



The Effectiveness of Engaging Parents and Family Members to Expand the Social Inclusion of Adults with Intellectual and/or Developmental Disabilities Living with Families

By Angela Amado, PhD, Kelly Ortenblad, MSW, LGSW, and Kathleen O'Donnell, MSW

rtc on community living

INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

The Effectiveness of Engaging Parents and Family Members to
Expand the Social Inclusion of
Adults with Intellectual/Developmental Disabilities
Living with Families

Angela Amado, Ph.D.

Kelly Ortenblad, MSW, LGSW

Kathleen O'Donnell, MSW

University of Minnesota, Institute on Community Integration

A huge Thank You and acknowledgments to all the families and individual family members who participated in this project. All the learning could not have happened without the generosity of your participation and efforts and sharing! Thanks also to the staff of the Arc Greater Twin Cities, who have provided invaluable partnership in having this project realized.

Recommended citation:

Amado, A.N., Ortenblad, K., & O'Donnell, K. (2018) The effectiveness of engaging parents and family members to expand the social inclusion of adults with intellectual/developmental disabilities living with families. Minneapolis, MN: University of Minnesota Research and Training Center for Community Living.

This product was developed under a grant from the National Institute on Disability and Rehabilitation Research to the Research and Training Center on Community Living (RTC/CL) (Grant #H1080005) at the Institute on Community Integration, University of Minnesota. The content, interpretations and conclusions are those of the authors and do not necessarily reflect the views of ICI or RTC/CL at the University of Minnesota or their funding sources. The University of Minnesota is an equal opportunity educator and employer. Alternative formats are available upon request.

For additional information or questions about this report, please contact

Angela Novak Amado, Ph.D., amado003@umn.edu

University of Minnesota, Institute on Community Integration

Photos on the cover, clock-wise from upper left:

1. Volunteering as an usher at a local community theater
2. Cribbage group that meets weekly at a local bar/restaurant
3. Daughter of a former staff person helping a friend learn to read
4. Ladies' coloring book club that meets monthly at a local coffee shop

ABSTRACT/EXECUTIVE SUMMARY

Since most individuals with intellectual/developmental disabilities live at home, engaging families in social inclusion efforts is important to build more inclusive communities. This project was exploratory, mixed methods research about supporting families in how to expand social inclusion for their adult children who were living at home. There was interest from 111 families, with representatives from 81 families attending an information session, 49 families beginning the project, and 17 families with 18 children continuing to project end after 30 months. There were several successful outcomes as well as some challenges.

Successful outcomes included the finding that strategies that had previously been used by human services agency staff to expand social inclusion for group home residents can also be successfully used by families, whether the adult child had a mild or more severe degree of disability. Families discovered the openness and willingness of community members to include and befriend their children. The project also affected family members seeing the gifts their children have, and what types of relationships with members of the larger community might be possible now and in the future.

Besides the challenges of connecting individuals with disabilities with other community members, the three principal project challenges were in measuring and tracking social relationships, family recruitment, and type of project structure. Similarities and differences found between training families and agency staff may also be useful for those engaged in training families in future endeavors. There was a significant need expressed by many families

for different types of social inclusion projects and efforts to impact this very important area of life.

I. INTRODUCTION

Views of people with disabilities and perspectives about what makes a quality life have greatly shifted in recent years. At one time, segregation was quite common, but services and supports have gradually changed to reflect the strong and still evolving beliefs in inclusion – in schools, workplaces, and all the places of ordinary community life. Benefits of inclusion have been noted for both those with disabilities and other members of the greater community.

In this shift toward inclusion, the benefits of friendships and relationships have also been noted. Our social relationships affect physical, mental, and emotional health, and result in increased longevity, less depression, and greater resilience (Cacioppo, 2014; Hafren, Karren, Frandsen & Smith, 1996; Kroenke, Kubzansky, Schernhammer, Holmes & Kawachi, 2006). Besides the health and other benefits that accrue from friendship, recreation specialists have also documented that the degree of “fun” we have is related to who we are participating with, in our activities. Whether we are biking, eating out, or going to the movies, it’s more fun based on sharing these experiences with others.

Although the majority of individuals with intellectual and developmental disabilities (IDD) are physically integrated within their communities, many are still socially isolated, with far fewer relationships than others (Verdonschot, deWitte, Reichraft, Buntinx, & Curfs, 2009). Community participation for those in residential services often consists of “activities” experienced outside of the home, but activities such as shopping or eating out rarely lead to the development and maintenance of social relationships (McVilly et al,

2006; Stancliffe, Harman, Toogood & McVilly, 2007). In contrast to physical inclusion, social inclusion entails such aspects and experiences as the development and maintenance of friendships and personal relationships between individuals with and without disabilities, membership in community entities and organizations, and socially valued roles in community life.

Inclusion in school settings has been rigorously studied, with the benefits of these inclusive environments documented (e.g., Cole, Waldron & Majd, 2004; Rossetti, 2011). For adults with IDD, many strategies have been identified over the years as effective in supporting the expansion of social inclusion (Abery & Fahnestock, 1994; Amado, 2010; Carlson, 2000; Carter, 2007; Stancliffe et al., 2013). The vast majority of these interventions have been focused on people who receive support within the formal services system, especially those living in community residences or attending segregated day programs (Verdonschot et al., 2009).

However, the great majority of adults with IDD live with their families (Larson et al., 2018). To date, intervention strategies designed to enhance social inclusion for adults living with their families have not been tested. Many families report that even if their children were in integrated school programs, once their children leave school they lose the majority of their social connections. Much is known about the characteristics of the social networks of adults with IDD and transition-age youth living with their families (Amado & Lakin, 2006; Krauss, Seltzer & Goodman, 1992); the most frequent pattern of relationships for most people with IDD who live with their families is that their relationships are mediated through the family (e.g., friends of the family rather than friends of the person with IDD themselves). There have been no studies that have

systematically documented effective interventions to expand social inclusion for adults with IDD who continue to live with their families once they leave school. Strategies and structures to counteract the loss of social connections upon graduation or school completion are therefore critical.

The purpose of this study was exploratory and used mixed methods, with the intention to evaluate interventions to improve the social inclusion of adults with IDD who were living with their families. Three different premises were addressed. The first was whether strategies that had been successfully used by staff in residential settings to expand social inclusion (Amado, 2010; Amado, 2013; Amado et al., 2015) could also be effectively used by family members to improve the social inclusion of their adult children who were living with them, or in what ways those strategies needed to be adapted for use by family members. A second purpose was to determine if strategies for transition-age youth differed for strategies for older adults. Lastly, the study addressed whether or not families that had in-home staff available to them differed from families that did not; that is, would families that have in-home staff be more successful in increasing social inclusion because they would also use their staff to support these efforts?

The specific research questions of this study included the following:

1. Compared to previous studies of social inclusion enhancement strategies used by direct support professionals in residential settings, how effective are these interventions when used by families for adults and transition-age youth with IDD living with their families?
2. What, if any, differences exist with respect to the impact of studied strategies on the social inclusion of adults and transition-age youth with IDD living with families when

they are used by families that have paid in-home support versus those without paid in-home support? To what extent do these strategies differ for families that have in-home support versus those who do not? In what manner, if any, does staff support or a lack thereof have an effect on levels of social inclusion? What factors contribute to success, in each treatment condition?

3. How, if at all, do effective social inclusion strategies need to be adapted to meet the unique needs of families? How can these strategies be effectively used as students transition out of school?
4. What are the challenges and benefits, beyond enhanced social inclusion, experienced by individuals and families that use social inclusion enhancement strategies?
5. To what extent do family characteristics (e.g., single parent, age of parent, etc.) impact the effectiveness of social inclusion interventions?
6. To what extent, if any, do personal characteristics of the focus person (e.g., age, level of IDD) influence the effectiveness of social inclusion strategies?

II. METHODOLOGY

The intervention was designed to last approximately 30 months, with staggered start dates based on different stages of participant recruitment. First, information meetings were held to inform interested families about what would be involved in participating in the project. The intervention itself consisted of two elements: (1) family members would attend an initial five-hour training session, with the family member with disabilities also welcome to attend, as well as any staff; (2) after the initial training, family members would be asked to come to follow-up sessions bi-monthly for 12-18 months, and then

quarterly for the last year. The time period for follow-up meetings was staggered because initial recruitment efforts took place over 4 months, but participants continued to be added for an additional 5 months.

Target Sample

Recruitment efforts were aimed at the seven-county metropolitan area of Minneapolis-St. Paul, Minnesota, and its suburbs. The proposed goal was to identify at least fifty culturally and linguistically diverse adults and transition age youth with IDD who live with their families and have no paid, in-home supports and an equal number who live with their families and who have paid, in-home supports. The hypothesis was that families that had in-home staff were going to be more successful in implementing project activities, due both to a higher level of support and also being able to use in-home staff to implement some activities. It was also intended that twenty-five percent of the sample would be composed of transition-age students ages 18-21, focused on those in their last years of secondary school, in order to address transition strategies from school to adult life over the three years of the project.

Participant Recruitment & Recruitment Experiences

Recruitment information about the study was distributed through: Arc Greater Twin Cities, Hennepin County Human Services and Public Health Department/Aging and Disability Services (serving the city of Minneapolis, suburbs and outlying areas), the Jewish Community Inclusion Program, and Ramsey County Community Human Services (serving Saint Paul, suburbs, and outlying areas). Other more suburban counties in the 7-county metropolitan area of Minneapolis-St. Paul were also asked to recruit families as needed to develop an adequate sample. Families with an adult member with IDD who

had graduated or left school were invited to come to information sessions about the project, as well as families with 18-21 year olds in their last year of school. At the initial information sessions, the study design was explained: an initial 5-hour training, and bi-monthly or quarterly follow-up meetings that were to continue for 2-1/2 years.

Responses from promotion efforts resulted in 111 families representing at least 117 family members with disabilities that were interested in participating. (Some families had multiple children with disabilities.) Of this interested group of 111, family members and young people representing 81 families with 85 family members with disabilities attended the introductory sessions. At the information sessions, 11 families directly expressed that they did not want to participate. Reasons for not participating in the project were gathered from three groups: the 11 attendees who expressed not wanting to participate at the information session itself, those who were followed up after the information sessions and then indicated they did not want to participate, and those who had expressed interest but did not make it to the information session itself. Reasons for not participating from all these three groups fell into six main categories:

(1) the families recognized social inclusion was important but wanted someone else to do it (i.e., when they found out that it was a matter of the families themselves implementing the strategies, they did not want to participate); (2) they were looking for a “friendship group”; (3) coming to the training meetings did not fit in the family schedule – they were too busy; (4) the family did not have enough staff or resources to attend training regularly (e.g., single mothers who had no other support at home); (5) families felt their young person was already sufficiently well connected; and (6) the young person who attended

the information session was not interested. One older mother expressed she was “just too tired” after all the years of advocating for her child.

Participation and Demographics

Throughout this report, the term “participant” refers to the parent or family member who was responsible for implementing the intervention strategies. The term “focus person” is used to refer to the young adult or adult (i.e., the child of the parents) who was the focus of the social inclusion efforts.

The initial 5-hour training was completed by participants representing 49 total families and 51 focus people at ten different sessions from the summer of 2014 through the summer of 2015. Of the participants who completed the initial training, representatives of 29 families with 31 focus people attended at least one follow up session. (Two families had more than one focus person in the project for a total of 31 focus people.) These follow-up sessions were held in several different areas distributed throughout the greater Twin Cities and its suburbs, primarily in meeting rooms in libraries and coffee shops, with attendance at any one follow-up session ranging from one to 7 participants. The length of time in which families who completed the project participated in follow-up meetings ranged from 21 through 29 months, based on their project starting time.

Within the first year, 3 of the 29 participants who attended at least one follow-up session dropped out of the project or discontinued contact. One expressed growing health concerns with the focus person and another had a lack of staffing support. During the second year of the study, an additional 9 participants dropped out of the study or discontinued contact. Reasons these families identified for not continuing in the project

included: health and/or behavior changes of the focus person, health issues with the participating parent or other family members, other family obligations getting in the way, the study wasn't the right fit for the family, the family was already engaged in activities, and the activities suggested at project meetings were not an appropriate fit for the focus person. During the last year of the study, one participant discontinued contact. Some of the comments from parents who stopped attending at different times included:

“The family is very active and always looking for ways to build community friendships; (the focus person) didn't feel like the recommendations were new ideas to her and her family.”

“I learned about how to help my son from the (initial) training and he has been doing really well. He recently started selling artwork and making more connections. (I) decided to stop participating since connectedness and friendships have been taking off, we are very busy. I found the other program participants to be discouraging.”

“I was not getting anything from the project and felt the ideas and suggestions were inappropriate; I did not like that it was suggested to bring my autistic child to a bar for painting classes” (note: an “Art and Wine” event had been suggested by others at a follow-up meeting).

The remaining 17 participants representing 18 focus people completed the study to its full duration, although one parent did not complete all the final surveys, so final data do not reflect comments from that family. Two participants were accepted into the project while their child was living in a group home; although the project was aimed at adults living with their families, these two families expressed a desire to implement the strategies themselves. Another focus person moved into a group home during the course of the study. Table 1 shows the participation

information from the start of the project and the demographic information of the 18 focus people (17 participants) whose family members continued to the project end.

