes of this study, items were modified slightly to be better understood by adults with mild MR. For example, instead of "criticized you" the item reads "said bad things about you" (See Appendix D).

Reciprocity toward family was measured with an index adopted by Horwitz et al. (1996) for adults with chronic mental illness. Individuals with MR are asked about their contributions in the seven areas of chores, economic contributions, providing care for others, companionship, participation in family activities, expressing affection, and giving gifts to the family member whom they select as most supportive. Possible responses of "a lot," "some," and "none" are summed to form an index of reciprocity. This index had an inter-item reliability of .80 with patients with mental illness (See Appendix E).
The Loneliness Questionnaire (LQ) is based on the 23 item Workers Loneliness Questionnaire (Chadsey-Rusch et al., 1992) and measures perceptions of loneliness, a variant of perceived social support. It is made up of 15 primary items on work (LQ-W), and 8 “distractor” items on leisure activities. The original questionnaire had split-half reliabilities between .81 and .83 for adults with mild to moderate MR, test-retest reliabilities of .76 to .89 and inter-rater reliabilities between .85 and .91. The three factors had respective alphas of .80 for Social dissatisfaction, .47 for Aloneness and .69 for Interest, and the correlations between factors were all low. For this study, an additional 15 items on residence loneliness were included (LQ-R), substituting the words “where you live” for “work”. Several of the items are reverse scored to control for acquiescence. Respondents can respond “yes,” “maybe” or “no,” to all of the items and the order of responses is varied, to control for bias (See Appendix F).

The Birleson Depressive Short form Self-Rating Scale (BDS-S) is based on a 37-item questionnaire developed for 7 to 12-year-old children (Birleson, 1981). There are three response categories: “Most of the time,” “Sometimes,” and “Never.” These are scored 0, 1 or 2 with the higher score reflecting depression. Some of the scale items are scored positively for depression whereas others are reverse scored. In the present study, an 18-item scale that Birleson found to discriminate between depressed and control groups of children was adopted. This scale was also used in Benson and Ivins’ 1992 study, where scores correlated significantly with informant ratings (See Appendix G).

The Quality of Life Questionnaire (QoL-Q; Schalock & Keith, 1993) is a subjective measure of quality of life, developed especially for adults with MR. It consists
of four scales: Satisfaction, Competence/Productivity, Empowerment/Independence and Social Belonging/Community Integration. Each subscale contains 10 items that are scored on a three point Likert scale. The QoL-Q is the most widely accepted quality of life questionnaire used for individuals with MR (Rosen, Simon, & McKinsey, 1995). One of its strengths is the extensive research base of the instrument (Schalock & Keith, 1993). The items have good inter-item reliability ($r=.83$), good content validity and adequate informant/client interrater reliability ($r=.67$). When administering the QoL-Q to individuals with MR, it is recommended to adjust the wording if necessary, to facilitate comprehension (Schalock & Keith, 1993; See Appendix H).

The Healthy Behaviors Screen (HBS) was developed specifically for this study and examines five health-related behaviors: smoking, alcohol consumption, exercise, illness, and doctor visits. Five questions on the frequency of these behaviors are rated on a three-point Likert scale. Both open and closed ended questions are asked as follow-up. The screen also checks for specific medical problems and disorders, as well as current medications, both psychotropic medications and those prescribed for physical health conditions (See Appendix I). Health related behaviors are examined individually and the illness score consists of the number of illnesses endorsed, the frequency of doctor visits and the overall severity of illness.

**Staff measures.** The following measures were administered to staff.

**Time 1:**
- Reiss Screen for Maladaptive Behavior
- Healthy Behaviors Screen (staff; HBS)
Time 2: Quality of Life Questionnaire (QoL-Q)
Reiss Screen for Maladaptive Behavior
Birleson Depression Scale (informant version; BDS-I)
Healthy Behaviors Screen (staff; HBS)

The Reiss Screen for Maladaptive Behavior (Reiss, 1988) is a screening tool for
dual diagnosis (aberrant behavior or psychopathology in adults with MR). It consists of
38 items that form 7 subscales: aggressive behavior, psychosis, paranoia, depression -
behavioral and depression - physical, dependent personality disorder, avoidant disorder
and autism, as well as a 26-item total score. Each subscale has an alpha coefficient above
.70, with very acceptable interrater reliabilities. While the scale is a valid instrument for
screening psychopathology, it is not recommended as diagnostic of specific disorders.
Each item is rated on a three-point scale of “no problem,” “a problem,” or “a major
problem.” Raters are asked to take frequency and severity of behavior into account in
their ratings. The Reiss Screen has the best psychometric properties for a scale of its type
(Aman, 1991; See Appendix J).

The Birleson depressive rating scale (informant version; BDS-I)) consists of five
items that most strongly discriminated between depressed and non-depressed children in
Birleson’s 1981 study. This measure was successfully adapted for adults with MR in
Benson and Ivins’ research (1992) where informant ratings of depressed mood correlated
significantly with self report. The three response alternatives are “most of the time,”
“sometimes” and “never.” (See Appendix K)
The Quality of Life Questionnaire, informant version is identical to the QoL-Q described under “self-report.” In the written instructions, the informant is encouraged to answer the items as if s/he is that person.

The Healthy behaviors screen (HBS), informant version, is identical to the screen described in the self-report section, but written in the third person.

Family member ratings. The following measure was administered to a family member selected by the participant. The amount of support given by the individual (reciprocity) is measured by asking the family member the identical questions about reciprocity asked to the individual with MR (see also Horwitz et al., 1996). Possible responses of “Not at all,” “seldom,” “sometimes,” and “frequently” are summed to form an index of social support provided by the individual with MR. The amount of support provided to the individual with MR is measured with a series of questions that were used in the Horwitz et al. study (1996) with individuals with chronic mental illness. The six items ask family members how much help they provided in the last year regarding: a loan of about a hundred dollars; a place to stay for a night or two; a place to stay for a long time; help with household tasks like shopping, cooking, cleaning, or laundry; talking about a personal problem; and help when the individual with MR was feeling really sick. In each area, possible responses are “not at all,” “seldom,” “sometimes,” and “frequently.” The Cronbach’s alpha coefficient of this index was .62 with parents and .70 for siblings of individuals with mental illness (See Appendix L).
Procedure

Potential participants with MR were approached by their service provider about the project and asked for permission to be contacted by the researcher. The researcher or one of two female research assistants then called each participant, explained the study in greater detail, and set up an appointment. Individuals with MR were interviewed by the researcher or research assistant, primarily at home, or at their work or residential agency, so long as it was in a private and comfortable room with which they were familiar.

Before the interview, each participant was required to give both oral and written consent. This procedure ensured that the risks and benefits of participation were fully understood. In reviewing the consent orally, each participant was required to answer four questions correctly:

1. What do you do if you do not want to answer? (say I don't want to answer)
2. What do you do if you do not want to answer any more? (say I am finished)
3. Who will I tell your answers to? (nobody)
4. Will anyone be mad at you if you don't want to do this or if you stop? (no)

Only after these responses were given could the person sign the written consent (Appendix M). If these items could not be answered correctly after a repeated explanation, then the participant would be excluded from the study. All participants understood the consent with this procedure. An additional consent form was read to participants after they completed the interview and were paid, regarding speaking with a family member (Appendix N).

In addition to understanding the consent form, consumers had to demonstrate adequate ability to respond to Likert scale measures in order to participate. To assess this
ability, an example item was given after each Likert scale instrument was explained. In addition to correctly responding to sample questions, prompt questions like, "Can you tell me more about that?" were asked intermittently to check for comprehension, acquiescence, and response biases. To facilitate responses, color-coded cards were provided with the response choices written on them, based on the method of Chadsey-Rusch et al. (1992).

At Time 1, following the consent procedure, consumers completed the PPVT-III and the four social support measures in this order: 1) Circles Technique 2) Social Support Self Report for mentally retarded adults (SSSR) 3) Functional Support Measure (FSM) 4) Inventory of Negative Social Interactions (INSI) 5) Reciprocity Measure. Next, individuals completed the Loneliness Questionnaire (LQ-W, LQ-R), the Birleson Depression short form self-rating scale (BDS-S) and the Healthy Behaviors Screen (HBS). Participants were then debriefed (Appendix O). During the debriefing of the first interview, the purposes of the study were reviewed and confidentiality of responses was reemphasized. Participants were reminded that they would be contacted six months later to complete a second interview. Each individual was paid $5.00 for participating in the first phase, which was not conditional upon completion of the study. The first interview typically took between 60 and 100 minutes to complete.

Staff were asked to complete the Reiss Screen for Maladaptive Behaviors and Healthy Behavior Screen (HBS) at the time of the first interview although many staff opted to complete the measures at a later time and returned them in self-addressed postage-paid envelopes. Each staff member was required to sign a written consent for
his/her involvement in the study. When, after two weeks, forms were not yet returned, a follow-up call was placed. A second call was placed two weeks later, and a final call was placed one week later. When staff reported that forms had been mailed but they were not received, a second copy was mailed out. Questionnaires from eight staff were not returned within two months of the interview.

The second interview was conducted no less than five months and three weeks after the first interview and no more than six months and two weeks after the first interview. Participants were contacted directly by the researcher or assistant between December 1997 and February 1998 to arrange a follow-up interview. Four individuals indicated that they did not wish to be re-interviewed. One man was being hospitalized for mental health reasons, another man was severely depressed and would not answer his phone or door on three separate occasions, and the remaining man and woman politely informed the interviewers without offering explanations that they did not wish to be re-interviewed.

For the remaining 80 individuals, the researcher or assistant returned to their house or a comfortable place, the consent that they signed previously was reviewed, and they were refamiliarized with the project. Two women were interviewed by a different research assistant than Time 1 because the former interviewer was now working with these women part time. The remaining 78 adults were interviewed by the same interviewer as Time 1. They were first administered the Quality of Life Questionnaire (QoL-Q) followed by the Birleson Depression short form self-rating scale (BDS-S) and the Loneliness Questionnaire (LQ-W, LQ-R). They were then given the Healthy
Behavior Screen (HBS), followed by the Social support Self-Report for mentally retarded adults (SSSR). Participants were debriefed and paid $5.00.

During or following the Time 2 interview, the staff person was asked to complete the Reiss Screen for maladaptive behaviors, the Birleson Depression Scale (Informant version; BDS-I), the Healthy Behavior Screen (HBS) and the Quality of Life Questionnaire (QoL-Q). Information was also requested on staff demographics as well as important life changes over the past six months for the participant. The questionnaires took approximately 15-30 minutes to complete. When staff surveys were completed, they were mailed back to the researcher in postage paid envelopes or collected by hand. The same two month rule was applied at Time 2 as Time 1. Seventy-four valid staff questionnaires were received at Time 2. While staff were not paid directly for their involvement, returned surveys were entered in a raffle for free movie coupons and department store gift certificates, to encourage compliance.
CHAPTER 3

RESULTS

Preliminary analyses

Results are based on findings from 84 adults with mild mental retardation (MR) interviewed by one of three interviewers. To determine if individuals interviewed by the three raters differed in age, PPVT-III scores, or any self-report variables, analyses of variance were carried out with interviewer as the between-subjects variable. No significant differences were found between interviewers on any of the measures administered.

To determine whether analyses should be carried out separately for the men and women in the sample, several t-tests were performed on the self-report and staff ratings, as well as the PPVT-III scores. Women scored significantly lower on PPVT-III scores than men ($t(1,81)=2.37, p<.05$), but the men and women did not differ on any of the other measures with the exception of loneliness at work (LQ-W) at Time 2 ($t(1,65)=2.71, p<.05$). Women reported significantly higher rates of loneliness than men (Note: this gender difference was also reported by Petrovski and Gleeson (1997) with adults with mild MR using the same measure). As this was the only significant
difference found between gender and it was only found at Time 2, analyses are based on data from men and women combined.

Finally, it was important to determine whether any of the self-report ratings were a function of receptive language ability or age. To test this, correlations between PPVT-III raw scores, age and all self-report variables were computed. The Inventory of Negative Social Interactions (INSI) was the only measure correlated with receptive language ability ($r=.31$, $p<.005$), suggesting that higher receptive language ability is associated with increased reports of negative social interactions. Therefore, PPVT-III scores were partialled out of all analyses involving the INSI. Age was negatively correlated with ratings of reciprocity with family members ($r=-.34$, $p<.005$), likely because older individuals had less family involvement.

**Time 1: conceptions of social support**

Table 1 presents the means, standard deviations, and range of the number of individuals named as members of the support networks of participants for each of the three social support questionnaires. On the Circles Technique, individuals typically listed the most names in the first circle. In some cases, there were no supporters remaining to be named for the outer circles. The greatest number of names were elicited with the SSSR, which asks for names of specific categories of support sources (e.g. uncles and aunts; friends at work). It should be noted that the large number of family members listed on the SSSR represents the number of immediate and extended family who exist, but does not imply that they are reliable support sources. Similarly, the high
number of staff named does not suggest that all staff are supportive. The degree of supportiveness of each group was assessed on the SSSR only after all of the names were listed. On the functional support measure, mean subscale scores of less than two suggest that many consumers reported that they did not receive certain forms of support from more than one or two people, if at all. As well, many individuals listed the same two or three individuals for each item, suggesting very concentrated support networks, with a mean number of supporters equal to 5.4 out of a potential 18.