Table 1. Demographic and Participation Information of Participants and Focus People

		N	%
NUMBER OF PARTICIPANTS	Attended Information Session	81	100
	Attended Initial Training Session	49	60
	Completed baseline surveys (N = focus people)	39	48
	Completed training and attended at least 1 follow-up	29	36
	Year 1 Follow-up (participating at end of Year 1)	26	32
	Year 2 Follow-up (participating at end of Year 2)	17	21
	FOCUS PEOPLE	(completed the project)	
Race	Caucasian	16	89
	Asian	1	6
	African	1	6
Sex	Male	9	50
	Female	9	50
Age	18-24	11	61
	25-31	6	33
	32+	1	6
Type of Disability	Mild Disability	6	33
	Moderate Disability	7	39
	Severe Disability	1	6
	Unknown Level of ID	2	11
	No diagnosis of ID	2	11
	Autism	11	61
	Cerebral Palsy	6	33
	Epilepsy	4	22
	Hearing Impaired	4	22

	Speech Impaired	1	6
	Visually Impaired	2	11
	Multiple	15	83
Staff Available	In home Staff	8	44
(At beginning of project)	No Staff	8	44
	Group Home	2	11

The focus people represented a range of types and severity of IDD. The vast majority of the focus participants were young adults in transition programs, or just recently graduated. Eleven focus people (61%) had a diagnosis on the autism spectrum, but overall 83 percent (15 participants) had more than one diagnosis. The largest response for participation in the project was from families in which the young person was in their 20's with mild degrees of autism or another disability, although some had a moderate to severe level of disability. The family members of many of the young people with autism in particular (including those at the information session who did not participate in the rest of the project) expressed recognition of the importance of social relationships for their child.

Of the 17 families (18 focus people) which participated until the end of the 30 month intervention phase, the follow-up meetings in 14 of these families were attended primarily by the mother, 1 only by the father, 1 by a sister, and in one family the mother and father either both attended or alternated. Thirteen of the 18 focus people (young adult or adult children) came to some meetings, with 5 coming to all or almost all of the meetings their parents attended. In addition, group home staff came to almost all of the meetings for one family, a PCA (personal care attendant) came to one meeting for another family, and a university LEND program fellow who was supporting one of the

other families in another project, also attended once. There were an additional three fathers, one fiancé, and one sister who came to a follow-up meeting, including two fathers in families that did not continue until the end of the project. Staff from ARC Greater Twin Cities who had assisted in family recruitment also attended many meetings to assist with brain-storming and learn more about the strategies to help additional families in the future.

Overall, the family members that continued to the completion of the project had college and graduate level education (as shown in Figure 1) and primarily worked at a professional level, in different fields. Information that was provided on these professions and occupations included:

Mothers' Professions Listed: Law Professor, R.N./Acupuncturist, Medical Technician, R.N., Dental Office, Translator and Interpreter of 5 Languages, Program Director, Trust Management, Office Manager, Physical Therapy Assistant, Home Maker

Fathers' Professions Listed: Dentist, Judge, CFO, Retired-Formerly a geologist, Tech Services at Boston Scientific, Business Owner, Marketing Consultant, Retired Mechanic-now auto parts, Handy Man

Family income is also shown in Figure 2.

Figure 1. Parents who Completed the Project -- Level of Education

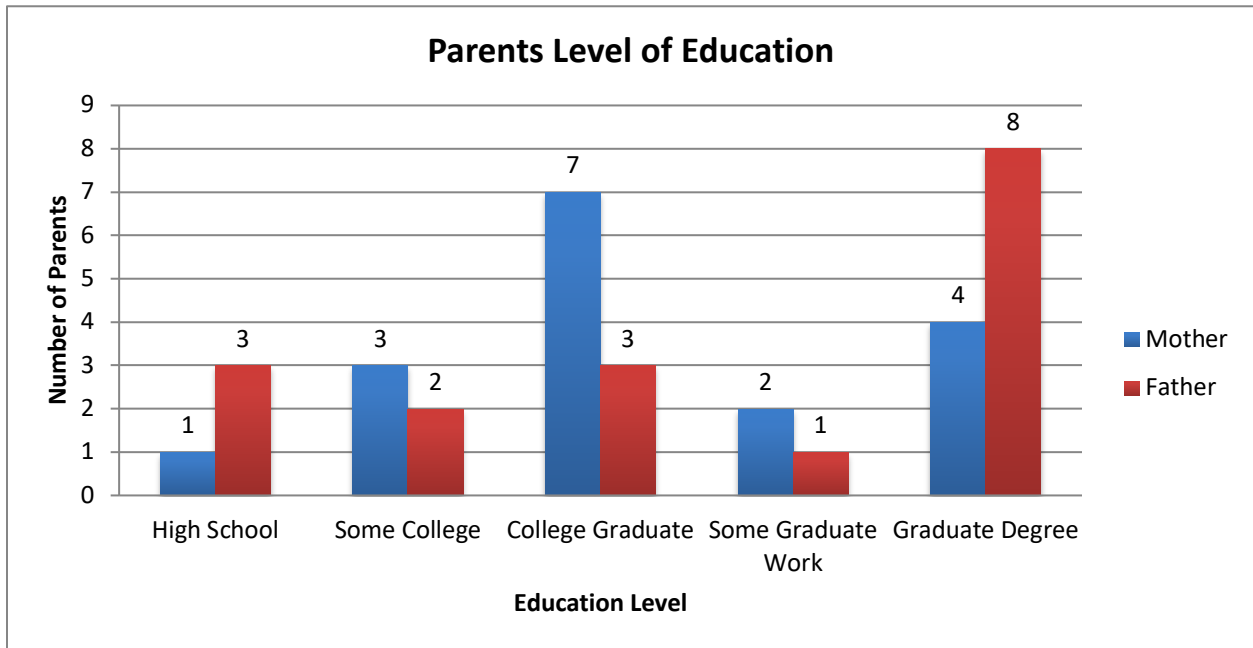
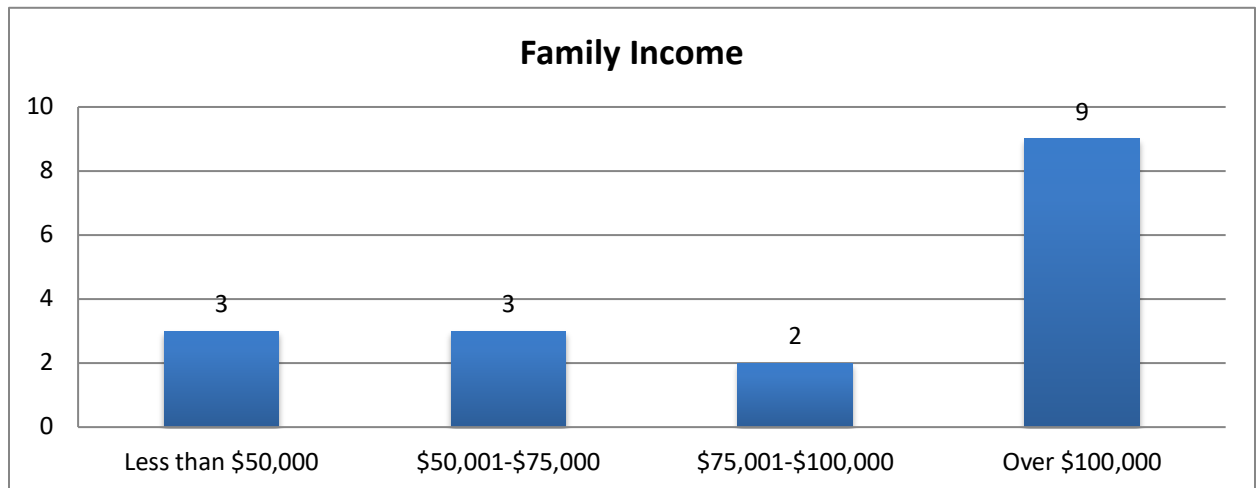


Figure 2. Parents who Completed the Project -- Family Income



III. RESEARCH DESIGN

The intervention phase of the study was designed to use mixed methods and to last up to two and a half years. Previous projects had demonstrated that building relationships takes time (Amado,2010; Amado, et al., 2015; Stancliffe. et al., 2013). As mentioned above, families were asked to attend an initial 5-hour training, meet bimonthly for the first year after the initial training, and quarterly in the last year.

Person-centered approaches were utilized throughout the project. At the initial training, first the importance of relationships between people with disabilities and other community members was described, including examples and stories of community member relationships from previous projects. Then a sequence of activities was followed, using worksheets and exercises designed to generate connecting ideas. The parent or family member identified their child's interests and gifts, including abilities and talents. Then ideas were brainstormed through seven community connection strategies that have been demonstrated to be successful with individuals in residential services (Amado, 2010; Amado, 2013), including the identification of community members, places and groups that could be accessed or relationships developed to increase social inclusion. These seven connecting strategies included two methods to connect people with similar interests and who will appreciate the focus person's gifts, two strategies focusing on one-to-one connections with community members, and 3 strategies for expanding community group membership and belonging. After ideas were brainstormed through the seven strategies, each participant selected their three best ideas to pursue. Action steps and plans were developed to focus the efforts of family members and staff to pursue these selected ideas prior to the next planned follow-up meeting.

After the initial training, family and staff face-to-face training activities occurred on a bimonthly basis in Year 1 and 2 and moved to quarterly during Year 2. (The start of “Year 2” was staggered based on different families starting the project at different times over a 6-month period). Ongoing follow-up meetings revisited action steps and plans from previous meetings. Successes were identified, as well as barriers encountered. Ideas were developed to address the barriers and brainstorm new ideas to increase social inclusion. Some follow-up sessions also included practicing skills such as making invitations to and requests of community members.

Instrumentation & Data Collection

This study utilized both quantitative and qualitative evaluation methods. Three social participation outcome areas were used and measured throughout the study to determine outcomes: individual friendships with community members, community group membership, and valued social roles. Four data-collecting measures were used: two quantitative, one qualitative, and one mixed. These were:

1. Eco-Mapping (Relationship Maps) (Quantitative)

A form of “Eco-Mapping” (Appendix A) was used to demonstrate the size and type of the individual’s social network, and changes in that network over the course of the project. Rempel and his colleagues (Rempel, Neufeld & Kushner, 2007) have advocated for the use of these relationship maps as graphic portrayals of personal and family social relationships, to facilitate increased understanding of anyone’s social network.

2. Participant Social Integration Survey (Amado, 2010; Amado, 2012) (Quantitative)

This survey (Appendix B) was used to assess the three areas of social participation outcomes. Survey questions were slightly modified from previous studies (in which the

survey had been used with staff in formal residential and other services) to address the fact that parents rather than staff were implementing the project strategies, as well as the fact that focus people were living in their family home rather than in group homes or other residential settings.

Data on the above two instruments were collected from the family member and also the person with IDD when appropriate. These two data collection components were administered to all participants at baseline and at the completion of Years 1 and 2. The end of the “Year” was approximately 12 months after the participant started but could range from 10 to 14 months based on when they attended a follow-up meeting in that time frame.

3. Sessions Notes Summaries (Qualitative)

In terms of qualitative information, group meeting content was captured to reflect family member discussions about successes, barriers, and other information shared at follow-up group meetings. The content of these meetings was recorded through note taking during the session. Reports of results during these meetings were again categorized into the three outcomes areas: individual friendships with community members, membership in community groups and associations, and valued social roles. Information gathered during the follow-up group meetings also reflected whether it was the family member, direct support staff, or the person with disabilities who pursued the different ideas and strategies.

4. Overall Program Evaluation Summaries (Mixed Quantitative/Qualitative)

At the last meeting of the project, family members and focus people were asked to complete an overall project evaluation survey, which included both quantitative, Likert-scale items, and open-ended questions to gather qualitative information.

IV. RESULTS

Of the four sources of data described above, results in each category are summarized below: Relationship eco-maps, qualitative analysis of narrative reports at meetings attended, surveys, and end of the project evaluations.

1. Relationship Eco-Maps (Appendix A) (Quantitative)

Relationship Eco-maps were provided to family members and focus people during the initial training meeting and again at the end of Year 1 and end of Year 2. These maps have been used in person-centered planning approaches (Mount, Ducharme & Beeman, 1991) and categorize membership in social networks. The type of relationship map used in this project had 10 categories (e.g., neighbors, family, church, etc.) and 3 levels to categorize depth of relationships: most intimate and close, secondary (people who know or participate with the focus person, but are not close relationships), and the third level of acquaintances. To score, the number of relationships in each of the 10 categories on the eco-map for all focus people were totaled to show an overall score of numbers of relationships in each category. The data is represented below in both a bar graph and a chart.

As indicated in Figure 3 and Table 2, of the 10 categories listed on the eco-map, overall there was an increase reported in the total number of people in the focus people's

networks from baseline to the end of Year 2 in 8 categories: family, leisure-rec, church, social/civic activities, friends, school, jobs, and neighbors. Some of these categories showed a decrease between baseline and the end of Year 1 but showed an overall increase over baseline by the end of Year 2. In two of the categories, there was a decrease by the end of Year 2 in the total number of people reported: children and paid service providers. None of the focus people had children, so what was being recorded in that category is unclear. The decrease in the number of paid service providers may have been due to focus people graduating from their school or transition programs, or staff turnover in the families that had in-home staff.