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CIRCLES TECHNIQUE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inner circle</td>
<td>6.45</td>
<td>4.3</td>
<td>0-23</td>
</tr>
<tr>
<td>Middle circle</td>
<td>2.76</td>
<td>2.3</td>
<td>0-12</td>
</tr>
<tr>
<td>Outer circle</td>
<td>1.88</td>
<td>2.4</td>
<td>0-10</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>11.10</td>
<td>6.2</td>
<td>0-38</td>
</tr>
<tr>
<td><strong>SOCIAL SUPPORT SELF REPORT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>6.75</td>
<td>6.8</td>
<td>0-61</td>
</tr>
<tr>
<td>Staff</td>
<td>3.44</td>
<td>2.0</td>
<td>0-9</td>
</tr>
<tr>
<td>Friends</td>
<td>4.76</td>
<td>2.6</td>
<td>1-12</td>
</tr>
<tr>
<td>Partner</td>
<td>0.44</td>
<td>0.4</td>
<td>0-1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>15.39</td>
<td>8.1</td>
<td>3-70</td>
</tr>
<tr>
<td><strong>FUNCTIONAL SUPPORT MEASURE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attachment</td>
<td>2.20</td>
<td>1.1</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td>Social integration</td>
<td>1.95</td>
<td>1.0</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td>Reliable alliance</td>
<td>1.89</td>
<td>1.0</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td>Guidance</td>
<td>2.05</td>
<td>1.0</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td>Reassurance of worth</td>
<td>1.76</td>
<td>1.1</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td>Give nurturance</td>
<td>1.74</td>
<td>1.1</td>
<td>0-3 (max = 3)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>11.43</td>
<td>4.6</td>
<td>2-18 (max = 18)</td>
</tr>
<tr>
<td>Total names listed</td>
<td>5.41</td>
<td>1.9</td>
<td>0-10 (max = 18)</td>
</tr>
</tbody>
</table>

Table 2 Number of individuals providing social support at Time 1 according to three social support measures (N=84)
Table 3 summarizes the distribution of roommates, family and staff as support sources across the three social support measures. As indicated in Table 3, names of roommates were not listed as frequently as were names of family and staff. Family tended to be placed in the inner support circle of the Circles Technique and staff made up a major proportion of the typical network on the FSM. Many support functions were served by staff, including companionship and emotional support, not required job functions. Participants reported turning to roommates the most frequently on the FSM for companionship or to provide support, rather than to obtain support.

<table>
<thead>
<tr>
<th>Support Measure</th>
<th>Roommates (N=56)*</th>
<th>Family (N=79)</th>
<th>Staff (N=79)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CIRCLES TECHNIQUE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>inner circle</td>
<td>34%</td>
<td>66%</td>
<td>40%</td>
</tr>
<tr>
<td>middle circle</td>
<td>14%</td>
<td>24%</td>
<td>25%</td>
</tr>
<tr>
<td>outer circle</td>
<td>4%</td>
<td>11%</td>
<td>12%</td>
</tr>
<tr>
<td>name listed in any circle</td>
<td>51%</td>
<td>79%</td>
<td>61%</td>
</tr>
<tr>
<td><strong>SOCIAL SUPPORT SELF REPORT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best or Second Best Friend</td>
<td>14%</td>
<td>8%</td>
<td>12%</td>
</tr>
<tr>
<td><strong>FUNCTIONAL SUPPORT MEASURE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Support</td>
<td>13%</td>
<td>25%</td>
<td>46%</td>
</tr>
<tr>
<td>Companionship</td>
<td>25%</td>
<td>11%</td>
<td>59%</td>
</tr>
<tr>
<td>Instrumental/personal help</td>
<td>13%</td>
<td>11%</td>
<td>71%</td>
</tr>
<tr>
<td>Advice/guidance</td>
<td>5%</td>
<td>20%</td>
<td>49%</td>
</tr>
<tr>
<td>Reassurance of worth</td>
<td>5%</td>
<td>18%</td>
<td>33%</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>27%</td>
<td>19%</td>
<td>25%</td>
</tr>
</tbody>
</table>

* 28% of participants lived alone

Table 3 Percentage of participants who listed roommates, family and staff as support sources on the three social support measures at Time 1
Hypothesis 1: Relationship between functional and structural support measures

The first hypothesis to be tested was whether functional measures were more strongly correlated with each other than they were with structural measures. The correlational matrix of the social support measures at Time 1 can be found in Table 4. Steiger's formula (1980) was used to compare the correlation between the SSSR (the most functional measure) and the FSM (\(r = .39, p < .01\)) to the correlation between the SSSR and the Circles Technique (the most structural measure) \( (r = .08, p > .05) \). As predicted, the correlation of the two functional measures was significantly greater than the correlation of the SSSR with the most structural measure, the Circles Technique \((t(1,79)=2.44, p < .05)\).

<table>
<thead>
<tr>
<th>Measure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Circles Technique total</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. SSSR total</td>
<td>.08</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. FSM total</td>
<td>.27*</td>
<td>.39**</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>4. INSI total</td>
<td>.15</td>
<td>.18</td>
<td>.36**</td>
<td>1.00</td>
</tr>
</tbody>
</table>

*\(p < .05\), **\(p < .01\)

Note:
SSSR = Social Support Self-Report for mentally retarded adults
FSM = Functional Support Measure
INSI = Inventory of Negative Social Interactions

Table 4 Intercorrelations among Time 1 social support and social strain measures
Hypothesis 2: Relationship between social support and social strain

The hypothesized independence of positive and negative support measures was examined with correlations among the Circles Technique, the SSSR, the FSM, and the INSI, a measure of negative social interactions (see Table 4). It was predicted that the relationship between the SSSR, a perceived support measure, and the INSI, a perceived negative interactions measure, would not be statistically significant. This hypothesis was supported. \( r = .18, p > .05 \). As the INSI was positively correlated with PPVT-III scores \( r = .31, p < .005 \), the partial correlation of the SSSR and the INSI, independent of the PPVT-III, was examined and a similar non-significant relationship was observed \( r = .21, p > .05 \). Thus, negative support is conceptually different from the absence of positive support.

Hypothesis 3: Relationship between self-report and family report of reciprocity

It was predicted that self-reports of reciprocity in relationships could be corroborated by reports of family members \((N=31)\). Furthermore, it was thought that those individuals that contribute to relationships would also receive more support and assistance from these relationships, according to family members. Therefore, it was predicted that the amount participants reported to reciprocate to family would be correlated with amount of support given by family members.

Family reports of support provided by the participant were significantly correlated with both participant reports of this support \( r = .64, p < .001 \) as well as family reports of support provided to the participant \( r = .67, p < .001 \). These results suggest that
in terms of family support, participants report their reciprocity with some degree of accuracy. Furthermore, support provided by the participant may in turn elicit more support from the family member or vice versa.

<table>
<thead>
<tr>
<th>Type of support</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Support to family (family)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Support from family (family)</td>
<td>.67*</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>3. Support to family (self)</td>
<td>.64*</td>
<td>.59*</td>
<td>1.00</td>
</tr>
</tbody>
</table>

*p<.001

Note:
1. Family report of support provided by participant to family (Appendix L)
2. Family report of support received from family to participant (Appendix L)
3. Self-report of support provided to family by participant (Appendix E)

**Table 5** Intercorrelations of family reciprocity ratings from participant and family member

**Hypothesis 4: Incidence of extra-individual sources of social support**

No specific extra-individual support measure was adopted to assess extra-individual support sources. Rather, on the Circle Technique, the SSSR, and the Functional support measure (FSM), extra-individual responses were coded as such. When a participant offered an extra-individual support response, the interviewer asked
for clarification, by saying “what do you mean?” If the participant maintained the extra-individual response, then it was scored as such. If upon questioning the participant provided an individual name or names, these were recorded instead. This scoring procedure is based on the procedure described by Felton and Berry (1992).

A similar proportion of extra-individual responses were elicited in each of the three measures. The proportion of participants giving extra-individual responses by category are listed in Table 6. Many of the individuals interviewed listed extra-individual support sources initially and when questioned about these responses, the majority of individuals maintained their community-level response (45% to 80%). In total, 40.5% of the sample (34 individuals) provided at least one extra-individual support sources that they maintained after further questioning. Had all extra-individual support sources been followed up and recorded, this number may have been higher. (Follow-up responses for 11 individuals who listed extra-individual support sources were not recorded). The most popular forms of extra-individual level responses were work group responses (e.g., people at work, coworkers, job supervisors) and staff responses (e.g., my staff, all my staff, the people who work here).

In addition, several of the examples of support sources mentioned by participants were neither extra-individual nor typically recognized individual support sources. Eighteen individuals listed deceased individuals as support sources, two individuals listed “God”, three individuals listed pets, one individual listed several characters from the World Wrestling Federation, and seven individuals listed themselves as an important support source.
<table>
<thead>
<tr>
<th>Category of extra-individual support</th>
<th>Percentage of individuals listing at least one extra-individual support sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Initial response</td>
</tr>
<tr>
<td>Work</td>
<td>32%</td>
</tr>
<tr>
<td>Group/place</td>
<td>14%</td>
</tr>
<tr>
<td>Staff</td>
<td>32%</td>
</tr>
<tr>
<td>Family</td>
<td>17%</td>
</tr>
<tr>
<td>Everyone</td>
<td>24%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>69%</td>
</tr>
</tbody>
</table>

*The percentage of participants that responded to follow-up questioning with an extra-individual source of support

Table 6: Proportion of participants who named extra-individual sources of support at Time 1

Time 2: depression, quality of life and perceptions of health

Table 7 presents the means, standard deviations and internal consistency data for subtotal and total scores on measures administered to participants and staff at Time 2. Each of the measures obtained satisfactory internal consistency (range: .61-.92). Results indicate low levels of depression and loneliness and high quality of life, according to both consumer and staff ratings. However, 38 of 74 participants obtained total scores of 9 or above on the Reiss Screen, exceeding the cutoff score for psychopathology.
<table>
<thead>
<tr>
<th>Measure</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
<th>α</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SELF REPORT</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support (SSSR)</td>
<td>40</td>
<td>20.92</td>
<td>7.9</td>
<td>.85</td>
<td>80</td>
</tr>
<tr>
<td>Loneliness (LQ)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work (LQ-W)</td>
<td>30</td>
<td>4.73</td>
<td>5.4</td>
<td>.86</td>
<td>67</td>
</tr>
<tr>
<td>Residence (LQ-R)</td>
<td>30</td>
<td>7.95</td>
<td>6.7</td>
<td>.87</td>
<td>79</td>
</tr>
<tr>
<td>Depression (BDS-S)</td>
<td>36</td>
<td>8.77</td>
<td>4.5</td>
<td>.76</td>
<td>80</td>
</tr>
<tr>
<td>Quality of Life (QoL-Q)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>30</td>
<td>22.57</td>
<td>3.7</td>
<td>.70</td>
<td>80</td>
</tr>
<tr>
<td>Competence</td>
<td>30</td>
<td>21.71</td>
<td>5.4</td>
<td>.84</td>
<td>80</td>
</tr>
<tr>
<td>Empowerment</td>
<td>30</td>
<td>24.21</td>
<td>3.2</td>
<td>.62</td>
<td>80</td>
</tr>
<tr>
<td>Social Belonging</td>
<td>30</td>
<td>20.29</td>
<td>3.5</td>
<td>.62</td>
<td>80</td>
</tr>
<tr>
<td>QoL-Q total</td>
<td>120</td>
<td>88.79</td>
<td>10.7</td>
<td>.83</td>
<td>80</td>
</tr>
<tr>
<td><strong>STAFF RATINGS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reiss Screen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression Physical</td>
<td>10</td>
<td>2.07</td>
<td>1.9</td>
<td>.61</td>
<td>74</td>
</tr>
<tr>
<td>Depression Behavior</td>
<td>10</td>
<td>1.67</td>
<td>1.6</td>
<td>.55</td>
<td>74</td>
</tr>
<tr>
<td>26 item Total</td>
<td>52</td>
<td>10.03</td>
<td>7.6</td>
<td>.88</td>
<td>74</td>
</tr>
<tr>
<td>Depression (BDS-I)</td>
<td>10</td>
<td>3.00</td>
<td>1.7</td>
<td>.46</td>
<td>74</td>
</tr>
<tr>
<td>Quality of Life (QoL-Q)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>30</td>
<td>21.80</td>
<td>3.4</td>
<td>.76</td>
<td>74</td>
</tr>
<tr>
<td>Competence</td>
<td>30</td>
<td>20.58</td>
<td>6.4</td>
<td>.92</td>
<td>74</td>
</tr>
<tr>
<td>Empowerment</td>
<td>30</td>
<td>24.94</td>
<td>3.3</td>
<td>.74</td>
<td>74</td>
</tr>
<tr>
<td>Social Belonging</td>
<td>30</td>
<td>22.21</td>
<td>3.8</td>
<td>.74</td>
<td>74</td>
</tr>
<tr>
<td>QoL-Q total</td>
<td>120</td>
<td>89.53</td>
<td>11.5</td>
<td>.88</td>
<td>74</td>
</tr>
</tbody>
</table>

**Note:** For summary of healthy behaviors data see Tables 10-12

Table 7 Means, standard deviations and Cronbach alphas for self-report and staff ratings at Time 2.
Hypothesis 5: Relationship between loneliness and depression

It was predicted that self-reports of loneliness would be positively correlated with self-reports of depression, as an index of construct validity. Twelve individuals reported that they were neither employed nor in an alternative day program and so they were not given the loneliness at work portion (LQ-W) of the loneliness questionnaire. Residential loneliness (LQ-R) and self-reported depressed symptoms (BDS-S) were significantly correlated (r=.48, \(p<.001\)), and loneliness at work (LQ-W) and the BDS-S were correlated as well (r=.38, \(p<.005\)). Overall loneliness (LQ; the sum of LQ-R and LQ-W for those participants who were employed) and loneliness at home (LQ-R) were also significantly correlated with staff ratings of depression on the BDS-I [r=.27 (\(n=61\)), \(p<.05\) and r=.25, (\(n=73\), \(p<.05\) respectively].