Figure 3. Number of People in Each Category Reported on Relationship Eco-Maps, Over 3 Reporting Occasions

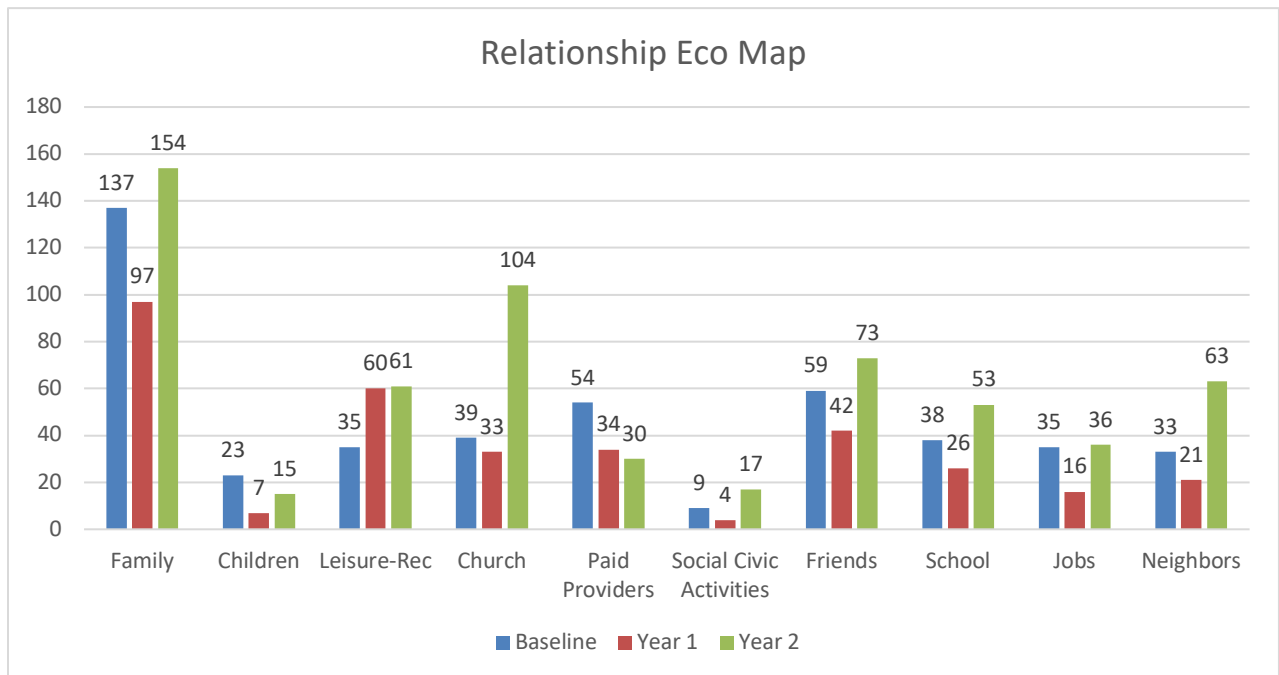


Table 2. Number of People in Each Category Reported on Relationship Eco-Maps, Over 3 Reporting Occasions

	Baseline	Year 1	Year 2
Category	Total Sum of People		
Family	137	97	154
Children	23	7	15
Leisure-Rec	35	60	61
Church	39	33	104
Paid Service Providers	54	34	30
Social Civic Activities	9	4	17
Friends	59	42	73
School	38	26	53
Jobs	35	16	36
Neighbors	33	21	63

Some of the increases and decreases in each category of the social network from year to year were due to changes in the focus person’s life circumstances - - for example, if they graduated from school, got a job, started volunteering, or got new staff. However, some of the reported increases and decreases were not necessarily due to changes in the social network, but the challenges of measurement and reporting on a social network. While they were filling out these maps, family members often reported that they could not remember who they had reported in a previous year, or in what category. At times they expressed not being sure of which of the 10 categories to use for some social network members (e.g., should someone be placed in “church” or “friend”?). One of the main issues in this study was the challenge of reporting and measuring relationships, an issue that has been reported in other studies about social relationships (summarized in Amado, Stancliffe, McCarron & McCallion, 2013). This issue is further discussed below in the section about Challenges of Measurement.

2. Session Notes Summaries (Quantitative)

Participants and focus persons attended bi-monthly follow-up sessions during the first and part of the second year of the project and continued with quarterly sessions in the second year, with timeframes staggered depending on when they started the project. The number of follow-up sessions attended per participant ranged from 5 sessions (6% of the total group) to 11 sessions (18% of the total group), with most attending 7 to 10 sessions. The table below details the number of participants and how many meetings they attended over the course of the project, including the final sessions.

Table 3. Number of Training/Follow-Up Meetings Attended by Family Members

Number of Meetings Attended	N	% of participants*
5	1	6
6	0	0
7	3	18
8	2	12
9	3	18
10	5	29
11	3	18

*Note: total more than 100 due to rounding.

During each session, written notes were taken on the results and barriers which participants reported that had happened since the previous meeting attended. Results that had happened were categorized into the three different outcome categories used in the study including: individual friendships with community members, membership

in community groups and associations, and valued social roles. Four additional categories were also used to categorize narrative information about other results or changes which the family members reported: new community connections or contacts (e.g., some connection with a specific person, such as the focus person meeting a new community member and learning their name), an increase in physical integration (e.g., going to a new specific community place), differences in relationships with family members, and ideas that were tried but were unsuccessful. These written summaries for the three-year period were analyzed collectively by project staff at the end of the project. Outcomes for focus persons are shown in Table 4. The categories reflect these 7 types of outcomes:

1. Friendships with community members
2. Membership in community organizations with non-disabled individuals
3. Valued social role with community members (e.g., church greeter)
4. Community connections and contacts-specific people/acquaintances
5. Physical integration – new places the person goes
6. Family relationships
7. Something about community relationships that was tried during the time period and didn't work

Table 4. Results Reported at Follow-Up Meetings (N = 17)

Variable	Total Number of Results Reported	Individual Average per All Focus People	Number of Focus People Reported This Result (% of Focus People)
1. Friendships with Community Members			
a. At least one new community friend	10	0.59	6 (35%)
b. Friendship prior to project, continued	9	0.53	6 (35%)
c. Reconnected with former friends	12	0.71	6 (35%)
2. Membership in Community Organizations			
a. New member	11	0.65	6 (35%)
b. Member prior to project, continued	4	0.24	3 (18%)
3. Valued Community Social Role			
a. New social role	18	1.06	9 (53%)
b. Social role prior to project, continued	5	0.29	4 (24%)
4. Community Connections/Contacts			
a. New contacts or connections	9	0.53	8 (47%)
5. Physical Integration			
a. Increased levels of physical integration	7	0.41	6 (35%)
6. Family Relationships			
a. Increased or improved family contact/relationship	4	0.24	3 (18%)
7. Tried Something and Didn't Work			
a. Staff/person/family tried something and didn't work out	21	1.24	15 (88%)
b. Staff/person/family had good ideas but did not try anything	0	0	0

Table 5. Results Reported in Each Category, Based on Number of Meetings Family

Members Attended

Focus Person	# of Sessions Attended by Family Member	1A	1B	1C	2A	2B	3a	3b	4a	5a	6A	Total 1-6	7A
1	10	0	0	0	0	0	5	1	0	1	0	7	2
2	11	0	3	3	0	0	1	0	0	0	0	7	1
3	10	0	0	0	0	0	0	0	0	0	0	0	1
4	8	2	0	1	0	0	0	0	0	1	0	4	1
5	7	0	2	0	1	1	0	0	0	0	0	4	0
6	10	0	0	0	2	0	2	0	1	0	0	5	2
7	8	0	1	1	0	1	2	0	0	0	2	7	1
8	7	0	1	0	0	0	1	2	0	0	0	4	1
9	9	0	0	2	0	0	2	0	0	0	0	4	1
10	9	1	0	2	2	0	3	0	1	1	0	10	1
11	9	0	1	0	0	0	1	0	1	0	0	3	1
12	10	2	0	0	2	0	0	0	1	0	0	5	1
13	5	0	0	0	2	0	0	0	0	1	0	3	0
14	11	3	0	0	0	0	1	1	2	0	1	8	3
15	10	1	0	3	2	0	0	0	1	2	0	9	1
16	7	1	0	0	0	0	0	0	1	0	0	1	1
17	11	0	1	0	0	2	0	1	1	1	1	7	3
Total	152	10	9	12	11	4	18	5	9	7	4	88	21
Average	8.9	.59	.53	.71	.66	.24	1.1	.29	.53	.41	.24	5.18	1.24

Table 5 shows the results reported in each of the 7 categories of results, according to the number of follow-up sessions which the participant attended. (One focus person was not included in the data as they had initially dropped out of the project after the first meeting and came back to the project at the end of Year 2, resulting in reports on 17 focus people.) On average, there were 5.18 results per focus person. Meeting attendance was not correlated with results in the seven categories of outcomes which were categorized from narrative reports at the meetings, except for the fact that if family members attended more meetings, they had more frequent occasions to report results.

These results also reflect that level of disability did not affect outcomes, since some of the individuals with a more severe level of disability had more outcomes. Examples include focus individuals 12, 15, and 16, all of whom had a more severe level of disability; the number of results for these 3 individuals ranged from 1 to 9. Examples of those with a more mild level of disability included focus individuals 1, 3, and 10, where the number of results ranged from 0 to 10. A variety of family and personal factors affected the types and quantities of results. For example, Focus Person # 3 had only a mild degree of autism, and was already fairly well-connected and participating with community members; his mother was focused on more personal friendships, which did not see much progress. Hence, individual situations varied greatly.

Examples of what was established in the three main outcome areas of individual friendships, community groups and clubs, and valued social roles are listed next. The length of time varied in which any individual outcome was sustained. For example, attendance at community group meetings in some cases only occurred once while in other cases group membership continued over the duration of the project. Any steps in all three

of these outcome areas take effort to continue to sustain, and numerous factors affected sustenance in all three categories.

Individual Relationships:

- A married couple gave a focus person a ride to their church twice a month
- Former staff person had the focus person stay overnight with her about once a month
- Several focus people reconnected with old friends from high school
- The focus person identified a man from church, saying “I want to meet that guy” and worked out with his parents to ask him to have lunch after church to get to know him better
- Another focus person connected with a fellow church-goer

Community Groups/Clubs: (listed according to order of frequency, from groups most frequently attended to least)

- A cribbage group that meets every Monday night
- Mother started a Youth Friendship Club at the family’s church
- Altar Guild monthly meeting
- University women’s hockey team fan club & University women’s basketball team fan club
- A church and church service the person really liked, with lots of music (the focus person who attended didn’t like to be around crowds/people)
- Ladies coloring book group
- Soul line dancing
- Weekly trivia group contest at a bar/restaurant

- Japanese Cultural Center and Geek Cultural Society
- Japanese Anime Convention

Valued Social Roles:

- Volunteering at Science Museum
- Volunteering at Children’s Museum
- Volunteering at a community theater
- Community chamber orchestra member
- Sunday school teaching assistant
- Job at pet food supply
- Helping wash communion cups at church
- Performing in a theater production
- Weather-watcher
- Pet Adoption Group volunteer

3. Participant Social Integration Surveys (Quantitative)

Annual surveys (Appendix B) were provided to participants at baseline and at the end of each year of the study. Sixteen participants (representing 17 focus people) completed surveys at baseline and at the end of Year 1 and end of Year 2. (One participant completed surveys for baseline and at the end of Year 2 only; this data was not included for the figures and tables listed below.) Responses to seven selected survey questions that reflected the main research questions were analyzed at the end of the study. Figure 4 and Table 6 show the results reported for these seven different types of engagement with community members. An explanation of the results in each of these questions follows Table 6, with references to the selected survey questions (Appendix B).

Figure 4. Results Reported on Annual Surveys, Over 3 Reporting Occasions

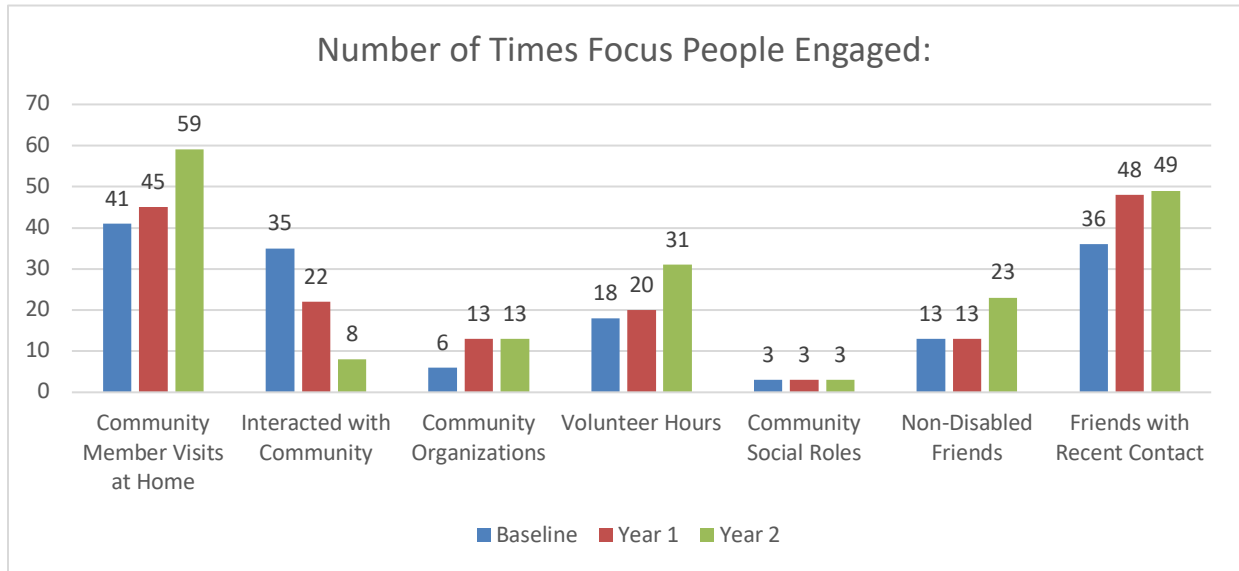


Table 6. Results Reported on Annual Surveys, Over 3 Reporting Occasions

Types of Engagement	Baseline	Year 1	Year 2
1. Community Member Visits at Home	41	45	59
2. Interacted with Community Member	35	22	8
3. Community Organizations	6	13	13
4. Volunteer Hours	18	20	31
5. Community Social Roles	3	3	3
6. Non-Disabled Friends	13	13	23
7. Friends with Recent Contact	36	48	49

1. The number of times per month community members visited the Focus Person in the home (Survey, p. 11)

The total number of times per month community members visited the focus person in their home increased each year, from 41 times per month at baseline to 59 by the end of Year 2. A total of 8 participants reported an increase in the number of monthly visits by a community member, 6 reported a decrease, and 3 reported no change. However, without an actual recording system for each occurrence, the accuracy of reporting is difficult to determine. On some surveys, it is likely that what was getting counted or reported by the family member changed over the 3 reporting occasions; for example, the number of reports in one case went from 24 to 2 over the 3 reporting periods, another decreased from 16 to 1, and another decreased from 12 to 6.5. In these cases, it is likely that the actual number of visits was not changing that dramatically, but rather what was changing was what was being counted or reported.

2. The number of times per month the Focus Person interacted with another community member (Survey Section VIII, p. 10)

The number of times the focus person interacted with another community member showed a large decrease from 35 at baseline, to 22 reported for Year 1 and 8 reported for Year 2. A total of 7 participants increased the number of times per month they interacted with another community member, 3 reported a decrease and 7 reported no change.

Again, the decrease in the total number is likely due to reporting discrepancies rather than actuality. One respondent said 21 at baseline, then 3 at Year 1 and 0 at Year 2, accounting for the drop in the total number reported.

3. Total number of community organizations the Focus Person belongs to (Survey Section IX, pg.12)

Participants were asked to document “how many community organizations the focus person belongs to.” Some of the responses included groups and organizations that are primarily for people with disabilities such as Special Olympics. Some responses included places in which the focus person may be attending an activity or service (e.g., YMCA, church) but it was not possible to ascertain if there was group membership, belonging, and active participation with other community members, as opposed to attendance without active involvement with others. Lastly, there were some community groups and organizations reported in which focus people did actively participate and belong with other community members. Table 7 lists the information on group membership in all these three types of group involvement.

The number of community organizations that participants were involved with increased and then stabilized during the project. On average, participants were involved with 0.35 community organizations at baseline, 0.76 organizations at Year 1, and 0.76 organizations at Year 2. Participants reported eight focus people had an increase in the number of community organizations they belonged to since the beginning of the project. while one focus person saw a decrease and 8 focus people had no change in their membership in community organizations.

Table 7. Types of Community Organizations Reported on Annual Surveys, Over 3 Years

Baseline		
Organizations for people with disabilities	Organizations focus people attend (services/activities)	Community wide organizations
Special Olympics	Church	Neo-catechism
Special Olympics	Bethlehem Baptist	Church Altar Guild and greeter
Special Olympics	Church	Bethel Orchestra
Powderhorn Park Special Olympics Tennis	Grace University Lutheran Church	Boy scouts
	YMCA	Music Lessons
	YMCA	Highland Friendship Club

End of Year 1		
Organizations for people with disabilities	Organizations focus people attend (services/activities)	Community wide organizations
Autism on the Town	St. Richard's Church	WCCO Weather Watcher
St. Paul Adapted Rec	Lakeview Church	Holy Family Friendship Club
ARHMS Work-Coffee Shop	Grace University Lutheran Church	Roller Blading Club
Game class	YMCA	Fast Break Club
Community Ed-Bingo	YMCA	Boy Scouts
	St. Stephen's Lutheran Church	Ladies Coloring Club
		Church Gardening Club
		Out on a Limb Dance
		Church Group
		Cribbage Meetup
		St Paul Community Ed-Cooking classes
		Bethel Orchestra
		Viola Lessons at Hopewell Music School
		Pet Adoption Group

End of Year 2		
Organizations for people with disabilities	Organizations focus people attend (services/activities)	Community wide organizations
Autism on the town	Holy Family Church	Highland Friendship Club
St. Paul Adapted Rec	Lakeview Church	Holy Family Friendship Club
	Grace University Lutheran Church	Gopher Dunkers
	YMCA	Irish Music
	YMCA	Boy Scouts
	St Stephen's Lutheran Church	Ladies Coloring Club
	Bethlehem Baptist church	Meetup
		Cribbage Meetup
		St. Paul Community Ed-Cooking classes
		Bethel Orchestra
		Hopewell Music School
		Lindstrom's Performing Arts
		Neo-catechism

4. Total number of volunteer hours that the Focus Person engaged in per week (Survey Section IX, Pg. 12)

There was a large increase in the total number of hours focus people spent volunteering each week, primarily due to one focus person who was volunteering in three different community places by the end of the project. At baseline focus people volunteered a total of 18 hours per week, Year 1 showed 20 hours per week, and Year 2 was 31 hours per week. Of the 17 participants that completed all three surveys, six reported an increase in the amount of volunteer hours focus people contributed in a week, two reported a decrease, and nine reported no change.

5. Community Social Roles (Survey, p. 12)

Participants were asked if focus people have any other community social roles, such as church greeter, etc. Two participants responded to the question, reporting the focus people have social roles with their church and with Eagle scouts. As listed above in Question 3 regarding membership in community organizations and Question 4 about volunteering, there were other community social roles which focus people experienced.

6. Total number of non-disabled community member friends that participant identified (Survey, p. 13)

Participants were asked to list the number of non-disabled community members they identified as friends of the focus people. Participants reported that the number of non-disabled community member friends stayed the same at baseline to Year 1 and reported a total of 13 friends at each of those times. There was an increase in Year 2 with participants reporting 23 community friends of the focus people.

7. Total number of community friends that had contact with the Focus Person in last 3 months (Survey, p. 16)

The total number of friends the focus person was in contact with in the “last three months” prior to each survey occasion showed a slight increase throughout the project. At baseline, the number of friends reported was 36 times, at Year 1 it was 48 times, and at Year 2 it was 49 times. The majority of contact with these friends was through social media websites sites such as Facebook. It was reported that nine focus people saw an increase in the number of friends they had contact with in the prior three months, 7 saw a decrease, and 1 saw no change.

4. Overall Program Evaluation (N=17) (Mixed Quantitative/Qualitative)

At the end of the intervention phase of the project, at the last meetings with participants, a program evaluation survey was distributed to all the family members attending, as well as the focus people if they were in attendance. Two of these “completion” sessions were held, with a request of participants to attend one of the two scheduled. During the session, summary information was reviewed about the purposes and activities of the project, and what the results to date were. The evaluation survey was handed out at the end of the session, with a total of 17 completed. One participant completed 2 evaluations as they had 2 focus people in the group. One participant was not able to make the final meeting and did not complete an evaluation. The project evaluation included questions about whether the project was valuable, what participants had learned, and what they will pursue in the future.

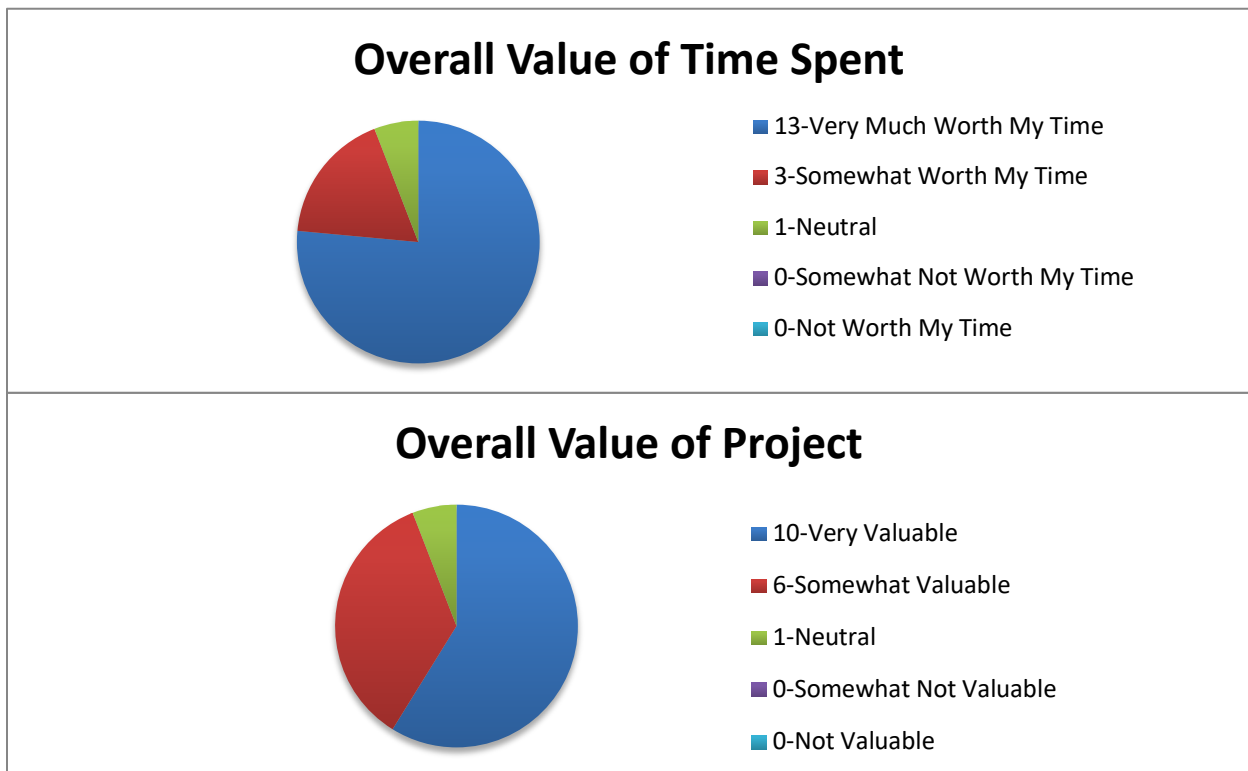
Survey responses are shown below in Table 8 and Figures 5 and 6. In addition to the Likert-type items, six open-ended questions were asked. A list of the responses for each open-ended question is provided in Appendix C. Overall, 59% (10) of participants reported that the project was very valuable, and 94% (16) found it either valuable or very valuable. Seventy-six percent (13) of the participants reported that the project was very much worth their time, with 94% (16) reporting it was either worth or very much worth their time. One parent was neutral on both questions.

Table 8. Results on Project Evaluation Surveys

	N	%
Overall Value of the Project		
Not Valuable	0	0
Somewhat Not Valuable	0	0
Neutral	1	6
Somewhat Valuable	6	35
Very Valuable	10	59
Average	4.53	
Overall Worth of My Time		
Not Worth My Time	0	0
Somewhat Not Worth My Time	0	0
Neutral	1	6
Somewhat Worth My Time	3	18
Very Much Worth My Time	13	76
Average	4.71	

Figure 5. and Figure 6. Project Evaluation Results

In general, as reflected in both the Likert items and the open-ended questions, the participants found the project worthwhile, got many ideas about how to pursue connections, understood that building relationships took time, and ended the project with a commitment to continue to pursue these types of approaches and the ideas that were generated.



V. COMPARISONS TO TRAINING STAFF

Two of the research questions of this project were: (1) whether strategies that were used by staff in residential and day program settings to increase social inclusion, could also be used by family members to increase the social inclusion of their adult children living at home, and (2) how the strategies needed to be adapted if used by families. We

found that the strategies themselves could be used by families without adaptation. However, in addition, as part of the exploratory nature of this project, there was significant information provided about both the similarities and differences between training staff and training family members. There were several similarities revealed, as well as some differences in training the two groups. For future projects involving the training of family members, some of these similarities and differences can be taken into account.