Hypothesis 6: Relationship between self-report and staff ratings of depression

It was predicted that staff and self-report measures of depression would be significantly correlated, suggesting agreement between measures and raters. As indicated in Table 8, staff ratings of physical and behavioral symptoms of depression on the Reiss Screen were moderately correlated with staff ratings of depression on the Birleson depression screen (BDS-I). Staff ratings of depression were also significantly correlated with total score on the Reiss Screen. None of the staff measures, however, were significantly correlated with participants' self-reports of depressed symptomatology (BDS-S). Thus, staff-client agreement on depression ratings was not found.
Hypothesis 7: Relationship between self-report and staff ratings of quality of life

It was predicted that staff ratings and self-reports of quality of life would be significantly correlated, as was found by Schalock and Keith (1993). As indicated in Table 9, self-report and staff ratings of quality of life were moderately correlated with the exception of the Life Satisfaction subscale. An example of a Life Satisfaction item is, "Overall, would you say that life: brings out the best in you (3 points), treats you like everybody else (2 points), or doesn’t give you a chance (1 point)?" The furthest right column of Table 9 presents interrater correlations for the standardization sample of the Quality of Life measure (N=374; Schalock & Keith, 1993). Agreement was lower for each subscale in the present study than was found with the standardization sample.
Table 9 Staff-client agreement on Quality of Life Questionnaire (n=73)

<table>
<thead>
<tr>
<th>Quality of Life Questionnaire Subscale</th>
<th>Interrater ( r )</th>
<th>1993 Interrater ( r^* )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>.18</td>
<td>.46**</td>
</tr>
<tr>
<td>Competence/Productivity</td>
<td>.56**</td>
<td>.82**</td>
</tr>
<tr>
<td>Empowerment/Independence</td>
<td>.66**</td>
<td>.73**</td>
</tr>
<tr>
<td>Community Integration/Social Belonging</td>
<td>.42**</td>
<td>.66**</td>
</tr>
<tr>
<td>Total Score</td>
<td>.49**</td>
<td>.73**</td>
</tr>
</tbody>
</table>

**\( p < .01 \)

* Reported in Schalock and Keith (1993)

Hypothesis 8: Relationship between quality of life and depression

It was predicted that quality of life ratings and ratings of depressed symptoms would be negatively correlated, as individuals with mental health problems are more vulnerable to having an impoverished quality of life (Schalock and Keith, 1993).

As hypothesized, depression and quality of life were significantly negatively correlated among self-report measures (BDS-S and Q of L-Q total \( r = -.54, p < .01 \)) as well as among staff ratings (BDS-I and Q of L-Q total \( r = -.38, p < .01 \)). Thus, depression was associated with lower quality of life for both self and staff ratings.
Perceptions of Health

The participants' healthy behavior according to self-report and staff ratings for
Time 1 and Time 2 are presented in Table 10. Similar proportions of individuals
partook in risky health behaviors at Time 1 and Time 2. There was adequate to excellent
agreement between staff and participants as indicated by Chi-square analyses and
correlations in the last column of Table 10. Staff seemed to be very aware of some
activities, such as the smoking habits of participants, but there was a statistically
significant discrepancy between reports of staff and participants regarding drinking
habits at Time 2.

<table>
<thead>
<tr>
<th></th>
<th>Self</th>
<th>Staff</th>
<th>( \chi^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Some</td>
<td>Daily</td>
</tr>
<tr>
<td><strong>Time 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>76%</td>
<td>4%</td>
<td>20%</td>
</tr>
<tr>
<td>Drinking</td>
<td>85%</td>
<td>13%</td>
<td>2%</td>
</tr>
<tr>
<td>Exercise</td>
<td>12%</td>
<td>46%</td>
<td>42%</td>
</tr>
<tr>
<td>Sickness total</td>
<td>4.77 (3.34)</td>
<td>2.74 (2.36)</td>
<td>( r = .43^* )</td>
</tr>
<tr>
<td><strong>Time 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>78%</td>
<td>4%</td>
<td>18%</td>
</tr>
<tr>
<td>Drinking</td>
<td>84%</td>
<td>12%</td>
<td>4%</td>
</tr>
<tr>
<td>Exercise</td>
<td>13%</td>
<td>47%</td>
<td>40%</td>
</tr>
<tr>
<td>Sickness total</td>
<td>4.84 (3.13)</td>
<td>3.14 (2.42)</td>
<td>( r = .44^* )</td>
</tr>
</tbody>
</table>

Note: Sickness total = Sum of all medical diagnoses and symptoms endorsed, frequency
of doctor visits and frequency of illness

Table 10: Healthy behaviors according to staff and participants at Time 1 and Time 2
As Table 11 indicates, a larger proportion of participants tended to report physical health problems than did their staff. Notably, two thirds of the sample self-reported experiencing headaches and between one quarter to one half of the sample self-reported problems of constipation, diarrhea, and nausea. There tended to be stronger agreement between staff and participants regarding medical conditions that had been diagnosed and treated such as diabetes, high blood pressure, or seizures, than less monitored conditions like chest pains, headaches, or lots of colds. Similar percentages of self-reports and staff ratings indicated that participants feel sick at least once a week (41% and 38%) and that they visit doctors at least monthly (33% and 33%).

Table 12 presents the percentage of participants taking prescription and non-prescription medications at Time 2, based on self-reports and staff ratings. When the two reports differed, the more detailed report was recorded. As can be observed, the majority of participants were taking some form of prescription medication (79%). Nearly one half of the sample was taking at least one psychotropic drug for symptoms other than seizure control and more than half of the sample was taking at least one prescribed medication for physical health concerns. The mean total number of prescribed medications was 2.27. Half of the sample was taking more than one prescribed medication and 15% of the sample was taking five or more prescribed medications at Time 2.
Table 11: Physical problems and occurrence of illness according to self-report and staff ratings at Time 2

<table>
<thead>
<tr>
<th>Physical health problems</th>
<th>Self-report (%)</th>
<th>Staff-report (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>heart problems</td>
<td>18</td>
<td>13</td>
</tr>
<tr>
<td>chest pains</td>
<td>25</td>
<td>6</td>
</tr>
<tr>
<td>headaches</td>
<td>67</td>
<td>35</td>
</tr>
<tr>
<td>constipation</td>
<td>33</td>
<td>16</td>
</tr>
<tr>
<td>shortness of breath</td>
<td>42</td>
<td>9</td>
</tr>
<tr>
<td>lots of colds</td>
<td>47</td>
<td>10</td>
</tr>
<tr>
<td>high blood pressure</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>nausea</td>
<td>33</td>
<td>13</td>
</tr>
<tr>
<td>diarrhea</td>
<td>44</td>
<td>18</td>
</tr>
<tr>
<td>diabetes</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>high cholesterol</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>back pain</td>
<td>25</td>
<td>5</td>
</tr>
<tr>
<td>seizures</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>sick at least once a week</td>
<td>41</td>
<td>38</td>
</tr>
<tr>
<td>less healthy than friends</td>
<td>23</td>
<td>23</td>
</tr>
<tr>
<td>doctor visits at least monthly</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>Medication class</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>anti-psychotic</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>antidepressant</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>mood stabilizer</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>anxiolytic</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>stimulant</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>at least one psychotropic</td>
<td>47%</td>
<td></td>
</tr>
<tr>
<td>anti-seizure</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>antiparkinsonian</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>physical med (prescribed)</td>
<td>51%</td>
<td></td>
</tr>
<tr>
<td>over counter meds</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>at least one prescribed med</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(psychotropic or physical)</td>
<td>79%</td>
<td></td>
</tr>
</tbody>
</table>

Table 12: Percentage of participants taking prescription and non-prescription medication (N=81) at Time 2

Time 1 - Time 2:

Relationships between social support, health, depression and quality of life

Prior to testing the predictive value of Time 1 measures on Time 2 measures (six months later), the stability of both self-report and staff ratings was examined. As indicated in Table 13, most scales were fairly stable across time, with the exception of SSSR social support provided by friends.
<table>
<thead>
<tr>
<th>Measure</th>
<th>r (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SELF REPORT</strong></td>
<td></td>
</tr>
<tr>
<td>Loneliness (LQ)</td>
<td></td>
</tr>
<tr>
<td>Loneliness - residence (LQ-R)</td>
<td>.56 (62)</td>
</tr>
<tr>
<td>Loneliness - work (LQ-W)</td>
<td>.53 (77)</td>
</tr>
<tr>
<td>total</td>
<td>.47 (62)</td>
</tr>
<tr>
<td><strong>Social Support (SSSR)</strong></td>
<td></td>
</tr>
<tr>
<td>family support</td>
<td>.79 (80)</td>
</tr>
<tr>
<td>staff support</td>
<td>.61 (80)</td>
</tr>
<tr>
<td>friend support</td>
<td>.30 (80)</td>
</tr>
<tr>
<td>partner support</td>
<td>.74 (80)</td>
</tr>
<tr>
<td>reciprocity</td>
<td>.63 (80)</td>
</tr>
<tr>
<td>total</td>
<td>.69 (80)</td>
</tr>
<tr>
<td><strong>Depression (BDS-S)</strong></td>
<td>.49 (77)</td>
</tr>
<tr>
<td><strong>STAFF RATINGS</strong></td>
<td></td>
</tr>
<tr>
<td>Reiss Screen for maladaptive behavior</td>
<td></td>
</tr>
<tr>
<td>depression - physical</td>
<td>.62 (69)</td>
</tr>
<tr>
<td>depression - behavioral</td>
<td>.45 (69)</td>
</tr>
<tr>
<td>total</td>
<td>.58 (69)</td>
</tr>
</tbody>
</table>

*Note: all correlations significant at .01 level*

Table 13 Stability of self-report and staff ratings of social support, loneliness and depression from Time 1 to Time 2

**Hypothesis 9: Time 1 social support predictors of health at Time 2**

It was predicted that social support at Time 1 would predict perceptions of health at Time 2, above and beyond the effects of demographic variables. Hierarchical multiple linear regression was performed with age, gender and receptive language scores entered.
as the first step and perceived social support (SSSR, LQ-R, and LQ-W) entered as the second step. The dependent variable, perceived health (Selfsick 2) consisted of the number of symptoms of illness endorsed and the frequency of doctor visits. As indicated in Table 14, perceptions of social support and loneliness predicted health perceptions within the same time period (Time 2). When all of the variables were entered into the regression equation, loneliness at home was a significant predictor of health perceptions ($\beta=.303$). Effects across time approached significance ($p<.10$) but are not presented here.