Similarities

There were several issues that arose in training family members that were similar to the challenges, issues and barriers that have arisen in three previous projects of training group home and other agency staff to expand social inclusion that had used a similar intervention design (e.g., an initial training and then follow-up sessions of bimonthly/quarterly meetings over a period of 2-3 years) (Amado, 2010; Amado, 2013; Amado et al., 2015). These issues were:

1. Time

At follow-up meetings both families and staff reported challenges of sufficient time to work on the ideas generated. Frequent reports are “not having enough time,” “we’re so busy” and “we have a lot going on.”

2. The Focus Person’s health

When a focus person with disabilities experiences significant health issues, that becomes the focus for both family and staff.

3. Courage to ask and invite

Both family members and staff experienced challenges in asking and inviting community members to engage with the individual with disabilities. In projects both with families and with staff, follow-up sessions often included encouragement to ask, to ask again, to identify what to ask or how to invite, and practicing what to say in the invitation.

At a follow-up meeting, one mother expressed this discovery about the power and necessity of invitation and the courage it takes. She had extended several invitations and was excited about the positive replies she had received: “I ASKED !!! ... I went out of my comfort zone ...”

4. Asking others for support

Many but not all of the family members indicated that it was a challenge to ask others in their social network, such as other family members or their PCA staff, for ideas about social inclusion or for them to support connections. With group home staff, there is also typically a great range of differences in individual staff’s willingness to ask others, including their own friends or family members; some staff are very willing and others not.

5. Structure helps

Similar to agency staff, several parents acknowledged that the structure of the bimonthly/quarterly follow-up meetings helped them get into action, and that “nothing would have happened without these meetings.” For example, some said they had had similar ideas in the past about how to pursue community connections, but they did not get into action about these ideas except for the project meetings.

Here are some comments made at meetings after family members reported taking actions they had developed at a previous meeting:

“I got (X) done because I was coming to this meeting ... this group does that”

“With the looming deadline of this meeting ...”

“(I had these ideas before but) I wouldn’t do it without these meetings.”

Differences

There were also some significant differences between training family members and training group home staff.

1. Continuation was voluntary

With family members it was voluntary to continue, and easier to cancel or not show up for a scheduled follow-up meeting. With projects with human services agencies and staff, typically the agency director makes the commitment to the project and staff need to continue to participate in the project, whether they are being successful or not. Attendance at meetings is not dependent on a single person, as it was with the family members. Often with group home staff, supervisors also ensure that ideas and actions are being pursued.

We had insufficient information from the families that did not continue in the project about why they did not continue, but it appeared that most of the families that did continue were ones that had sufficient support at home (one exception was one single mother who always brought her son to meetings), were experiencing at least some level of success, or at least appreciated the ideas and support from the group meetings for this arena they considered important.

2. Parental health

The attendance of some family members at follow-up meetings was erratic due to their own health issues. With agency staff, usually there is a group or team of staff participating and meetings can be held even if a particular staff person is sick.

3. Identifying “gifts”

A key part of the approach to social inclusion in this project was the person-centered value of identifying an individual’s “gifts” and talents, what they have to contribute to others. While many parents found their child’s gifts easy to identify, for some of the families, this was a new concept. Some also found it difficult to identify what their child had to contribute to others. With a group of agency staff, usually at least some of the staff can identify gifts of an individual resident.

4. Resource knowledge

Many of the parents that participated in this project were quite knowledgeable about resources and programs and were quite savvy about obtaining services and supports; they had knowledge about many arenas of disability/service programs as well as programs and activities available to the broader community. Those who were more knowledgeable about these resources contributed information and ideas to other participants who did not. (For example, at one larger meeting several parents provided advice and tips to a family member new to the area about how to have the family member with disabilities qualify for PCA services.) One of the key things that many parents reported that they enjoyed about the project was meeting other parents, getting ideas, sharing, and finding out about resources (see comments in Appendix C). When families get together, they talk about many different areas, including

housing, provider agencies, how to find staff, qualifying for services, and transportation. Group home staff in general are not as knowledgeable about other services and disability programs beyond their own agency, although some are quite knowledgeable about community resources and activities.

5. Formal plan goals

Although approximately half the families had some in-home staff at some point during the project, in most cases their support hours were limited. Focus people often had limited or no formal annual support plans beyond a number of service hours; if they did have a plan, there was usually no goal about community inclusion. Group home staff are typically dealing with formal annual support plans and some annual goals about community activities or participation. For the participating parents whose children resided in group homes, it was a revelation to them to find out during the project that they could request formal goals going beyond community activities and that they could ask the group home staff to work on increasing community relationships for their child.

6. Group encouragement

For some individual parents, when an idea for connecting to community members was brought up, a frequent response was a “but” about why the idea wouldn’t work (for example, things had been tried before but not worked; community members would not be open, etc.). With group home staff, even if one of the staff on a team had reasons why something won’t work, usually at least one other team member would be more encouraging. A group of staff usually provide some encouragement to each other. In some cases in this project, follow-up meetings were

attended by only one or two parents, and it was difficult to create a sense of group encouragement. At meetings which more family members attended, the participants gave encouragement to each other in a manner more similar to a group of staff.

7. Types of relationships pursued

Family members were often quite knowledgeable about previous relationships that were important to their child, including friends from school or former staff. Connecting with old friends was a very successful strategy in many cases. This is in contrast with group home staff, who often do not have that knowledge of former relationships. Even when residential agency staff find out that information from family members, they do not have the same connection as mothers do, in asking old friends to come visit or to reconnect.

VI. SUMMARY OF FINDINGS – RESEARCH QUESTIONS

Findings regarding the six research questions are summarized in this section.

1. Compared to previous studies of social inclusion enhancement strategies used by direct support professionals in residential settings, how effective are these interventions when used by families for adults and transition-age youth with IDD living with their families?

Overall, as an exploratory study, we found that the strategies could be effectively used by the families participating. However, the number of families participating was insufficiently large or diverse, to provide adequate information about what strategies could be used by different types of families, or to determine what were the salient characteristics of families that could successfully use different strategies. As noted

above, the approach of supporting individual relationships and connections through re-connecting with former friends and former staff was a more effective strategy for family members than evidenced in the projects with direct support staff.

2. What, if any, differences exist with respect to the impact of studied strategies on the social inclusion of adults and transition-age youth with IDD living with families when they are used by families that have paid in-home support versus those without paid in-home support? To what extent do these strategies differ for families that have in-home support versus those who do not? In what manner, if any, does staff support or a lack thereof have an effect on levels of social inclusion? What factors contribute to success, in each treatment condition?

Only one family of the 8 that had in-home staff at the beginning of the project utilized a staff member during the project to support social inclusion; this family had the most weekly and daily hours of in-home support among all the project families and their staff person was already used to going many places in the community with that focus person. The remaining families that did have staff had far fewer weekly hours of in-home support and primarily used their staff hours for respite purposes, to provide care in the home while the family members did other things. On the initial surveys, the roles of in-home staff had been characterized as respite, caretaker, direct support worker, PCA (personal care attendant), and ILS worker (independent living services). Almost all the families that did have in-home support faced staff turnover during the 30 months or so of project activity and spoke about finding it challenging to find staff; for several families, whether they had staff or not varied greatly during

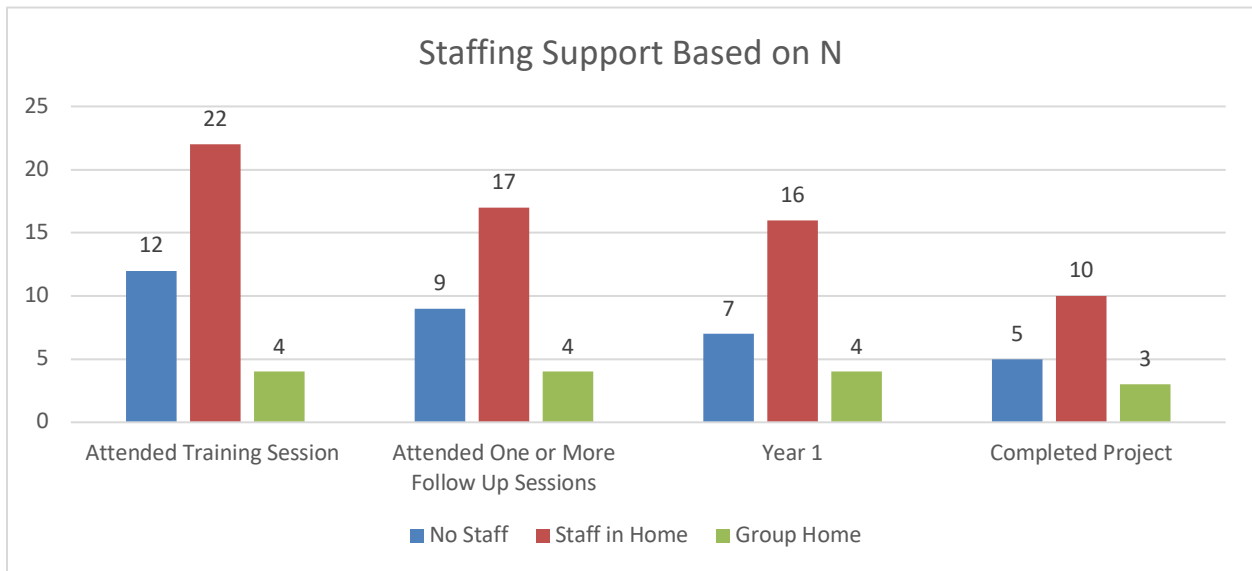
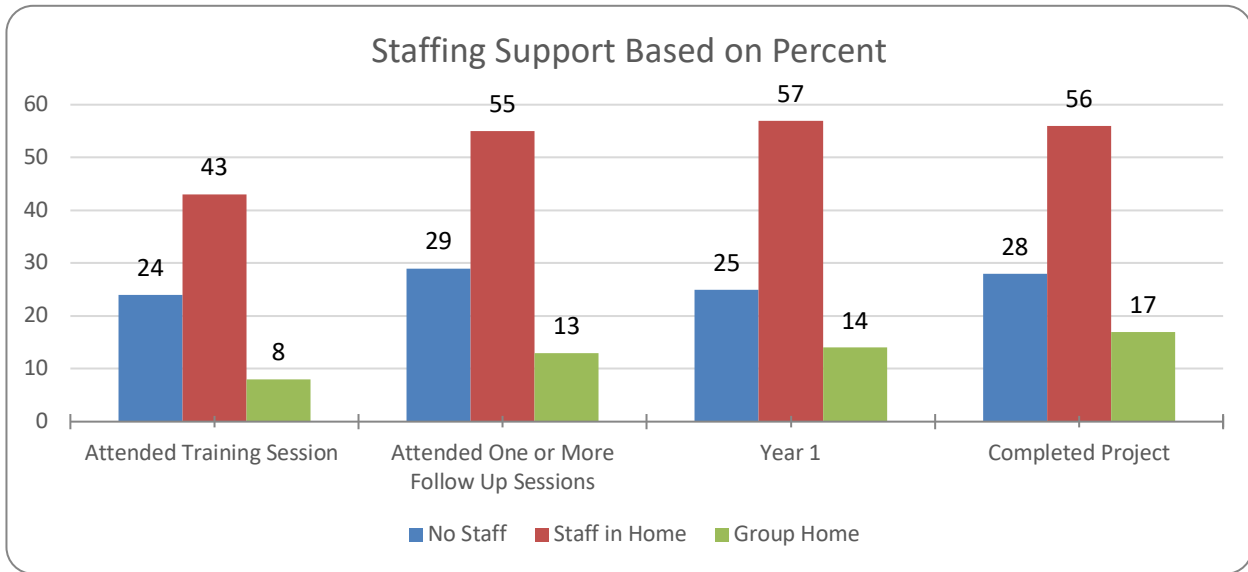
the course of the project. Table 9 and Figure 7 show the families that did or did not have in-home staff in the different phases of project activity.

Two families that started the project had their child living in a group home. It was a revelation to them that they could ask the group home staff to support social inclusion. A third family had their child move into a group home during the course of the project and ensured that group home staff knew that social inclusion was an expectation. This family also wrote an announcement for their church bulletin that their daughter had a new home and invited church members who knew her to visit her in her new home.

TABLE 9: Number of Focus People who Received Staff Support (in Families Participating in Any Project Activity)

Attended Training Session	N=51	%
Baseline Surveys Completed	38	75
No Staff in Home	12	24
Staff in Home	22	43
Lives in Group Home	4	8
Attended One or More Follow Up Sessions	N=31	%
Baseline Survey Completed	30	97
No Staff in Home	9	29
Staff in Home	17	55
Lives in Group Home	4	13
End of Year 1	N=28	%
Baseline Survey Completed	27	96
No Staff in Home	7	25
Staff in Home	16	57
Lives in Group Home	4	14
Completed Project (at end of project)	N=18	%
Baseline Surveys Completed	18	100
No Staff in Home	5	28
Staff in Home	10	56
Lives in Group Home	3	17

FIGURE 7: Focus People/Families Receiving Staff Support (Families Participating in Any Project Activity)



3. How, if at all, do social inclusion strategies need to be adapted to meet the unique needs of families? How can these strategies be effectively used as students transition out of school?

There was insufficient diversity in the number of families participating to determine specific adaptations that might be needed to the strategies. Overall, the strategies were used as they had been by staff. As students were transitioning out of school, there were school friends identified who could continue their relationships after graduation. In some cases where the young person had already completed school, some families were successful in reconnecting the focus person with old school friends. For these families, the strategy regarding one-to-one relationships was a key one.

In terms of comparing strategies for transition-age youth versus strategies for older adults, the closer the focus person was to having transitioned out of school, the easier it was for the mother to identify former school friends with whom the focus person could connect. If the focus person was still in school, there were some friends that could be identified which the focus person would want to continue seeing after graduation.

4. What are the challenges and benefits, beyond enhanced social inclusion, experienced by individuals and families that use social inclusion enhancement strategies?

Challenges have been described in the previous section on comparisons between training staff and training families (i.e., time, health issues of focus person or family member, courage to ask or invite, asking others for support).

In terms of benefits, for a few families, there were benefits gained of new perspectives regarding what was possible for their children. One mother of a child who had a more severe level of disability found it eye-opening to see that her child could have friends in her life, who were not family members or others with disabilities -- she had never thought that before. During the initial training when the topic of “gifts” came up, another mother expressed that she had never thought of her son as having “gifts” to contribute to others.

A significant benefit was the discovery by some parents that community members were more than willing to befriend their children. Examples of these types of discoveries include:

- One mother reported, *“I have friends who say, “nice to meet you, nice to have a new friend – when are you guys coming again?”*
- One son wanted to get to know friends of his father more. The dad asked his friends and was surprised by the positive responses he received; one of his friends said they were *“humbled and honored”* that the dad had asked him to be supportive of his son.
- One potential friend, when asked, said, *“I would love to spend time with her.”*

5. To what extent do family characteristics (e.g., single parent, age of parent, etc.) impact the effectiveness of social inclusion interventions?

Family member characteristics which were able to be examined included whether parents were married, the level of income, parental education and profession. Three of the 17 parents were not married, and one of those 3 had a

partner. As noted above, the levels of income and education were higher than the average population. In general, it appeared that most of the families that were able to participate in the project until project end were those in which there was sufficient family support at home, sufficient knowledge of the support system to have in-home staff support, and/or sufficient stability in the family situation to “afford” the time to participate in project activities.

As noted above in the Recruitment section, many of the families who were interested in the project but did not participate did not have sufficient home support to be able to attend an information meeting. Of those who came to an initial information meeting, several expressed that they had insufficient support at home to be able to participate in project meetings. Many of these families were probably the most in need of support for social inclusion for their adult children; a different project design not based on family effort would probably be very beneficial.

6. To what extent, if any, do personal characteristics of the focus person (e.g., age, level of IDD) influence the effectiveness of social inclusion strategies?

The strategies were able to be used by families of children who had both mild and more severe levels of disability, as well as those who were younger or older. There was an insufficient number of participants to conduct more extensive analysis of the influence of personal characteristics on the effectiveness of different strategies.

VII. DISCUSSION

This project was exploratory research about supporting families in how to expand social inclusion for their adult child who was living at home. There were several successful outcomes as well as some challenges.

Successful outcomes included the finding that these strategies can definitely be used by some families to increase the social inclusion of their adult child. In terms of comparison to social inclusion projects with agency staff, family members were much more able to identify particular community members with whom to connect their child, such as former school friends and former staff. Staff do not typically know of such past relationships; an effective avenue for staff pursuing more social inclusion may be to research such relationships with people they support or their families.

Secondly, the study found that strategies can definitely work whether the child has a mild or more severe degree of disability. Third, many families discovered the openness and willingness of community members to include and befriend their children. Lastly, the project affected some family members seeing the gifts their children have, and what types of relationships might be possible now and in the future. For example, one mother of a child who had a more severe level of disability found it eye-opening to see that her child could have friends in her life who were not family members or others with disabilities -- she had never thought that before. Another expressed, “(This project has) shaped a perspective going forward – what I am thinking long term for her. It’s been valuable.”

Challenges

Besides the challenges of connecting individuals with disabilities and other community members in meaningful relationships, there were three principal challenges that arose in this exploratory project. These were challenges of measuring and tracking social relationships, family recruitment, and type of project structure.

A. Challenges of Measurement

One of the main difficulties in characterizing the outcomes in this project is due to the challenges regarding measurement of the quantity and quality of social relationships. Amado and colleagues (Amado, Stancliffe, McCarron & McCallion, 2013) summarized various frameworks that have been proposed in different studies to characterize integration, inclusion, participation, and relationships and that the lack of consistency in measurement in social inclusion research is one of its main challenges.

For example, Conroy, Fullerton and Brown (2002) had proposed assessing integration based on three factors of frequency, choice, and intensity. Assessing these three different factors requires different forms of measurement: determining the frequency with which someone sees another person, is it their choice, and how “deep” do the people in the relationship consider their connection? While frequency is the easiest to measure of these three factors, it needs a sufficiently rigorous tracking system to be accurate, as opposed to relying on a respondent’s memory of how many times in a month they saw or talked with someone, or how long they were on the phone or meeting with them. Determining choice and quantifying depth of relationship are even more challenging.

In this project, there were four particular challenges with measuring relationships, due to the types of instruments used. Some of these challenges came to light in narrative comments as family members were filling out the Relationship Eco-Map and the Participant Social Integration Survey:

1. Who gets counted as a “friend”?

The families made comments while they were filling out the Map and the Survey about the uncertainty of who to consider a “friend.” What qualifies as “friend” is different to different people, and there is no set standard. As parents and family members were filling out the forms, a typical question was “Should I count (X person) as a friend?”

2. Do frequency and type of contact matter?

Should they count a Facebook friend as a “friend”? What if the participant sees the person only once or twice a year – do they still count as a “friend”?

3. Latency of reporting

We asked for the Relationship Eco-Map and Participant Social Integration Survey to be filled out once a year. Sometimes there had been information reported at face-to-face sessions earlier in that year, that was not reported on the surveys at the end of the year.

4. Different data sources - the same information in different formats

Having different sources for data collection was important but also presented some problems. For example, after filling out the Relationship Eco-Map at a meeting, some families did not feel it necessary to repeat the same information on similar questions on the Participant Social Integration Survey. Information that

was reported verbally at a face-to-face follow-up meeting was frequently not recorded on the Participant Social Integration Survey or Relationship Eco-Map. The qualitative narrative data gathered at meeting sessions frequently did not match the quantitative data reflected on the Survey or the Map. For example, 23 community friends were reflected on the Surveys, and 31 were reported at the follow-up meetings. There was a total of 73 friends recorded on the Eco-maps, but this number may have included friends with disabilities. Clearly, multiple and different forms of measurement provide a richer picture of a given individual's social network and can provide more avenues to explore the quantity, quality and types of their relationships.

B. Family Recruitment

For other projects or researchers who wish to conduct research with families of individuals with disabilities, this project revealed several elements to consider. The biggest issue was the family's perception of their capacity to be involved in project activities. Probably some families that could have significantly benefitted did not have the time or resources to participate, such as sufficient support at home. It was also important to schedule meetings for the convenience of the families' participation. In this project, what made a difference was convenience for both the meeting time (weekday evenings, as opposed to weekends) and the variety of meeting locations (in different geographic areas in the greater metropolitan area close to participants' home or work, such as meeting rooms in libraries and coffee shops).

C. Project Structure

While the project structure was not in itself a challenge, the type of structure affected the results as well as the accuracy of reported results. For example, the follow-up sessions after each initial training session occurred two to three months apart. While this gave parents and family members some time to implement the ideas they had developed at a meeting, there may have been more outcomes, for example, if family members had been contacted weekly to support them in taking actions and seeing what progress they had made. It's possible that different outcomes may have resulted if meetings had been held in family homes with the whole family. Families were asked to complete the Relationship Eco-Map and Participant Social Integration Survey at the end of 12 months without referencing what they had written on these instruments the previous year. In the future, different project structures would likely result in different types of reported outcomes.

VIII. IMPLICATIONS FOR THE FUTURE

There is a definite need for programs regarding families supporting increased social inclusion of their adult children, and a need for different types of programs. Parents expressed that their biggest desire was a friend who would reach out to their son or daughter - for example, to schedule getting together. A frequent concern was finding someone to drive the son/daughter to different community places. Many families were interested in increasing social relationships for their child, but wanted different structures, such as friendship groups or other personnel doing the integration work as opposed to themselves.

The challenge of measurement in social inclusion projects needs to continue to be addressed in future projects. While setting a measurement standard may be helpful, some approaches are more time-consuming for participants. For example, Newton and Horner (1993) used 15-minute blocks of time for visits or phone calls, to determine increases in group home residents' contacts with community members; however, this type of recording required rigorous training of staff that family members would probably not undertake. It would be helpful to standardize some types of data collection systems, across studies, to determine what types of approaches are most helpful. Multiple types and approaches to collect data also provide more in-depth and better information.

There is a need for research to identify what types of families need what type of support, and how to best support families through ups and downs of social inclusion efforts. In addition, any endeavors in this arena require long-term, more extended, or perhaps more intense support to assist relationships to move beyond physical presence

and acquaintance to deeper friendships and relationships between individuals with disabilities and community members.

REFERENCES

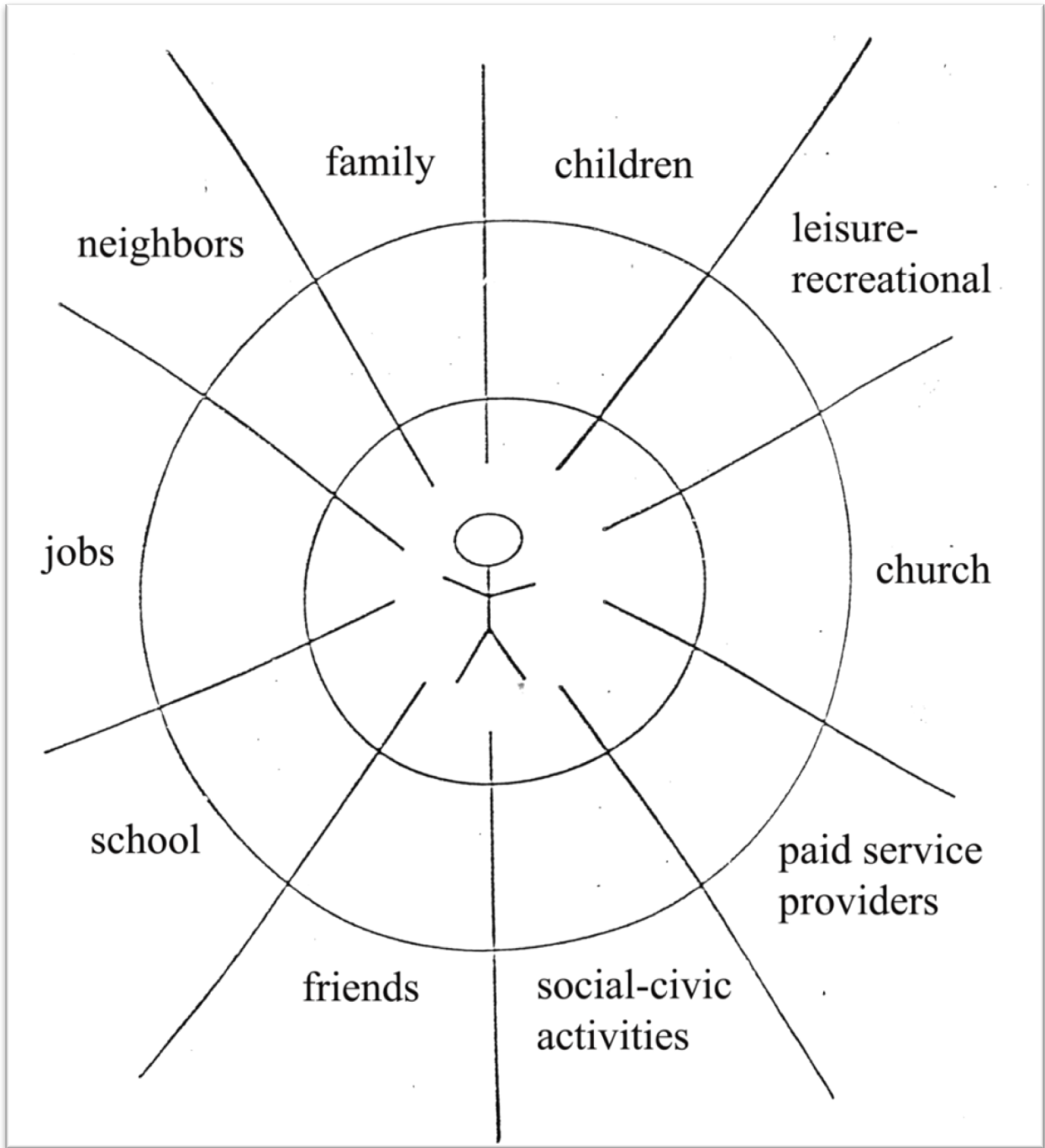
- Abery, B., & Fahnestock, M. (1994). Enhancing the social inclusion of persons with developmental disabilities. In M. Hayden & B. Abery (Eds.). *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities* (pp. 345-380). Baltimore: Paul H. Brookes.
- Amado, A.N. (2010) *Agency Factors and Structures which Increase Successful Outcomes in Community Participation and Socially Valued Roles*. Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Amado, A.N. (2012) Impacting Social Relationships between Adults with Intellectual/Developmental Disabilities and Community Members. Presentation at the conference of the International Association for the Scientific Study of Intellectual Disability, Halifax, July 2012.
- Amado, A.N. (2013) *Friends: Connecting people with disabilities and community members*. Minneapolis, MN: Research and Training Center on Community Living.
- Amado, A.N., & Lakin, K.C. (2006). Contribution and community life: Fostering social relationships, community participation and full inclusion. In S. Pueschel (Ed.), *Adults with Down Syndrome*, (pp. 201-224). Baltimore, MD: Paul H. Brookes.
- Amado, A.N., Stancliffe, R.J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, 51, 360-375.
<http://dx.doi.org/10.1352/1934-9556-51.5.360>.