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$F$</th>
<th>$R^2_{change}$</th>
<th>$F_{change}$</th>
<th>$\beta$ weights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>.139</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td>-.118</td>
</tr>
<tr>
<td>PPVT-III</td>
<td>1.59</td>
<td>.071</td>
<td>1.59</td>
<td>.052</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR 2</td>
<td></td>
<td></td>
<td></td>
<td>.172</td>
</tr>
<tr>
<td>LQ-R 2</td>
<td></td>
<td></td>
<td></td>
<td>.303*</td>
</tr>
<tr>
<td>LQ-W 2</td>
<td>2.57*</td>
<td>.136</td>
<td>3.37*</td>
<td>.170</td>
</tr>
</tbody>
</table>

Dependent variable=Selfsick 2
* $p<.05$
** $p<.01$
Adj. $R^2=.127$

Note:
PPVT-III=Peabody Picture Vocabulary Test, Third edition
LQ-R 2=loneliness (residence) at Time 2
LQ-W 2=loneliness (work) at Time 2
SSSR 2=social support at Time 2
Selfsick 2=self report of illness at Time 2

Table 14 Summary of hierarchical multiple linear regression of social support on perceptions of health at Time 2 (N=66)
Hypothesis 10: Time 1 social support and health predictors of depression at Time 2

It was hypothesized that perceived social support and health would predict changes in depressive symptoms, according to self reports of individuals with MR. Thus, several variables were entered into a hierarchical linear regression equation (Table 15). To control for the effects of demographic variables and receptive vocabulary, gender, age and PPVT-III scores were entered as the first step. Self-reported depressed symptoms at Time 1 was entered as the second step to control for prior depression level. The third step consisted of perceived social support (SSSR), and residential (LQ-R) and vocational loneliness (LQ-W), both variants of perceived support. The final step consisted of the number of medications both for physical symptoms (Physical Med 1) and psychiatric symptoms (Psychotropics 1), and symptoms of illness and frequency of doctor visits (Selfsick 1). As can be seen in Table 15, each of the models that included depression at Time 1 were significant (Steps 2, 3, and 4). While other variables in combination significantly predicted change in depression scores, inserting the additional variables did not improve the model significantly from Step 2. Thus, the hypothesis about the predictive power of social support and health on changes in level of depressed symptoms was not confirmed.
### Table 15 Summary of hierarchical multiple linear regression of social support and health at Time 1 on change in depression scores at Time 2 (N=61)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>F</th>
<th>R² change</th>
<th>F change</th>
<th>β weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.116</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.181</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPVT-III</td>
<td>2.92*</td>
<td>.133</td>
<td>2.92*</td>
<td>-.100</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDS-S 1</td>
<td>8.41**</td>
<td>.242</td>
<td>21.72**</td>
<td>.448**</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-R 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-W 1</td>
<td>4.72**</td>
<td>.009</td>
<td>0.25</td>
<td>.018</td>
</tr>
<tr>
<td><strong>Step 4</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Med 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotropics 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selfsick 1</td>
<td>4.02**</td>
<td>.062</td>
<td>1.86</td>
<td>.273*</td>
</tr>
</tbody>
</table>

Dependent variable=BDS-S 2

* p<.05
** p<.01

Adj. R²=.335

Note:
PPVT-III=Peabody Picture Vocabulary Test, Third edition
BDS-S 1=Birleson depression screen at Time 1
LQ-R 1=lodeliness (residence) at Time 1
LQ-W 1=lodeliness (work) at Time 1
SSSR 1=social support at Time 1
Physical Meds 1=prescribed medication for physical health problems at Time 1
Psychotropics 1=prescribed medication including anti-seizure medication at Time 1
Selfsick 1=self report of illness at Time 1
BDS-S 2=Birleson depression screen at Time 2
Two post-hoc analyses were conducted, therefore, to examine the relationship between social support, health and depression, not including prior depression levels. A similar model to that in Table 15, of demographic variables, followed by social support and loneliness, followed by health factors, was tested to explain depression levels at Time 2. In this model, rather than examine change in depression levels across time, the relationship between social support and health at Time 1 and depression six months later was examined. As indicated in Table 16, the model with demographics, as well as the model with social support and health, significantly predicted levels of depression at Time 2. Furthermore, adding health variables in Step 3 obtained a significant increase in $R^2$. Thus, while social support and health did not explain changes in depression, health variables did prove to be significant predictors of depression over time.

In the last multiple regression model, demographic variables and receptive vocabulary, social support and loneliness and health factors at Time 2 were entered in that order to account for self-reported depression at Time 2. In this model, rather than examine change in depression levels across time, the relationships between social support, health and depression at one time were examined. As indicated in Table 17, the model with social support, as well as the model with social support and health, significantly predicted levels of depression in the same time period. Furthermore, adding Step 2 and Step 3 each explained a significant increase in $R^2$. Thus, while social support did not explain changes in self-reported depression from Time 1 to Time 2, it did prove to be a significant predictor of depression at Time 2.
<table>
<thead>
<tr>
<th>Predictors</th>
<th>F</th>
<th>R² change</th>
<th>F change</th>
<th>β weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>.099</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td>-.161</td>
</tr>
<tr>
<td>PPVT-III</td>
<td>2.92*</td>
<td>.133</td>
<td>2.92*</td>
<td>-.028</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR l</td>
<td></td>
<td></td>
<td></td>
<td>.006</td>
</tr>
<tr>
<td>LQ-R l</td>
<td></td>
<td></td>
<td></td>
<td>.064</td>
</tr>
<tr>
<td>LQ-W l</td>
<td>1.61</td>
<td>.019</td>
<td>0.39</td>
<td>.040</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Med l</td>
<td></td>
<td></td>
<td></td>
<td>-.013</td>
</tr>
<tr>
<td>Psychotropics l</td>
<td></td>
<td></td>
<td></td>
<td>-.039</td>
</tr>
<tr>
<td>Selfsick l</td>
<td>2.64*</td>
<td>.166</td>
<td>4.13*</td>
<td>.449*</td>
</tr>
</tbody>
</table>

Dependent variable=BDS-S 2

*p<.05
**p<.01

Adj. R²=.197

Note:
PPVT-III=Peabody Picture Vocabulary Test, Third edition
LQ-R l=loneliness (residence) at Time 1
LQ-W l=loneliness (work) at Time 1
SSSR l=social support at Time 1
Physical Meds l=prescribed medication for physical health problems at Time 1
Psychotropics l=prescribed medication including anti-seizure medication at Time 1
Selfsick l=self report of illness at Time 1
BDS-S 2=Birleson depression screen at Time 2

Table 16 Summary of hierarchical multiple linear regression of social support and health at Time 1 on depression scores at Time 2 (N=61)
<table>
<thead>
<tr>
<th>Predictors</th>
<th>$F$</th>
<th>$R^2$ change</th>
<th>$F$ change</th>
<th>$\beta$ weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.053</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.125</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPVT-III</td>
<td>2.53</td>
<td>.109</td>
<td>2.53</td>
<td>-.005</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR 2</td>
<td>-.222</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-R 2</td>
<td>-.046</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-W 2</td>
<td>3.14*</td>
<td>.133</td>
<td>3.45*</td>
<td>.128</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Med 2</td>
<td>-.016</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotropics 2</td>
<td>-.045</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selfsick 2</td>
<td>4.22**</td>
<td>.162</td>
<td>5.08**</td>
<td>.456**</td>
</tr>
</tbody>
</table>

Dependent variable = BDS-S 2

* $p<.05$
** $p<.01$

Adj. $R^2 = .309$

**Note:**
PPVT-III = Peabody Picture Vocabulary Test, third edition
LQ-R 2 = loneliness (residence) at Time 2
LQ-W 2 = loneliness (work) at Time 2
SSSR 2 = social support at Time 2
Physical Meds 2 = prescribed medication for physical health problems at Time 2
Psychotropics 2 = prescribed medication including anti-seizure medication at Time 2
Selfsick 2 = self report of illness at Time 2
BDS-S 2 = Birleson Depression Screen at Time 2

**Table 17** Summary of hierarchical multiple linear regression of social support and health at Time 2 on depression scores at Time 2 (N=66)
Hypothesis 10: Time 1 social support and health predictors of quality of life at Time 2

It was also of interest to determine whether perceived social support and health could predict quality of life in six months time. To test this, similar hierarchical multiple linear regressions were conducted to those described under hypothesis 9. Primarily, it was of interest to examine whether social support and loneliness at Time 1, as well as health predictors at Time 1 could predict self-reported quality of life at Time 2. As can be seen in Table 18, both the model with social support (SSSR) and loneliness (LQ-W and LQ-R), as well as the model with social support, loneliness and health (Step 3) explained a significant amount of variance in quality of life (QoL-Q). The change in $R^2$ was significant both at Step 2 and Step 3, suggesting that both social support and health factors are important contributors to future well-being.

A post-hoc analysis was performed within Time 2 to predict quality of life, as was done with social support, health and depression. As Table 19 indicates, both the model with social support and the model with social support and health accounted for significant variance in quality of life. Adding social support variables explained significantly more variance in quality of life scores than could demographics and receptive language. Adding health variables explained significantly more variance in quality of life than could demographics, receptive vocabulary and social support. Interestingly, medications for physical conditions was a significant predictor of quality of life 6 months later ($\beta=.270, t=2.18, p<.05$) but not concurrently. Age was also a significant predictor of quality of life 6 months later ($\beta=-.279, t=2.28, p<.05$), whereby older individuals reported poorer quality of life.
<table>
<thead>
<tr>
<th>Predictors</th>
<th>$F$</th>
<th>$R^2$ change</th>
<th>$F$ change</th>
<th>$\beta$ weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.279*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.042</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPVT-III</td>
<td>1.90</td>
<td>.091</td>
<td>1.89</td>
<td>-.075</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR 1</td>
<td></td>
<td>.058</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-R 1</td>
<td></td>
<td>.085</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-W 1</td>
<td>2.58*</td>
<td>.132</td>
<td>3.06*</td>
<td>-.256*</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Med 1</td>
<td></td>
<td>.270*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotropics 1</td>
<td></td>
<td>-.048</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selfsick 1</td>
<td>3.63**</td>
<td>.168</td>
<td>4.68**</td>
<td>-.395**</td>
</tr>
</tbody>
</table>

**Dependent variable=QoL-Q 2**

* $p<.05$
** $p<.01$

$\text{Adj } R^2 = .283$

**Note:**
- LQ-R 1=loneliness (residence) at Time 1
- LQ-W 1=loneliness (work) at Time 1
- SSSR 1=social support at Time 1
- Physical Meds 1=prescribed medication for physical health problems at Time 1
- Psychotropics 1=psychotropic medication including anti-seizure medication at Time 1
- Selfsick 1=self report of illness at Time 1
- QoL-Q 2=Quality of Life Questionnaire Total at Time 2

**Table 18** Summary of hierarchical multiple linear regression of social support and health at Time 1 on quality of life scores at Time 2 ($N=61$)
<table>
<thead>
<tr>
<th>Predictors</th>
<th>F</th>
<th>R^2 change</th>
<th>F change</th>
<th>β weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.129</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.081</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPVT-III</td>
<td>2.05</td>
<td>.090</td>
<td>2.05</td>
<td>.007</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSSR 2</td>
<td></td>
<td>.291*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-R 2</td>
<td></td>
<td>-.127</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LQ-W 2</td>
<td>3.99**</td>
<td>.199</td>
<td>5.51**</td>
<td>-.109</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Meds 2</td>
<td></td>
<td>.164</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotropics 2</td>
<td></td>
<td>-.180</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selfsick 2</td>
<td>4.44**</td>
<td>.127</td>
<td>4.07*</td>
<td>-.360**</td>
</tr>
</tbody>
</table>

Dependent variable=QoL-Q 2

* p<.05
**p<.01

Adj. R^2=.323

**Note:**
PPVT-III=Peabody Picture Vocabulary Test, third edition
LQ-R 2=loneliness (residence) at Time 2
LQ-W 2=loneliness (vocational) at Time 2
SSSR 2=social support at Time 2
Physical Meds 2=prescribed medication for physical health problems at Time 2
Psychotropics 2=psychotropic medication including anti-seizure medication at Time 2
Selfsick 2=self-report of illness at Time 2
QoL-Q 2=Quality of Life Questionnaire - Total at Time 2

Table 19 Summary of hierarchical multiple linear regression of social support and health at Time 2 on quality of life scores at Time 2 (N=66)
Hypothesis 11: Additional Time 1 predictors of quality of life and depression at Time 2

It was predicted that social strain, reciprocity and community sources of social support would explain significant variance in self-reported quality of life ratings and depression ratings six months later, above and beyond effects of social support. This hypothesis was tested with hierarchical multiple linear regressions, with either social strain, reciprocity, or community sources of social support entered as the last step. Reciprocity and community sources of social support were not significantly correlated with any of the outcome measures and offered no predictive power in hierarchical regression analyses. Social strain, however, positively correlated with depression at Time 1 ($r=.40, p<.001$) and was found to be a significant predictor of depression over time.

As indicated in Table 20, the various social support measures did not account for a significant proportion of variance in self-reported depression at Time 2. Negative support or social strain as measured by the INSI combined with positive support measures (Step 3) accounted for a significant proportion of variance in depression scores and explained a significant change in $R^2$. These findings suggest that social strain combined with social support is a more powerful predictor of future depression than social support alone. Negative support did not exert a similar effect on quality of life, however, suggesting that social strain combined with social support does not explain a significant increase in variance of future quality of life when compared with social support alone.
<table>
<thead>
<tr>
<th>Predictors</th>
<th>F</th>
<th>$R^2$ change</th>
<th>F change</th>
<th>$\beta$ weights</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>.137</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td>-.276*</td>
</tr>
<tr>
<td>PPVT-III</td>
<td>2.78*</td>
<td>.115</td>
<td>2.78*</td>
<td>-.105</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FR1</td>
<td></td>
<td></td>
<td></td>
<td>.009</td>
</tr>
<tr>
<td>FW1</td>
<td></td>
<td></td>
<td></td>
<td>.068</td>
</tr>
<tr>
<td>SSSR1</td>
<td>1.73</td>
<td>.031</td>
<td>.73</td>
<td>-.114</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>INSI</td>
<td>2.24*</td>
<td>.062</td>
<td>4.67*</td>
<td>.281*</td>
</tr>
</tbody>
</table>

Dependent variable = BDS-S 2

*p<.05  
Adj $R^2 = .115$

**Note:**
FR1 = loneliness (residential) at Time 1  
FW1 = loneliness (vocational) at Time 1  
SSSR1 = social support at Time 1  
INSI = Instrument of Negative Social Interactions at Time 1  
BDS-S = Birleson depression screen at Time 2

**Table 20** Summary of hierarchical multiple linear regression of social support and social strain at Time 1 on depression scores at Time 2 (N=68)
CHAPTER 4
DISCUSSION

The purpose of this study was to examine the ability of perceived social support to predict depressive symptoms and quality of life for adults with mild mental retardation (MR). A secondary purpose was to examine how social support perceptions influence self-reported physical health and how perceived health influences mental health and well-being. Eighty-four individuals with mild MR were interviewed about their positive and negative interpersonal relationships, perceptions of their health, depressive symptoms and quality of life. The results of this research indicate that the interpersonal relationships of individuals with mild MR and their perceived health are important predictors of future depression and quality of life.

Discussion of Hypotheses

Time 1: Conceptions of social support

Examination of the social support of adults with mild MR revealed several interesting findings, all of which suggest the importance of examining their social support using multiple measures, combining quantitative and qualitative methods. The participants' descriptions of their social networks differed somewhat depending on the
manner of questioning, and there was wide variation in the reports of support available and support satisfaction. Thus, individuals with mild MR are not a homogeneous group in terms of their support needs, and no one measure of social support adequately captures the complexity of their relationships (See also Newton et al., 1993).

Individuals with MR tended to place a greater proportion of people they knew in their most intimate circle, in contrast to individuals without MR (Antonucci, 1986). The participants may not have understood the instructions for the Circles Technique and therefore did not restrict their inner circle to the most intimate relationships. Alternatively, the high proportion of intimate supports may be a function of how they perceive relationships, that they interpret greater intimacy than exists. Other researchers have reported similar findings (Clegg & Standen, 1992; Green et al., 1995; Mest, 1988; Sparrow and Mayne, 1990). A prior study reported a tendency for adults with mild MR to display a positive cognitive bias in perceptions of social support (Lunsky and Benson, under review). Such biases may be the result of a lack of experience with true friendship and the misguided belief that greater frequency of social contact indicates friendship (Green et al., 1995).

Two important trends were observed with respect to the social networks of the participants. First, many of the individuals with roommates did not list their roommates as important support sources. This finding is not likely to be an artifact of any one measure because it was noted on all three measures. One possible explanation for this is that the participants did not play an active role in the roommate selection process and therefore were placed with roommates that were not to their liking. A second possible
explanation is that the participants lacked the skills and supports necessary to resolve conflicts and maintain relationships with their roommates who they may have liked initially. There is extensive research on the interpersonal problem solving deficits of adults with mild MR (Wehmeyer & Kelchner, 1994). Many of the individuals who endorsed social strain items noted that their roommates were the source. Therefore, in addition to not seeking support from their roommates, they found that interactions with their roommates were a source of stress.

The second important trend in the social network findings is that a large proportion of participants identified staff as the providers of most support functions. Other studies have commented on the importance of staff as instrumental support providers and therefore this finding may not be unique to the MR population. In one study, aging individuals without MR living in supervised settings also listed staff as an essential part of their networks (Pruchno & Faletti, 1983), however, they differentiated the support provided by staff from that provided by kin and friends. In contrast, Rosen and Burchard (1991) noted that 30% of the individuals identified as best friends by a group of adults with mild MR were staff. In the present study, only 12% of participants identified staff as best friends, yet 59% of the participants listed staff as providers of companionship. When staff provide some functions of support typically supplied by friends, this could result in problems for both staff (Karan & Bothwell, 1997) and the individuals with MR (Lowe & De Paiva, 1991). As Lowe and De Paiva (1991) discussed, staff are confronted with “the incompatible duality of their role between teacher/carer and friend.” It may be that the staff give ambiguous messages about their
relationship to the individuals they support. The individuals in turn may develop false hopes about their relationship with staff and face later disappointment. Unfortunately, relationships with staff may be more reliable than relationships with other individuals in the lives of persons with MR, making such relationships more attractive.

Three additional aspects of social support were measured in the present study, each worthy of discussion. First, the degree to which individuals with MR reciprocate in their relationships was examined, as it has been suggested by some researchers that reciprocity in their relationships is not common (e.g. Rosen & Burchard, 1991).

Participant reports of reciprocity were compared with reports of a close family member in order to check for accuracy. As has been found for individuals with chronic mental illness (Horowitz et al., 1995), reports of reciprocity of individuals in this study matched closely with reports of family members. That is, in relationships where reciprocity was reported, both the individual with MR and the family member reported reciprocating. It was rare that one reported to be reciprocating and the other not. It is possible that the amount of support provided by one individual in turn influenced the support provided by the other individual. The symmetry of reciprocity found in this study is in stark contrast to reports provided solely by caregivers in Krauss et al. (1992) where caregivers reported that network members offered twice as much to relationships as did individuals with MR. While the present results are based only on relationships with one family member and may not generalize to other relationships, they suggest that reciprocating in relationships may bring about further support from others.
A second aspect of social support examined in this study was the concept of alternative sources of social support, such as extra-individual or community sources of support. Indeed many individuals in the present study conceptualized some of their support as coming from groups or places. While other authors have discussed this issue in the context of persons with MR (see Neely & Lunsky, 1998) this is the first study in which interviewers queried participants when they listed non-individual support sources to clarify what they meant. One possible reason for reports of such forms of support is that communication or memory deficits of the participants prevented them from being more specific. For example, some participants described people rather than giving them names, such as “the woman right there.” An alternative explanation is that participants did conceptualize their support extra-individually. When a more specific source of support was requested by interviewers, group level support was again given as a response 75% of the time. When one participant was asked to identify who he meant by “work friends,” he said “I can’t separate them.” Even those participants who gave specific names after being queried about their group level response may have conceptualized their support extra-individually, but gave a more specific name because they wanted to meet expectations of the interviewer.

A number of participants indicated that deceased individuals were important sources of support for them. Case studies of persons with MR (e.g. Nadarajah et al., 1994) have described this phenomenon but no group data have been reported until now. Deceased individuals have been named as sources of support by aging adults without MR (Pruchno & Faletti, 1983). This finding combined with the finding that elderly
individuals conceptualize support extra-individually suggest that some ways in which elderly individuals conceptualize their social support bear close similarity to the ways adults with MR understand their relationships. Pets and television characters were reported as sources of support in the present study. While not mentioned as support sources in past research with adults with MR, they have been identified in non-MR studies as support sources for children (Bryant, 1994). Thus, the manner in which children conceptualize their support may also bear some similarity to the MR group.

Lastly, the presence and effects of social strain were examined. Participants often reported social strain in their relationships, particularly with roommates. Social strain was found to be independent of social support and only negative support, rather than positive support, predicted depression six months later. The measure of social strain or negative support used in this study, the INSI, proved to be a reliable measure with this population. The Cronbach's alpha obtained for the INSI in this study (.93) was similar to that obtained in Lakey et al.'s 1994 study (.94). In this study, however, the alpha level may have been inflated because three rather than five alternatives were offered. The significant positive correlation found between negative support and receptive vocabulary suggests that either better language skills are needed to understand the negative support items, or that individuals with greater receptive language ability are better able to discern and report negative social interactions.

Evidence for the validity of the social strain construct in this population stems from its correlation with related constructs (depression), and the absence of a correlation with unrelated constructs (loneliness and social support) as evidenced in the general
population (see Lakey et al., 1994). Further evidence comes from the explanations that consumers provided when the questionnaires were administered. Many individuals remarked that they were pleased that they were able to discuss their frustration about the difficulties they encountered in some of their relationships. These findings corroborate findings of Nezu et al. (1995), Bramston et al. (1993), and Lunsky and Havercamp (under review) regarding social strain and psychological distress in this population. It is the first study to show this effect prospectively with a reliable and detailed index.

**Time 2: Depression, Quality of Life, and Health**

The outcome variables of interest in this study were depression, health and quality of life. Findings relating to these variables were based on self-report and informant ratings. As well, staff provided ratings of overall psychopathology. As a group, quality of life scores (self-rated and staff-rated) were very similar to scores obtained with the standardization sample of 115 adults with mild MR (Schalock & Keith, 1993). Reiss Screen depression and total scores (staff psychopathology ratings) were slightly higher in the present study than the scores for the national sample without dual diagnosis and slightly lower than scores for those with dual diagnoses (Reiss, 1988). This can be explained by the fact that some of the individuals recruited for this study carried dual diagnoses and others did not. Depression scores on the Birleson self-report and staff measures were similar to scores obtained by Benson and Ivins (1992).

Outcome measures administered at Times 1 and 2 (BDS-1 and Reiss Screen) were significantly correlated, suggesting that self-reported levels of depression and staff
reports of psychopathology remained somewhat stable for the duration of the study. Staff-client agreement was not as high as has been reported in other studies, however. Staff and participants agreed less on both the Quality of Life questionnaire and the Birleson Depression Screen than in studies by Schalock and Keith (1993) and Benson and Ivins (1992) respectively. In fact, the correlation between staff and self-reports of depression was non-significant.

The lack of agreement between participants and staff either calls into question the validity of the self-reported depression ratings or is suggestive of a larger problem with staff versus self-perceptions of internal states. Self-reported depression was significantly correlated with other measures than it theoretically would be expected to correlate with (e.g. loneliness). Furthermore, many participants disclosed depressive symptoms, including suicidal ideation, suggesting that self-reports of depression were valid. A second explanation for the poor agreement is that staff may have overlooked depressive symptoms in their clients or not seen them as problems. Potential downplaying of psychopathology by staff may be an example of diagnostic overshadowing where symptoms of mental illness are attributed to the MR itself (Reiss & Szyzsko, 1983). The phenomenon of diagnostic overshadowing has been discussed at length with regard to recognizing symptoms of depression in this population (Rojahn, Warren, & Ohringer, 1994). Another possibility is that the items on the staff and self-rated depression scales were not very similar. As it is difficult for staff to rate a subjective phenomenon like depression, most of the depression items on the staff questionnaires were behavioral examples of depressed symptoms. A similar explanation
was offered by Rojahn et al. (1994) to explain the lack of agreement between various measures and methods of rating depression with a similar sample.

Low correlations between staff and participants on the Quality of Life Questionnaire, as well as lower alpha coefficients than those reported with the standardization sample, may be in part an artifact of how the staff were involved in the study and how well the interviewers were trained to administer the questionnaire. In the standardization sample, staff met with researchers to complete their questionnaires and discuss the measure in detail (Schalock, 1998 in communication). In the present study, staff were invited to ask the researchers questions by telephone, but only one staff called with questions about the measure. While interviewers in the present study followed the instructions in the manual, they had less practice rephrasing items than the interviewers in the standardization sample, potentially affecting responses of the participants with MR. Other researchers have reported poorer interrater reliability and lower alphas with the Quality of Life Questionnaire than what was reported for the standardization sample and have suggested that staff tend to overrate the quality of life of the clients for whom they act as informants (see Rapley, Ridgway, & Beyer, 1998).

The present study examined physical health as both an outcome measure and a predictor of mood and quality of life. Overall, staff and participants agreed about the frequency of particular health related behaviors. At Time 2, however, they differed significantly on their ratings of the frequency of alcohol consumption. They also tended to agree about the occurrence of particular health problems such as diabetes and high cholesterol. Usually when disagreement occurred between staff and participant, staff
under-reported health problems and problematic behaviors. It may be that participants purposely hid these sorts of issues from their staff. One man, for example, reported that he drinks daily but that he avoids being near staff because “beer stinks.” An alternative explanation may be that staff were unaware of unhealthy behaviors and health problems because of lack of training and an inability to recognize them (Bond et al., 1997). A third possibility is that participants exaggerated their health problems to the interviewers either because they misunderstood how to assess the frequency of these problems or because they thought that the interviewers wanted them to endorse symptoms (acquiescence; Heal & Sigelman, 1995). It is possible that some participants with emotional issues or frustrations expressed them through mild physical problems like stomach difficulties or headaches.

The occurrence of physical illness in this population, as well as the frequency of prescribed medications, replicates findings of others (e.g. Beange et al., 1995; Howells, 1986; Minihan & Dean, 1993). Seventy-nine percent of the sample was reported to be taking some form of medication, suggesting that as a group these individuals are not healthy, or that they are being over-prescribed medication. Many of the individuals were taking psychototropic medications, including neuroleptic medications, without psychotic disorder diagnoses. Lennox and Chaplin (1996) commented on a similar phenomenon in England. As has been discussed by Beange et al. (1995), there were several individuals in the present study who were taking multiple medications (interclass polypharmacy) and some medications from the same drug class (intraclass polypharmacy). This situation may have occurred because of poor communication.
among physicians, poor training of physicians, and/or restricted access of study participants to physicians with greater awareness of such issues (see also Reiss & Aman, 1998).