- Amado, A.N., Wesely, E., Stancliffe, R., & O'Donnell, K. (2015) *Promoting relationships with community members: What are the best strategies?* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, August.
- Cacioppo, J. (2014) Rewarding social connections promote successful aging. Reported by *The Guardian* online newspaper.
<http://www.theguardian.com/commentisfree/2014/feb/17/loneliness-report-bigger-killer-obesity-lonely-people>
- Carlson, C. (2000) *Involving All Neighbors: Building Inclusive Communities in Seattle*. Seattle, WA: Department of Neighborhoods.
- Carter, E. W. (2007). *Including people with disabilities in faith communities: A guide for service providers, families, and congregation*. Baltimore: Brookes.
- Cole, C. M., Waldron, N., & Majd, M. (April 2004). Academic progress of students across inclusive and traditional settings. *Mental Retardation*, 42(2), 136-144.
- Conroy, J. W., Fullerton, A., & Brown, M. (2002, June). *Final Outcomes of the 3 Year California Quality Tracking Project*. Report Number 6 of the Quality Tracking Project for People with Developmental Disabilities Moving from Developmental Centers into the Community. Narberth, PA: Center for Outcome Analysis.
- Hafen, B., Karren, K., Frandsen, K. & Smith, N.L. (1996) *Mind/Body Health: The effects of attitudes, emotions and relationships*. Boston: Allyn & Bacon.

- Krauss, M. W., Seltzer, M. M., & Goodman, S. (1992). Social support networks for adults with retardation who live at home. *American Journal on Mental Retardation*, *96*(4), 432-441.
- Kroenke, C.H., Kubzansky, L.D., Schernhammer, E.S., Holmes, M.D., & Kawachi, I. (2006) Social networks, social support and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, <http://jco.ascopubs.org/content/24/7/1105.full>
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- McVilly, K.R.; Stancliffe, R.J.; Parmenter, T.R.; Burton-Smith, R.M. (2006) “I get by with a little help from my friends”: Adults with intellectual disability discuss loneliness. *Journal of Applied Research in Intellectual Disabilities*, *19*, 191–203, doi:10.1111/j.1468-3148.2005.00261.x.
- Mount, B., Ducharme, G., & Beeman, P. (1991) *Person-Centered Development: A Journey in Learning to Listen to People with Disabilities*. Manchester, CT: Communitas, Inc.
- Newton, J.S. & Horner, R.H. (1993) Using a social guide to improve social relationships of people with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, *18*, 36-45.

- Rempel, G.T., Neufeld, A., & Kushner, K.E. (2007) Interactive use of genograms and ecomaps in family caregiving research. *Journal of Family Nursing*, 13(4), 403-19, November. Doi: 10.1177/1074840707307917.
- Rossetti, Z. S. (2011). "That's how we do it": Friendship work between high school students with and without autism or developmental disability. *Research & Practice for Persons with Severe Disabilities*, 36(1-2), 23-33. doi: 10.2511/rpsd.36.1-2.23
- Stancliffe, R.J., Wilson, N.J., Gambin, N., Bigby, C. & Balandin, S. (2013) *Transition to retirement: A Guide to Inclusive Practice*. Sydney: Sydney University Press.
- Stancliffe, R., Harman, A., Toogood, S. & McVilly, K. (2007) Australian implementation and evaluation of active support. *Journal of Applied Research in Intellectual Disability*, 20(3), 211-227.
- Verdonschot, M. M. L., deWitte, L. P., Reichraft, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303–318. doi: 10.1111/j.1365-2788.2008.01144.x

APPENDIX A: RELATIONSHIP MAP



APPENDIX B: FOCUS PERSON SOCIAL INTEGRATION SURVEY

For Office Use Only	
Participant ID # _____	Group # _____
Residence ID # _____	Category # _____
Service Type _____	Survey Year _____

Participant Physical & Social Integration Survey

“Participant” in this survey refers to the family member who has a disability, who is the focus of the project.

Participant’s Name: _____

Participant’s Address: _____

Who answered this survey? _____ Date _____

____ 1. Participant

____ 2. Participant with help from another person/other people

Who helped? _____
Relationship? _____

_____ How long known? _____

Who helped? _____
Relationship? _____

_____ How long known? _____

____ 3. Another person on behalf of the participant

Who? _____
Relationship? _____

_____ How long known? _____

II. DESCRIPTIVE INFORMATION

Please indicate the participant's:

1. Age in years: _____

2. Sex (mark one):

- 1. Male
- 2. Female
- 8. Don't know

3. Race (mark one):

- 1. White
- 2. Black
- 3. Oriental/Asian/Pacific Islander
- 4. American Indian/Alaskan Native
- 5. Other/Unknown: _____
- 8. Unknown

4. Hispanic Origin (mark one):

- 1. Hispanic
- 2. Not Hispanic
- 8. Don't know

5. Diagnosis of intellectual/developmental disabilities? (mark one):

- 1. No such diagnosis
- 2. Mild (IQ 52-70) intellectual disability
- 3. Moderate (IQ 36-51) intellectual disability
- 4. Severe (IQ 20-35) intellectual disability
- 5. Profound (IQ under 21) intellectual disability
- 6. Intellectual disability, but unknown level
- 8. Don't know

6. Diagnosis of Epilepsy/seizures? (mark one):

- 1. Does not have epilepsy
- 2. Has epilepsy, but no active seizures
- 3. Has epilepsy but experiences less than 12 seizures per year (1/month or fewer)
- 4. Has epilepsy with seizures more than one time per month, but less than weekly
- 5. Has epilepsy with seizures weekly or more often
- 8. Don't know

7. Other diagnoses/disabilities? (mark all that apply):

- 1. Autism
- 2. Cerebral palsy
- 3. Deaf or hearing impairment (describe: _____)
- 4. Blind or vision impairment (describe: _____)
- 5. Formal social/behavioral diagnosis (describe: _____)
- 6. Mental health diagnosis (describe: _____)
- 7. Other (please specify): _____
- 8. Don't know

8. Physical health problems/diagnoses (mark all that apply):

- 1. Health problems requiring regular medical care:

- 2. Health problems requiring special medical procedures or treatment by the family and/or direct support provider:

- 3. Health problems limiting daily and/or community/social activities (please describe limitations, activities affected, and adaptations/modifications needed):

- 8. Don't know

8. Mobility (mark one for *both* home and in the community):

	At Home	In the Community	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1. Walks without difficulty
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2. Walks, but sometimes needs help on stairs, etc.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3. Walks with assistive devices (cane, walker, etc.)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4. Propels own wheelchair or scooter (manual or electric)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5. Must be pushed in wheelchair
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8. Don't know

9. Use of adaptive equipment or aids (mark one):

- 1. No adaptive equipment is needed for this person
- 2. Yes, this person uses adaptive equipment (mark all that apply):
 - a. Hearing aid
 - b. Eyeglasses/contacts
 - c. Walker/cane
 - d. Manual wheelchair
 - e. Electric wheelchair or scooter

 - f. Adaptive eating utensils
 - g. Adaptive grooming supplies

- h. Communication board/picture symbols
 - i. Synthesized speech device/other electronic communication device
 - j. Computer to accommodate writing, communicating, etc.
 - k. Other: _____
 - l. Other: _____
8. Don't know if adaptive equipment is needed

11. Modifications to the individual's current home (mark one):

1. Modifications which have been made (please specify):
- _____
- _____
- _____
2. No modifications have been needed for this person
8. Don't know

III. ACCESSIBILITY TO COMMUNITY

1. What types of transportation does the participant use most frequently for leisure activities? *(Indicate "1" for the most often used method and "2" for the next most often used method)*

- Walking (may include using an assistive device, manual or electric wheelchair or scooter)
- Public bus
- Family vehicle
- Agency or staff vehicle
- Private/Professional transportation agency (e.g. KARE Cabs, Metro Mobility)
- Taxicab
- Other (specify): _____

2. If using public transportation or a private transportation agency the individual: *(Please check even if the person does not currently use public transportation)* (mark one):

- 1. Can use transportation independently
- 2. Requires or would require only oral/verbal assistance or reminders
- 3. Requires or would require physical assistance with some aspects of the skill
- 4. Requires or would require physical assistance with most or all aspects of the skill
- 8. Don't know

IV. LANGUAGE AND COMMUNICATION SKILLS

Please indicate the language and communication skills that this individual uses to communicate with other people.

1. This participant communicates with others by (mark *all* that apply):

- 1. Talking
- 2. Using formal sign language
- 3. Using a symbol system (points to pictures or symbols such as Bliss symbols on a symbol board)
- 4. Using synthesized speech system (e.g., electronic speech generating device)
- 5. Making sounds or gestures/pointing/nodding head
- 6. May cry or smile, but otherwise unable to communicate
- 7. Other: _____
- 8. Don't know

2. When talking or signing the individual is (mark one):

- 1. Easily understood by the average person
- 2. Somewhat difficult for the average person to understand (can usually be understood, but has difficulty with some words or symbols)
- 3. Hard for the average person to understand (can be understood only with difficulty, usually cannot be understood well by a stranger)
- 4. Does not talk or sign
- 8. Don't know

3. The individual (mark one):

- 1. Understands most normal conversation and/or signing
- 2. Understands simple requests, directives, questions
- 3. Has problems understanding even simple sentences
- 4. May turn toward speaker; doesn't seem to understand
- 8. Don't know

4. When using the telephone to contact other family members (outside the home) or friends, the individual:

- 1. makes calls by himself/herself (including programmed dialing)
- 2. makes calls with staff assistance only
- 3. Does not initiate calls, but family or friends may call
- 4. Does not contact family or friends at all using the phone
- 5. Other: please describe: _____

4a. In a typical month, what is the total number of times the person contacts family members (who live outside the home) or friends by phone?

5. The person uses a computer, iPad and/or email to contact family members outside the home or friends:

Yes – independently _____ (how frequently?) _____
Yes – with help _____ (how frequently?) _____
No _____

V. CHALLENGING BEHAVIOR

Please indicate which challenging behaviors are exhibited by the participant and provide requested information for each.

1. Purposely hurts self: (hits, bites, scratches self, bangs head, etc.)

___ 1. Yes ___ 2. No ___ 8. Don't know

a. If yes, please describe the primary problem(s): _____

b. How serious is this behavior right now (mark one):

- ___ 1. Not serious; not a problem
___ 2. Slightly serious; a mild problem
___ 3. Moderately serious; a moderate problem
___ 4. Very serious; a severe problem
___ 8. Don't know

2. Purposely hurts other people: (hits, bites, scratches, pulls hair, verbal aggression, etc.)

___ 1. Yes ___ 2. No ___ 8. Don't know

a. If yes, please describe the primary problem(s): _____

b. How serious is this behavior right now (mark one):

- ___ 1. Not serious; not a problem
___ 2. Slightly serious; a mild problem
___ 3. Moderately serious, a moderate problem
___ 4. Very serious; a severe problem
___ 8. Don't know

3. Purposely destroys property: (breaks windows, furniture, tears things up, etc.)

___ 1. Yes ___ 2. No ___ 8. Don't know

a. If yes, please describe the primary problem(s): _____

b. How serious is this behavior right now (mark one):

- 1. Not serious; not a problem
- 2. Slightly serious; a mild problem
- 3. Moderately serious; a moderate problem
- 4. Very serious, a severe problem
- 8. Don't know

4. Purposely breaks law: (steals, commits sex offenses, drug use, etc.)

1. Yes 2. No 8. Don't know

a. If yes, please describe the primary problem(s): _____

b. How serious is the behavior right now (mark one):

- 1. Not serious; not a problem
- 2. Slightly serious; a mild problem
- 3. Moderately serious; a moderate problem
- 4. Very serious, a severe problem
- 8. Don't know

5. Describe any other problem behavior the participant exhibits. Please include if the person is socially withdrawn. (If none, write "none")

Indicate the severity of other problem behavior the participant exhibits (mark one):

- 1. No other problem behavior
- 2. Not serious; not a problem
- 3. Slightly serious; a mild problem
- 4. Moderately serious; a moderate problem
- 5. Very serious, a severe problem
- 8. Don't know

VI. CURRENT DAY-TIME OR EMPLOYMENT ARRANGEMENT

1. Is the participant in school? Yes _____ No _____

a. If yes, what year of school? _____

b. What program? _____

2. Is the person in a transition program? Yes _____ No _____
- a. If yes, for how many more years? _____
- b. What program? _____
3. Is the participant in supported, competitive employment, or a day program?
1. ___ no
 2. ___ supported employment (how many hours a week?) _____
 3. ___ competitive employment (how many hours a week?) _____
 4. ___ day program
 5. ___ sheltered workshop
 6. ___ other
- a. What type of job do they have? _____

VII. CURRENT LIVING ARRANGEMENTS

1. The participant currently lives in a home: (check one):
- ___ 1. Owned or rented by his/her parents or relatives
 - ___ 2. Owns their own home
 - ___ 3. Rents their own apartment, etc.
 - ___ 4. Home or apartment owned or rented by a non-related *individual* or *family* that provides services to the participant
 - ___ 5. Owned or rented by an *agency* that provides services
 - ___ 6. Owned or rented by someone else: _____
 - ___ 8. Don't know
2. **Excluding the participant**, do any other persons with developmental or other disabilities live in the home ?
- Yes _____ If so, how many ? _____
- No _____
3. **Other than the participant**, how many people are present in the home on a typical evening (4pm-10pm)?
(enter a number for each applicable category):
- ___ 1. This resident's natural or adoptive family members (including spouse)
 - ___ 4. Foster family members (the foster family owns or rents the home)
 - ___ 5. Support providers who have another home (i.e. paid to be there/provide care)
 - ___ 6. Other(s): _____
 - ___ 8. Don't know
- a. Are there any paid support staff supporting the participant in their living situation?
- Yes _____ No _____

If yes, how many? _____

What is their role:

- a. PCA _____
- b. In home respite _____
- c. Other _____

b. How many hours a week does each staff person work?

c. What is their schedule during a typical week?