A unique contribution of this study is its emphasis on perceptions of health by persons with MR, in contrast to other studies which consider only staff perceptions or chart records. While some study participants evidenced a strong understanding of their health treatments and needs, others had only a cursory understanding, not knowing the names or functions of their medications and not recalling the names of their health conditions. Fifteen individuals taking prescribed medications did not know when during the day they were to take them. One man who had recently moved to a less supervised setting had chosen to stop taking Trazedone and Tegretol for behavioral concerns but did not think that there was a problem with that. When asked what her medications were for, one woman answered (directing her reply to both herself and the interviewer), “Why you taking stuff you don’t know what it’s for?” It appeared that she had never questioned the fact that she was unfamiliar with her medications until that moment. Some individuals did not know whether their medications were for mental or physical concerns. One woman reported that she took Prozac to make her happy. When asked why she takes Synthroid, she responded “to make me happy too.” It is possible that some of the illnesses reported by participants may have been side-effects of their medications. Without an understanding of their medications, they would be unlikely to report such symptoms to a physician or staff.
Time 1 - Time 2:

**Relationship Between Social Support, Health, Depression and Quality of Life**

Perhaps the most important findings from the present study were that (1) social support and health predicted quality of life six months later, (2) health and social strain predicted depression six months later, and (3) social support predicted depression within the same time frame, beyond the effects of gender, age and receptive vocabulary scores. A further finding from the present study was that social support predicted health within the same time period. These results taken as a whole suggest that one can predict with some accuracy an individual’s quality of life and mood six months after assessing his or her interpersonal relationships and perceptions of health. No other studies have examined the prospective influence of these variables within this population. These results confirm findings from the general population about the importance of positive relationships and the absence of negative relationships for one’s health and well-being, as well as the importance of good health for one’s quality of life.

It is of interest to consider why social support was a significant predictor of quality of life but not depression six months later, and why social strain was a significant predictor of depression but not quality of life. Helgeson (1993) discusses this phenomenon in the general population whereby negative aspects of social relationships predict scores in negative affective domains while positive aspects predict scores in positive affective domains. It may be that the predictor variables in this study are symptom specific, as has been found more generally (Helgeson, 1993). The presence of individuals who cause stress in one’s life may lead to depression, but should not produce
as strong an effect on one’s job, one’s sense of independence or of social belonging, all of which are subscales on the Quality of Life Questionnaire. The absence of positive relationships, in contrast, may lead to decreased social interactions and community integration and decrease the individual’s enjoyment of his or her job, all quality of life variables. The absence of positive relationships is not as powerful a predictor of depression as the presence of negative relationships. Several researchers in the non-MR field have reached similar conclusions (Helgeson, 1993; Lakey et al., 1994; Pagel et al., 1987; Rook, 1984) and preliminary evidence for this phenomenon has also been reported for persons with mild MR by Nezu et al. (1995).

A second reason for the lack of association between Time 1 social support and Time 2 depression may be that there was more measurement error at Time 1, when the social support measures were administered. Specifically, it is possible that at Time 1 participants were not forthcoming about feelings of depression. At Time 2 the interviewers were more familiar with the participants who, in turn, may have felt more comfortable disclosing information including depressive symptoms. Increased familiarity and comfort with the interviewers and participants may explain why social support and depression were significantly negatively correlated at Time 2 ($r = -.31$, $p < .01$), in contrast to Time 1 - Time 2.

The present study is one of the first to demonstrate the importance of perceived social support and social strain for persons with lower cognitive ability. Similar to the findings of Rosen and Burchard (1991), perceptions of support were found to be significant predictors of quality of life. These results highlight why it is important to ask
individuals about their perceptions of their relationships rather than rely exclusively on observations (e.g. Berkson & Romer, 1981) or caregiver reports (Krauss et al., 1992). As has been argued for persons without MR (Barerra, 1986), perceived support may be the fundamental element of social support and it can only be measured through self-report. A similar argument can be made for social strain, a second perceived support concept. Whether the reports of strain are observed by staff or go unnoticed by others, one's own perception of being bothered or stressed by someone's support is predictive of his or her subsequent mental health. These findings apply to persons both with and without MR and should therefore be measured for both groups.

Perceived health, in addition to social support, was a strong predictor of depression and quality of life six months later. There are several ways to interpret these findings. The simplest explanation is that those individuals who suffered from poor health were forced to lead more restricted lives as a consequence. Their poor health prevented them from participating in community activities, succeeding on the job, and feeling independent, leading to depression in some as well as lower quality of life. Correspondingly, sickness at Time 1 was correlated with depression at Time 2 ($r=.45$, $p<.05$). A second possibility is that a depressogenic cognitive schema resulted in these individuals adopting more sedentary lifestyles and giving rise to various physical illnesses. In addition it is possible that these individuals somaticized some of their emotional difficulties. Often in group home situations individuals with MR learn that, in order to gain attention or support, they need to be physically ill. In line with this explanation, depression at Time 1 was correlated with sickness at Time 2 ($r=.43$, $p<.05$).
Another possibility is that restrictive lifestyles and lack of stimulation led to both health problems and depression. Several researchers have hypothesized that health problems of individuals with MR living in the community are influenced by sedentary lifestyles (Golden & Hatcher, 1997; Pitetti & Campbell, 1991; Rimmer et al., 1993) but no objective measure of lifestyle was incorporated into this study. Thus, while the predictive value of health on depression and quality of life is suggestive of a causal relationship, other explanations for this relationship cannot be ruled out.

Limitations

There are several limitations to this study which should be considered when interpreting the results. Although important findings were obtained regarding social support, there are some specific problems related to social support measurement. All social support measures were self-report. Findings are limited to social support as it is perceived by persons with MR. It is unknown whether similar relationships exist for observations of social interactions or informant support ratings.

Social support and social strain were not found to be associated with informant reports of depression, but only to self-reported depressive symptoms. This study did not examine whether interpersonal relationships can predict who receives a diagnosis of depression. Many other variables influence the assignment of a depressive disorder diagnosis besides self-reported depressed symptoms, especially for persons with MR with limited verbal skills. Informant reports can be very important in making a diagnosis even though they may not relate to self-reports. It may be that the
relationships identified between social support and depression or health and depression are limited to self-report. Also, results from this study are based primarily on a non-clinically depressed sample. Expanding the range of depressed symptoms in the sample may strengthen the relationships reported and improve the staff-client agreement of depression ratings.

Findings from this study are limited to adults with mild MR in a supported living setting. The relationships between social support, health and quality of life may vary for people receiving different kinds of support (e.g. primarily family versus professional). Burchard (1994) found different predictors of well-being to be significant depending on the residential setting of participants in the Vermont Normalization studies. Differences in reciprocity, for example, between the present study and findings of Krauss et al. (1992) may be partly due to the residential setting studied (supported living versus family). Empowerment aspects of quality of life have been reported as lower by individuals living in group homes than those in this study (Wehmeyer & Schwartz, 1998). Differences in healthy behaviors have also been attributed to residential setting with individuals in community settings having more health problems than individuals living in institutional settings (Martin et al., 1997; Rimmer et al., 1994).

It is unknown whether the relationships reported here hold across the IQ spectrum. It is not simple to measure interpersonal relationships and depression in the same manner across the intelligence spectrum. Self-reports of persons with lower IQ's than the individuals in this study have questionable validity (Heal & Sigelman, 1995). Comprehension, self-awareness and verbal expression abilities are all affected by IQ and
would have an impact on the responses of adults with more severe disabilities.
Informant perceptions of the emotions and relationships of others may not be a viable
alternative as they may not agree with self-perceptions. Thus, examination of these
constructs across the IQ spectrum would require a different methodology from that of
self-report, which would likely alter the meaning of the constructs measured.

Before major conclusions can be drawn about the effects of health on mood and
quality of life, empirically tested measures of health perceptions will be required. There
has been little research in this area with people with MR and no existing measures to
use. Findings from this study, while attractive, are preliminary. The health/sickness
score used in regression analyses is a combination of several items, rationally derived
and scored on several scales (both nominal and ordinal). A future measure of perceived
health status should assess the severity of physical symptoms rather than treat them
nominally. A comprehensive assessment would also contain objective health indices
such as Body Mass Index and blood pressure. Data on the reliability and validity of
newly developed measures should be collected with this population.

Implications

This study has several important research as well as clinical implications.
Persons with mild MR can effectively report how they perceive their positive and
negative relationships with others as well as how healthy they feel. These reports
correspond with their own reports of depression and quality of life, highlighting the
importance of self-report data. Perceived social support, perceived social strain, and
perceived health are important quality of life measures and can serve as warning signs of
potential clinical difficulties.

In terms of the study methodology, the structured interview process using both
quantitative and qualitative methods proved to be effective with this population.
Participants showed a willingness to participate and follow-up interviews were relatively
simple to organize. The high completion rate (80/84) was evidence of this. Most
individuals appeared very eager to welcome back the interviewers and report on how
their lives had changed since the prior interview. Greater effect sizes with some
measures may have been found at Time 2 than Time 1 because of this increased comfort,
thus underlying the importance of establishing a rapport with the research participant in
this type of research. The lack of agreement between participants and staff on some
measures highlights the importance of obtaining information from adults with mild MR
directly rather than relying solely on informant reports. It is possible that as more adults
with MR become convinced that their perceptions are valid and important, the more
comfortable they will feel expressing them.

As was hypothesized, participants described receiving extra-individual support in
addition to traditional forms of social support. Future research should consider such
support sources to be as valid as individual support. It would be interesting to examine
whether informants consider activities and groups to be forms of social support for those
under their care. Their not doing so would be a further demonstration of why it is
important to solicit self-report information. It would also be interesting to understand
why extra-individual support is so common in this population and whether it develops in
the same way as individual support. Do those individuals who receive primarily extra-individual support differ in any way from individuals who also receive support from specific individuals? In addition to raising further questions about the role of extra-individual supports, findings from this study suggest that social support intervention should target both individual and extra-individual support sources.

Participants in this study were very capable of discussing their experiences of social strain, which had powerful effects on their subsequent mood six months later. Neither researchers nor service providers have paid sufficient attention to the detrimental effects of stressful interpersonal interactions on people with MR. There has not been a strong enough emphasis on teaching adults with mild MR how to avoid or resolve such negative situations. This study suggests that without attention to interpersonal concerns, depression may follow. One participant, when faced with social strain in his home on a continual basis, left his residence despite waiting for years to move into such a setting. When the stress occurred at work, other participants opted to become unemployed. When the stress came from family, participants described feeling the need to limit family involvement rather than correct it. Extensive work has been done teaching consumers with schizophrenia how to avoid or resolve difficult interpersonal relationships in a socially appropriate manner (see Bellack, Mueser, Gingerich, & Agresta, 1997). Conflict avoidance and conflict resolution strategies should be taught to adults with MR as well.

Participants in the present study were also able to give important information about their perceptions of their health, a topic which has been minimally researched.
Their reports agreed somewhat with that of their staff, although they tended to report more problems than their staff. Again this highlights the importance of obtaining self-report information. Are professionals and researchers ignoring many of the minor health difficulties in this population because this information is not solicited from them directly? If staff are not trained to note health difficulties, does it result in illnesses getting diagnosed in later stages when intervention is less effective and more costly? Researchers have noted that illnesses tend to be diagnosed in later stages with this population (e.g., Beange et al., 1995).

Many participants in the present study were lacking information about their health care. A final question that must be asked is: why are they not informed about the medical disorders they may have and the medications they are taking? The current climate in the MR field is one of inclusion and self-determination (Butterworth, Steere, & Whitney-Thomas, 1997) whereby adults with MR have the right to make their own decisions as members of the broader community. Recently major attempts to involve them in residential decisions (Karan & Bothwell, 1997) and in vocational decisions (Kiernan & Marrone, 1997) have been made. Such efforts should be extended to health care. For informed choice and decision making in the health arena, adults with MR require information and support, as do their health care practitioners.

**Future Directions**

This study demonstrates the value of self-reports of interpersonal relationships by persons with mild MR. Their perceptions of social support should continue to be studied
in a structured interview format, combining qualitative and quantitative methods, as was done in this study. The importance of community support and reciprocity should be further investigated. Can extra-individual support compensate for the lack of individual relationships? Reciprocity could be studied in greater depth across relationships, particularly friendships to determine whether the individuals who reciprocate in their friendships report a higher quality of life.

Further research on the social strain construct is necessary. How is social strain related to other forms of psychopathology in persons with MR? There is extensive research on expressed emotion in the schizophrenia area (see Hooley, 1985). Might individuals with mental retardation and severe mental illness also be more vulnerable to relapse in the presence of social strain? Are staff capable of recognizing social strain when it occurs and would they agree with the social strain perceptions of those under their care? It may be that staff recognize social strain and can identify when clients do not get along with others, but that they are unaware of the long-term implications. Social skills training designed to decrease the occurrence of negative support for persons with MR would be valuable. Whether learning interpersonal relationship skills improves one's quality of life could be evaluated.

Future research should focus on the long-term effects of poor physical health and a sedentary lifestyle in persons with mild MR. Further self-report instrument development in the health area is important. Research should also evaluate the effects of life changes, including the onset of illness and more minor stressors, on depression and quality of life (see Ghaziuddin, 1988).
Conclusion

The results of this research indicate that the positive and negative interpersonal relationships of individuals with mild MR as well as their perceptions of their own health are important predictors of future depression and quality of life. Similar results have been found in studies of the general population. Obtaining the perspective of adults with mental retardation is a vital aspect of this research. Improving their perceived social support, diminishing levels of social strain and fostering healthier lifestyles should become a focus of mental and physical health promotion for adults with MR in the future.
LIST OF REFERENCES


104


Appendix A

Circles Task
Pretend this is you in the middle (point to the center of the middle circle where it says “ME.”) We are going to put down the names of everybody who is important to you in these circles around you. I want you to think of all the people who are important in your life right now.

1. Tell me the people who you feel so close to that it is hard to imagine life without them:

2. Now tell me the people who you don’t feel as close to but who are still very important to you:

3. Now tell me the people who you didn’t mention yet but who are close enough and important enough to be in your circle.

*After each name ask:
   Who is that? Or Where do you know him or her from?
   Also ask: Which of these people does _____ know?
   If they give a non-personal name, ask: Who do you mean?

I will ask you lots of questions about things you do with people. For each question, you can say "a lot," "sometimes" or "not at all."
1st check: If I asked you: How often do you go to the movies, what would you say?
2nd check: If I asked you: How often do you drive a truck? What would you say?
Appendix B

Social Support Self Report (SSSR)
1. Who lives at this address with you? _______________________

2. Are you married? [If yes] Spouse's name ____________ [If unmarried] Do you have a boyfriend or girlfriend? ____ What is his or her name? ______________ Where does s/he live? ______________________

3. Is your mother alive? ______ Where does she live? ______________________

4. Is your father alive? ____ Where does he live? ______________________


6. Who do you get along with best? __________________________

7. Do you have any friends? ______ Who are they? ______________________

8. Who is your best friend? ___________ Your second best friend? ___________

9. Where do they live? ______________________

10. Do you have roommates? ______ Who are they? ______________________

11. Do you have friends at work? ____ Who are they? ______________________

12. Do you have any staff? ______ Who are they? ______________________

13. Is there any body else important to you? ______________________

For each important person identified... (a lot, sometimes, not at all)
A. How often do you see or talk to _______________ on the phone?
B. How often do you talk to _______________ about your feelings?
C. How much do you like _______________?
D. How much does _______________ help you with your problems?
E. How much do you help _______________ with his/her problems?

<table>
<thead>
<tr>
<th></th>
<th>family</th>
<th>staff</th>
<th>friends</th>
<th>partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>A talk</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C like</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E recip</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C

Functional support interview
Now I am going to give you descriptions of things people do sometimes for other people. You tell me if there are people who do these things for you. You can name me up to three people for each.

(If they just give one or two names, ask: Is there anyone else? IF they give a non-personal name, ask: Who do you mean?)

1. Is there someone you can count on for sympathy and understanding? Like if something bad happened to you and you needed a friend who would understand and help you feel better?
   A.  
   B.  
   C.  

2. Is there someone you can count on for pleasant companionship? Like to do fun things with and keep you company?
   A.  
   B.  
   C.  

3. Is there someone you can count on for help with household or personal tasks? Like if you needed help with cleaning the house or your banking, or writing a letter?
   A.  
   B.  
   C.  

4. Is there someone you can count on for advice if needed? Like if you had a problem, and didn’t know what to do about it?
   A.  
   B.  
   C.  

5. Is there someone you know who recognizes special abilities that you have? Like who knows about the things that you are really good at and tells you so?
   A.  
   B.  
   C.  

6. Is there someone who relies on you for their care or part of their care? Like if they need something, or need help or need a friend, do they count on you?
   A.  
   B.  
   C.  

6b. What sorts of things do you do for people?
Appendix D

Inventory of negative social interactions for adults with MR
I would like you to tell me some of the ways that people have stressed you or made life more difficult for you over the past month. I will read you a list of things that other people might have done to you in the last month. Please tell me how often these things happened to you.

You can say:  
Not at all = 0  
Sometimes = 1  
A lot = 2

1. Said bad things about you  
2. Ignored you  
3. Left you out of a social plan  
4. Told bad things about you to another person  
5. Yelled at you  
6. Took something of yours without asking  
7. Acted bossy  
8. Lied to you  
9. Told private things about you to another person  
10. Didn’t pay back borrowed money  
11. Friends spent less time with you  
12. Didn’t call or come over when they said they would  
13. Didn’t return your phone calls  
14. Bothered you by talking about their problems  
15. Didn’t clean up after themselves  
16. Asked you to do something unreasonable, too hard  
17. Made a scene  
18. Butted in your business  
19. Gave you unwanted or bad advice  
20. Talked down to you like you were a kid  
21. Went back on their word  
22. Overemphasized something they did for you, made too big a deal about it  
23. Damaged your property  
24. Put you down for what you believe  
25. Hung around you too much  
26. Wanted you to take care of their responsibilities  
27. Didn’t listen to you  
28. Bothered you by complaining  
29. Flirted with your boyfriend or girlfriend  
30. Made you sick with a cold or flu
31. Friend believed a rumor about you
32. Friend sided with the other person in an argument
33. Didn’t return favors
34. Mimicked or imitated you
35. Took advantage of your being nice
36. Refused to discuss an important topic with you
37. Friend’s doing drugs or drinking made your relationship hard
38. Didn’t take your problems seriously
39. Didn’t take positive things that were important to you seriously
40. Did rude things that made you uncomfortable
Appendix E

Reciprocity Measure
Which person in your family is most supportive of you? ____________
So far we have talked a lot about what people have done for you.
Now I want to know how much you do for _____________. Think about how much
you have contributed in the last year.

For each thing, you can say “a lot,” “sometimes” or “not at all.”

1. How much did you help ________ with chores (like shopping, cooking, cleaning,
   laundry, picking things up from the store)?
2. How much did you help ________ by giving money?
3. How much did you help ________ by providing care for him/her?
4. How much did you help ________ by being a friend?
5. How much did you help ________ by participating in family activities?
6. How much did you help ________ by showing affection (like hugs or kisses)?
7. How much did you help ________ by giving gifts?
Appendix F

Loneliness Questionnaire (LQ)
Now I am going to ask you some questions about how you feel. For these questions, you can answer: yes (2), sometimes (1) or no (0). If I asked: do you like ice cream...

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1. Is it easy for you to make friends at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Do you like to look at magazines?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Do you have people to talk to at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Are you good at working with other people at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Do you watch TV a lot?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Is it hard for you to make friends at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Do you like work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8. Do you have a lot of friends at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. Do you feel alone at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10. Can you find a friend at work when you need one?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11. Is it hard to get people at work to like you?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12. Do you like to cook?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13. Do you have people to talk to at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14. Do you like music?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15. Do you feel left out of things at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16. Are there people you can go to when you need help at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17. Do you like to draw and paint?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>18. Are you lonely at work?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19. Do people at work like you?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20. Do you like playing card games?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21. Do you have friends at work?</td>
</tr>
</tbody>
</table>

|     |     | 1. Is it easy for you to make friends where you live? |
|     |     | 2. Do you have people to talk to where you live? |
|     |     | 3. Are you good at getting along with other people where you live? |
|     |     | 4. Is it hard for you to make friends where you live? |
|     |     | 5. Do you like where you live? |
|     |     | 6. Do you have a lot of friends where you live? |
|     |     | 7. Do you feel alone where you live? |
|     |     | 8. Can you find a friend where you live when you need it? |
|     |     | 9. Is it hard to get people where you live to like you? |
|     |     | 10. Do you have people to talk to where you live? |
|     |     | 11. Do you feel left out of things where you live? |
|     |     | 12. Are there people to go to when you need help? |
|     |     | 13. Are you lonely where you live? |
|     |     | 14. Do people where you live like you? |
|     |     | 15. Do you have friends where you live? |
Appendix G

Birleson Depression Short Form Self-Rating Scale (BDS-S)
I have just a few more questions about how you feel. I am going to say something and I want you to tell me how much this sounds like you. You can say most of the time (2), sometimes (1) or never (0).

For example, how much does this sound like you? I love it when it rains. Would you say most of the time, sometimes, or never? (Point to cards when you give choices)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Most</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I look forward to things as much as I used to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I sleep very well</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I feel like crying</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I like to have fun</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I feel like running away</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I get stomach aches</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I have lots of energy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I enjoy my food</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I can stick up for myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I think life isn’t worth living</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I am good at things I do</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I enjoy things I do as much as I used to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I like talking with my family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I have horrible dreams</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I feel very lonely</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I am easily cheered up (become happier)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>I feel so sad that I can hardly stand it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I feel very bored</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If they respond to I think life isn’t worth living, say “so sometimes (or most of the time) you think that life isn’t worth living?” IF they say yes, say, “so that means that you don’t want to be alive?”

If they say yes, ask: Have you told anyone about this? If they say no, ask if you can tell their staff. Let them know that you are concerned, that they need help if they feel that way and that you will need to tell you teacher about it.

Ask:
1. have you ever thought about hurting yourself?
2. Do you know how you would do it?
3. Have you ever tried to do it?

Ask them if you could share this information with a staff.
Appendix H

Quality of Life Questionnaire (QLQ)
Satisfaction

1. Overall, would you say that life:
   Brings out the best Treats you like every-
   in you? body else? Doesn't give you a
   Doesn't give you a chance?

2. How much fun and enjoyment do you get out of life?
   Lots Some Not much

3. Compared to others are you better off, about the same, or less well off?
   Better About the same Worse

4. Are most of the things that happen to you:
   Rewarding Acceptable Disappointing

5. How satisfied are you with your current home or living arrangement?
   Very satisfied Somewhat satisfied Unsatisfied or very unsatisfied

6. Do you have more or fewer problems than other people?
   Fewer problems The same number of problems as others More problems than others

7. How many times per month do you feel lonely?
   Seldom, never more Occasionally, at least 5
   than once or twice or 6 times a month once or twice a week

8. Do you ever feel out of place in social situations?
   Seldom or never Sometimes Usually or always

9. How successful do you think you are compared to others?
   Probably more successful than the average person Less successful than the average person
       About as successful as the average person

10. What about your family members? Do they make you feel:
    An important part of the family Sometimes a part of the family Like an outsider

Competence/Productivity

11. How well did your educational or training program prepare you for what you are doing now?
    Very well Somewhat Not at all well

12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?
    Yes, definitely Probably I'm not sure, or definitely not

NOTE: IF a person is unemployed, do not ask 13-20. Score items 13-20 as “1”

13. How good do you feel you are at your job?
    Very good, & others I'm good, but no one I'm having trouble on
       tell me I am good tells me my job

14. How do people treat you on your job?
    The same as all other employees Somewhat differently Very differently than other employees
15. How satisfied are you with the skills and experience you have gained or are gaining from your job?

Very satisfied  Somewhat satisfied  Not satisfied

16. Are you learning skills that will help you get a different or better job? What are these skills?

Yes definitely (1 or Am not sure, maybe No, job provides no more skills mentioned (vague, general skills) opportunity for learning new skills

17. Do you feel you receive fair pay for your work?

Yes, definitely  Sometimes  No, I do not feel I am paid enough

18. Does your job provide you with enough money to buy the things you want?

Yes, I can generally buy those reasonable things I want

I have to wait to buy some items or not buy them at all

No, I definitely do not earn enough to buy what I need

19. How satisfied are you with the benefits you receive at the workplace?

Very satisfied  Somewhat satisfied  Not satisfied

20. How closely supervised are you on your job?

Supervisor is present  Supervisor is frequently present whether or not I need him or her

Supervisor is constantly on the job and looking over my work

Empowerment/Independence

21. How did you decide to do the job or other daily activities you do now?

I chose it because of pay, benefits / interests

Only thing available or that I could find

Someone else decided for me

22. Who decides how you spend your money?

I do  I do, with assistance

Someone else decides

23. How do you use health care facilities (doctor, dentist etc.)?

Almost always on my own  Usually accompanied or someone makes the appt.

Never on my own

24. How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?

Complete  Some  Little

25. When can friends visit your home?

As often as I like or fairly often

Any day so long as someone approves or is there

Only on certain days

26. Do you have a key to your home?

Yes, I have a key and use it as I wish

Yes, I have a key but it only unlocks certain areas

No

27. May you have a pet if you want?

Yes, definitely

Probably yes, but I would Need to ask

No
28. Do you have a guardian or conservator?
No, I am responsible
Yes, limited guardian
Yes, I have a full guardian
29. Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry?
No
Yes, and those problems occur once a month or once a week
Yes, and those problems occur every day or more than once a day
30. Overall, would you say that your life is:
Free
Somewhat planned for you
Cannot usually do what you want

Social Belonging/Community Integration
31. How many civic or community clubs or organizations do you belong to (including church or other religious activities)?
2-3
1 only
None
32. How satisfied are you with the clubs or organizations (including church or other religious activities) to which you belong?
Very satisfied
Somewhat satisfied
Unsatisfied / very unsatisfied
33. Do you worry about what people expect of you?
Sometimes but not all the time
Seldom
Never or all the time
34. How many times per week do you talk to your neighbors, either in the yard or their home?
3-4 times per week
1-2 times per week
Never or all the time
35. Do you have friends over to visit your home?
Fairly often
Sometimes
Rarely or never
36. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?
3-4 per month
1-2 per month
Less than 1 per month
37. Do you participate actively in those recreational activities?
Usually, most of the time
Frequently, about ½ the time
Seldom or never
38. What about opportunities for dating or marriage?
I am married, or have the opportunity to date
to date or marry
I have limited opportunities
I have no opportunity
anyone I choose
to date or marry
39. How do your neighbors treat you?
Very good or good
Fair
Bad
(invite you to activities)
(say hello, visit etc.)
(avoid you, bother you etc.)
40. Overall, would you say that your life is:
Very worthwhile
Okay
Useless
Appendix I

Healthy Behaviors Screen
I want to ask you some questions now about how you have been feeling lately and some of the activities that you have been doing. Remember, there are no right or wrong answers and I won't tell anyone what you say. So be as honest as you can.

1. How often do you smoke?
   - Never
   - 1 or 2 times a week
   - Every day
   Follow-up...
   - How many packs do you smoke in a day? (<1, how many cigarettes?)
   - How long have you been smoking for?
   - IF not
     - Did you ever smoke? How much?
     - Why did you quit?

2. How often do you have a drink like wine or beer?
   - Never
   - 1 or 2 times a week
   - Every day
   Follow-up...
   - What do you like to drink?
   - How many drinks will you have in one night?
   - Do you like to drink with people or alone?

3. Do you get exercise?
   - Never
   - 1 or 2 times a week
   - Every day
   Follow-up...
   - What do you like to do?
   - How much time do you do (the activity) for?
   - Who do you do (the activity) with?
   - Is this a new activity or have you been doing it a long time?

4. How often do you feel sick?
   - Never
   - 1 or 2 times a week
   - Every day
   Follow-up...
   - What is usually the matter?
   - Are you more or less healthy than your friends?
   Here is a list of health problems people might have.
   Which of these things happen to you?
   - Heart problems
   - Chest pains
   - Headaches
   - Constipation
   - Shortness of breath
   - High blood pressure
   - Nausea (wanting to throw up)
   - Diarrhea
   - Any other sickness?
   Do you take any sorts of medication, pills or vitamins?
   Follow-up...
   - (After each one...)
   - What do you take?
   - How often?
   - What is it for?

5. How often do you go to see the doctor?
   - Never
   - 1 or 2 times a year
   - Every month
   - Every week
Appendix J

Reiss Screen of Maladaptive Behavior
1. AGGRESSIVE Attaches or threatens others; the attacks may be physical or verbal in nature. Examples: fighting, violent acts, hitting, insulting.

2. ANXIOUS Feels nervous or tense. Examples: nervous, panicky, trembly (shaky), apprehensive, worried.

3. ATTENTION-SEEKING Tries to gain the attention of others in excessive or inappropriate ways. Examples: approaches people repeatedly within a short time-span, repeatedly seeks approval, dramatic behavior, flamboyant.

4. BODY STRESS Complains about aches and pains. Examples: headaches, stomachaches, dizziness, constipation, diarrhea.

5. COMPLAINING Has an overly critical, negative attitude and tends to find fault with others or with situations. Examples: finds fault with job, rules, or coworkers.

6. CONFUSED THINKING Disconnected (poorly related) ideas or thoughts. Examples: thoughts are hard to follow, thoughts jump from one topic to another. disoriented as to time or place.

7. CRYING SPELLS Periodic bouts of uncontrollable sobbing. Examples: quickly or easily moved to tears, cries over minor annoyances.

8. DELUSIONS Firmly held beliefs that are not based on reality. Examples: believes that others are out to get him/her, believes that he/she is in contact with the devil, believes that he/she is somebody else.

9. DEPENDENT An excessive reliance on others. Examples: seeks help to an excessive degree, excessive advice seeking, excessive need for companionship.

10. DESTRUCTIVE Deliberately damages property. Examples: breaks windows, tears books/papers, vandalism.

11. DRUG/ALCOHOL ABUSE Excessive drinking or excessive use of drugs. Examples: drunkenness, uses cocaïne, heroin addict. (Do not include cigarette smoking or coffee drinking)

12. EATING PROBLEM The person is gaining or losing weight. Examples: overeats, poor appetite.

13. ECHOLALIA Usually repeats what others say to him or her. Examples: when you say “How are you doing today, Joan”}, Joan says “How are you doing today, Joan”, when you say “I like ice cream”, s/he says “I like ice cream”.

No Problem  | Problem  | Major Problem
<table>
<thead>
<tr>
<th>No Problem</th>
<th>Problem</th>
<th>Major Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. EUPHORIA</td>
<td>Has sudden bursts of energy that may last for periods of a couple months. <em>Examples: has periods of excitement, excessively cheerful, too much laughter, excessively optimistic, rapid speech, ideas race from one topic to another.</em></td>
<td></td>
</tr>
<tr>
<td>15. FEARFUL</td>
<td>Is afraid of something to the extent that everyday functioning is affected. <em>Examples: afraid to go places, afraid to try new activities, afraid of many different things.</em></td>
<td></td>
</tr>
<tr>
<td>16. HALLUCINATIONS</td>
<td>Experiences things that are not really there. <em>Examples: hears voices, hears sounds, has visions, strange bodily sensations.</em></td>
<td></td>
</tr>
<tr>
<td>17. HOSTILE</td>
<td>Experiences anger and/or expresses anger in ways that are inappropriate for the situation. <em>Examples: gets mad easily, argues a lot with others.</em></td>
<td></td>
</tr>
<tr>
<td>18. IMPULSIVE</td>
<td>Acts without thinking. <em>Examples: demands must be met immediately, reacts without considering consequences of behavior.</em></td>
<td></td>
</tr>
<tr>
<td>19. INATTENTIVE</td>
<td>Pays little attention to people or to events around him/her. <em>Examples: pays little attention when spoken to, &quot;spaced out,&quot; preoccupied.</em></td>
<td></td>
</tr>
<tr>
<td>20. LOW ENERGY</td>
<td>Lacks energy for everyday activities. <em>Examples: too tired to participate in everyday events, moves slowly, lacks initiative.</em></td>
<td></td>
</tr>
<tr>
<td>21. NONASSERTIVE</td>
<td>Fails to express preferences and opinions. <em>Examples: lets others make decisions, doesn't ask for help or information, gives into demands, lets others take advantage.</em></td>
<td></td>
</tr>
<tr>
<td>22. OBJECT ATTACHMENT</td>
<td>Strong and persistent attachment to a particular object. <em>Examples: often wants to hold a ball; likes to carry around a key chain and gets upset when the keychain cannot be found.</em></td>
<td></td>
</tr>
<tr>
<td>23. OVERACTIVE</td>
<td>Excessive movement to the point where the person has difficulty staying still. <em>Examples: appears to be in constant motion, excessive physical movement.</em></td>
<td></td>
</tr>
<tr>
<td>24. OVERLY SENSITIVE</td>
<td>Excessive or inappropriate reactions to criticism. <em>Examples: reacts to failure by crying, withdraws when criticized, quits easily.</em></td>
<td></td>
</tr>
<tr>
<td>25. PARANOIA</td>
<td>Excessive mistrust and suspicion of others. <em>Examples: quick to assume that others have bad intentions, tends to blame others for own faults, thinks that he/she is treated unfairly.</em></td>
<td></td>
</tr>
</tbody>
</table>
26. REGRESSIVE BEHAVIOR  A noticeable deterioration in everyday self-care skills. Examples: a person who used to bathe now neglects to do so; deteriorated personal habits; unkempt or unshaven appearance (when this represents a deterioration of behavior).

No Problem  Problem  Major Problem

27. SADNESS  Feelings of unhappiness that last for significant periods of time. Examples: fail to adjust to death, rejection, or a significant loss.

No Problem  Problem  Major Problem

28. SELF-INJURY  Repeatedly injures body on purpose. Examples: bites arm, hits self repeatedly, repeated head-banging.

No Problem  Problem  Major Problem

29. SELF-STIMULATORY BEHAVIOR  Repetitive movements that are performed frequently and appear to be nonfunctional. Examples: body-rocking, object twirling, head-rocking.

No Problem  Problem  Major Problem

30. SEXUAL PROBLEM  Either a disturbance of sexual functioning, or repeated efforts to perform sexual acts that are socially disapproved. Examples: makes inappropriate sexual advances, masturbates in public, marital problem related to sex.

No Problem  Problem  Major Problem

31. SLEEP PROBLEM  A disturbance of usual sleeping patterns. Examples: does not get enough sleep, sleeps too much, has trouble falling asleep, wakes to early.

No Problem  Problem  Major Problem

32. SOCIAL INADEQUACIES  Has difficulty relating to peers in appropriate or satisfying ways. Examples: has no friends, tends to be disliked, insensitive to the feelings of other people.

No Problem  Problem  Major Problem

33. STEALING  Takes property that belongs to others. Examples: takes roommate's possessions, shoplifting, purse snatching.

No Problem  Problem  Major Problem

34. SUICIDAL TENDENCIES  Seriously thinks about killing himself/herself. Examples: says that s/he would like to die, threatens to take an overdose of pills, cuts own wrists, tries to get run over by cars.

No Problem  Problem  Major Problem

35. TEMPER TANTRUMS  Angry outbursts when frustrated or disappointed. Examples: shouts and yells when not given in to, has outbursts when asked to do something s/he does not want to do.

No Problem  Problem  Major Problem

36. TIREDNESS  Lacks motivation to perform everyday activities. Examples: listless, inactive, easily fatigued.

No Problem  Problem  Major Problem

37. UNUSUAL MOTOR MOVEMENTS  Repetitive movements beyond the control of the person. Examples: blinks a lot, strange motor movements, frequent shrugs, hand-
flapping, grunts a lot.

No Problem    Problem    Major Problem

38. WITHDRAWN Avoids personal contact with other people. Examples: excessively shy, doesn’t participate in group activities, prefers to be alone, socially isolated.

No Problem    Problem    Major Problem
Appendix K

Birleson Depression Scale - Informant version (BDS-I)
Please indicate how the client has felt recently

<table>
<thead>
<tr>
<th></th>
<th>Most of time</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. He or she feels like crying</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. He or she has lots of energy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. He or she enjoys the things he or she does as much as ever</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. He or she likes talking with his or her family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. He or she is easily cheered up</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix L

Family Reciprocity Scale
(To be said aloud to the family member)

First I want to ask you how much help ________ has given you in the past year for each of these things.

For each thing, you can say “a lot,” “some,” “a little,” or “not at all.”

1. How much did ________ help you with chores (like shopping, cooking, cleaning, laundry, picking things up from the store)?
2. How much did ________ help you by giving money?
3. How much did ________ help you by providing care for him/her?
4. How much did ________ help you by being a friend?
5. How much did ________ help you by participating in family activities?
6. How much did ________ help you by showing affection (like hugs or kisses)?
7. How much did ________ help you by giving gifts?

Now I will ask you some questions about the support that you provided in the last year. For each question, you can answer “not at all,” “seldom,” “sometimes,” or “frequently.”

How much help did you provide ________ in the last year regarding:

1. A loan of about a hundred dollars
2. A place to stay for a night or two
3. A place to stay for a long time
4. Help with household tasks like shopping, cooking, cleaning, or laundry
5. Talking about a personal problem
6. Help when ________ was feeling really sick
Appendix M

Consent form
I understand that the reason for this meeting is to find out what I think about people I know. I will be asked questions about myself and about people in my life who help me and spend time with me and who listen to me. We will meet once to do this for about one hour and a bit. Then, I know that _________ will call me again to do another interview where she will ask me some of the same questions and some different questions about how I feel about my life.

I have a choice to have this meeting or not. Once I start, I can always tell _________ that I had enough and don't want to talk anymore. I know that _________ will pay me five dollars for talking to her at the end of our meeting. Even if I do not finish the meeting, Yona will still give me the five dollars. I know that _________ will pay me five more dollars at the end of our second meeting.

What I tell _________ will be only for her and me to share because that way, I will feel free to talk and nobody will be mad at me for what I say.

I know that my worker will also answer some questions about me and people who I spend time with. All this is part of Yona Lunksky's project at Ohio State University, where she goes to school. I was told that the reason why _________ wants to talk to me is so she can understand more about myself and the people I know.

Any results that come from this will not give my name or my worker's name. I understand that nothing bad will happen to me because I take part in this. A good thing that could happen is that people can learn from this and help other people like me and other people in general.

This has been explained to me by: _______________________

participant: ____________________________ name printed: _______________________

SS#: __________________________________

witness: ______________________________ name printed: _______________________

date: _________________________________
Appendix N

Auxiliary Consent for family interview
I give my permission to ____________ to contact ________________, my ________________. Her/his phone number is _________________. I understand that I will not get in any trouble if I do let her call, or if I don’t let her call.

The reason why she wants to call _________________ is to find out how they feel about spending time with me, and what sort of things they like to do.

I know that Yona can not tell them anything that I said during our interview. I also know that Yona will not tell me anything they said in their interview. Everything we say is private. This is all part of the same research study at Ohio State where Yona is a student.

This has been explained to me by: ________________

participant: ____________________________  name printed: ________________

SS#: ____________________________

witness: ____________________________  name printed: ________________

date: ____________________________
Appendix O

Debriefing Script
Thank you very much for having the talk with me. Now that we had our talk, I want to go over what we did and why.

I am interested in who you like to spend time with and why. I had lots of questions.

Today, I asked you which people you spend time with. You told me when you see those people and what you talk about, and how much they help you and you help them. I want to know if some people spend more time with friends than other people, and if everybody has the same number of people they like or different numbers. I want to come back in six months to talk to you more about the people you spend time with and how you feel about that.

Remember. Only you and I know what we said during this talk. If I write anything about this, your name will not be used. If you have any questions after this about what we did or what I found out, please call me or my teacher, Dr. Benson, at the Nisonger Center, 292-8365.

Thank you very much for helping me by having this talk. You have been a great help and you did a really good job.