7. How far away are the following community resources or activities (if more than one choose the one that the person uses most often)?

Grocery store

_____ Miles OR _____ Minute drive

Movie theatre

_____ Miles OR _____ Minute drive

Restaurant

_____ Miles OR _____ Minute drive

Sports facility (gym, pool, etc.)

_____ Miles OR _____ Minute drive

VIII. COMMUNITY ACTIVITIES

In an average month, how many times does the person go to:

		Who do they go with? (enter # of times in the month for each category of companion and how many people go with)						
	Number of Times in an Average Month	By Them selves	With Staff	With (non-paid) Family Member	With Paid Family Member	With Another Community Member	With Other	What community members do they interact with there?
Restaurant								
Grocery Shopping								
Other Shopping								
Movies								
Church/Synagogue								
On a walk								
Visit family members								
Other regular Community places Visited								
Other _____								
Other _____								

On average:

**Number of
Times a week or Times a month**

How many times is the participant scheduled to participate in community activities with paid staff (outside of day program, jobs, etc.):

During the week

On weekends

For this participant, how many times do the scheduled activities actually occur?

During the week

On weekends

How many times do other people with disabilities (other than family) come to the home and visit this participant

During the week

On weekends

How many times do community members (other than family) come to the home and visit this participant

During the week

On weekends

IX. CONNECTIONS AND RELATIONSHIPS

1. What community organizations or groups does the person belong to?
 (For this question, we are asking about groups that are not specifically for people with disabilities)

For each organization or group, please list:

NAME OF GROUP/ ORGANIZATION	NATURE OF THE PERSON'S PARTICIPATION (e.g., attend monthly meetings, etc.)

2. Does the person volunteer anywhere (either through the transition or day program, family, etc.)?

Yes _____ No _____

If yes, for each place please list:

VOLUNTEER SITE	FREQUENCY	VOLUNTEER ACTIVITIES

d. Does the person have any other community social roles, such as church greeter, etc.

Yes ____ No ____

If yes, please describe:

Please list the person's friends

Name (First Name & Last Initial)	<input type="checkbox"/> Family Member/relative <input type="checkbox"/> Peer (other person with disabilities) <input type="checkbox"/> Non-disabled community member <input type="checkbox"/> Staff <input type="checkbox"/> Former Staff <input type="checkbox"/> Family member of current staff <input type="checkbox"/> Other (Please describe):	Where did they meet?	Frequency of Contact	When they get together, what do they typically do?
1.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
2.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
3.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
4.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
5.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
6.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
7.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
8.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
9.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
10.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
11.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
12.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
13.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
14.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
15.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			

What ISP or Program Goals does the person have regarding community activities, connections, and/ or relationships. Please list the person's current goals in these areas:

1. _____

2. _____

3. _____

4. _____

5. _____

X. SOCIAL NETWORK

Part A: Family

Outside of any family members who live in the home with the participant:

IN THE PAST 3 MONTHS, has the person been in contact with any other member of his/her family? (circle one) **Yes / No**

If there has been contact with a family in the past member 3 q3months, with whom has this contact been?

Family Member	No. of Contacts In The Past 3 Months	Average Duration Of Each Contact (Hours)	Was Contact Initiated / Requested By The: P = Person F = Family O = Other	Was Contact F = Face-to-face T = Telephone W = Written O = Other	Where Did Contact Take Place? What Activities Did They Do Together? Comments.
TOTALS					

If **No**, was there any attempt to contact any other member of their family? **Yes / No**

If there was an attempt at contact but this did not occur, briefly say why the contact did not occur?

Part B: Friends

Does the person have any friends that are not a family member/staff member? **Yes / No**

IN THE PAST 3 MONTHS, has the person been in contact with any of these friends (again, not a family member or staff member)? **Yes / No**

If there has been contact with a friend in the past 3 months, with whom has this contact been?

Gender / Approx. Age e.g., F/28	Does the Friend Have A Disability: Yes / No?	How Do They Know This Person?	No. of Contacts In The Past 3 Months	Average Duration Of Each Contact (Hours)	Was Contact Initiated / Requested By The: P = Person F = Friend O = Other	Was Contact F = Face-to- face T = Telephone W = Written O = Other	Where Did Contact Take Place? What Activities Did They Do Together? Comments.
TOTALS							

If **No**, was there any attempt to contact any person considered to be 'a friend' (not a family member or staff member)? **Yes / No**

If there was an attempt at contact a friend but this did not occur, briefly say why the contact did not occur? _____

**APPENDIX C: EVALUATION OF OVERALL PROJECT –
SPECIFIC RESPONSES**

These were the responses to the six open-ended questions of the project evaluation.

The first responses in each section were from a focus person, and the remaining were from the family members.

The most valuable part of the project was:

- Good friends; Accessibility; Getting my Dad to play cribbage too (*note: from a focus person who joined a cribbage group with her dad as part of the project*)
- New ideas for ways to meet and make friends, the different levels of friends, family, colleagues. Getting to know about the Holy Family Friendship club.
- Getting a variety of suggestions from other parents, Angela & Arc Staff on ways to help my son make more social interactions
- Brainstorming ideas for connections and hearing what worked/did not work for other families
- Thinking about ways to get engaged in the community, talking with other parents about things they have tried, brainstorming with the project director - in essence, putting the time into coming up with ideas
- Getting ideas of different people to talk with about being community members and ideas to try for volunteering
- My son liked Caribou "Branch off my ideas"; mom liked meeting other parents, listening to their perspective (*note added: Caribou is a local coffee-shop chain, their meeting rooms were used for several follow-up meetings*)

- Meeting other families and connecting with activity that my son could participate in the community.
- Discussions with other families, hearing their ideas; I really enjoyed seeing the results of the project
- Ideas! The input of Angela, the ARC volunteers and the other parents was invaluable, a concentration of resources which I couldn't have gotten anywhere else
- Ideas; Ideas for who to get my sons involved in activities and friendships
- Hearing other's Ideas-Required updates to encourage us to keep making progress- my daughter attending updates to hear other's stories and share hers.
- Learning resources to get out and socialize. Meeting other parents and hearing their stories. Being kept on track to follow through with ideas that were generated at the meetings. Meeting Angela- appreciate her knowledge and creative thinking
- Getting me to think about how to get my child more involved with non-family members and non-caregivers
- Making me think and consider "what else" there might be for my son to do. Also, how lucky we are that he has built a few activities over time.
- A change of attitude about what is possible in the realm of friendship for my daughter

The least valuable part of the project was:

- Nothing
- Not sure
- I really can't think of anything which I thought wasn't valuable. The information was concrete, specific, and thus valuable, and the moral support and sharing was just as valuable in keeping me optimistic about our options.

- I think it must have been of value because I kept coming. There were times I felt like I didn't want to come yet I did. It was most difficult when I encountered people who seemed unable to think about any options to move into the new activities
- One regret is that I didn't have the group home supervisor come. A previous one was invited but didn't come then there was turnover.
- When certain participants (i.e. parents) dominated the conversation
- For some of us, our child has difficulty making/maintaining friendships with disabled peers and disabled community as well as those in typically abled community settings. For me, friendships of any kind would be beneficial to my son so focusing only on the larger community was somewhat narrow
- TYZE started out good and became very non-user friendly
- Forms do not record data, friends, map - challenging to remember prior data, changes, etc.
- The time. People not feeling comfortable yet of exposing their loved one with disabilities. Family being afraid to ask
- Too many meetings at the start of the project
- Evenings can be tough with my busy schedule-coordinating with or missing other activities
- Lack of my time. My ability to put them into practice. The past couple of years have been extremely busy for my husband and me and distracted us from our goal. This should end in the next year or so (or less) and I hope to be able to try out more ideas.
- It would have been nice to have access to someone who could do the spadework to find a network - so lack of help - having to do it all myself

The most disappointing part of the project was:

- Nothing
- Not seeing some of the same people at the meetings.
- My inability to act on some of the good ideas suggested, due to my limited free time.
This will change in the near future and then I hope to try out some of the suggestions
- Not being able to find PCA in the evening when those meetings are held.
- Being so busy. The Pet adoption group that asked my son not to come back because he was "too busy" and made them (a few of them) uncomfortable.
- Starting out optimistic, but then getting discouraged when faced with the challenges of finding suitable activities. It's not a criticism of the project but a sad reality of the challenges we face.
- TYZE. See previous
- We weren't able to find a community partner yet. We are still looking. Been working on medical stuff for the last 4 months at Mayo.
- Nothing really transpired from the ideas discussed, everyone we contacted wasn't available, the young man we thought would work with my son didn't work out. We initially thought someone would be doing the connecting.
- We didn't make as much progress as I'd hoped.
- We never actually found a friend.
- I was not as successful in finding friends for my child as I would have liked
- I had hoped I would connect with people more, the group was far more diverse than I expected.

- Didn't make as much progress as hoped for in getting my daughter connected with other people.
- At the very beginning, I was disappointed when I realized that this was not a group that actually provided activities for the participant. But then I started to really understand how it worked and quickly realized that brainstorming together and having us pursue different options ourselves is in fact the best and most sustainable way to do it.

The most enjoyable part of the project was:

- Learning different ways to play cribbage; ex 8 handed & cross cribbage (*note added: this item is from a focus person who joined a weekly cribbage group as part of the project*)
- The people, ideas and possibilities
- Meeting other parents and hearing their stories
- Meeting other families
- Talking with other parents who face similar challenges (speaks to the need/value of support groups for the parents of disabled children, regardless of age).
- Meeting and networking with other parents
- Meeting people, going to Caribou for coffee. I liked the Caribou location and room conversation (*note added: Caribou is a local Minnesota coffee-shop chain*)
- Connecting with church members and people in the community who are interested in knowing more about our issues
- Meeting new people, discussing issues, concerns, ideas with other families

- Sharing stories and experiences with other parents. It felt like a support group in the understanding, empathy, and open sharing of ideas that always went on in the meetings. Hearing from parents of adults with more severe disabilities than my participant was particularly inspiring and encouraging.
- Hearing success stories
- Meeting other parents and getting information and ideas from them
- Meeting other parents
- We did make a lot of progress in other social areas. It was interesting to hear other families' issues
- Thinking creatively about options
- Meeting other parents and the occasional child

What I learned from the project was:

- That I need to take my time and concentrate (*note: from a focus person who joined a cribbage group as part of the project*)
- That I limit my thinking on ways my daughter can make friends. Also, there are so many ways, groups to get to know people
- How to approach community members and get them to interact with my son. Not to be afraid to ask
- There are no easy answers or magic bullets. However, being willing to take a risk and ask paid off. My daughter will have a walking date on Sunday and a swimming date next Thursday.
- Think creatively - Start with strengths and interests and look to opportunities from there.

- I learned to seek more opportunities for my son's independence like alone time in home or riding bike alone. Because I heard others were doing that. The questions really made me think deeper and ask why not?
- That I wasn't alone with inclusion issues for my son - - that was an eye opening.
- Learned about some community things I wasn't aware of and websites for those with common interests
- The variety of resources, both governmental and non-governmental, which is available for special needs adults. There is so much info for babies or young children but very little for adults.
- Keep trying
- There are a lot of opportunities available to involve my sons in the community.
- Openness of Jaycees and other community groups to people with disabilities
- There is a big problem with people with cognitive delay disabilities being able to make friends. There are a lot of resources to get out and do things, but extremely difficult to take the next step of actual friendship
- New resources - sharing with others about ideas/community activities
- We are not alone, and all the challenges we face are so much less than they could be. Other people are faced with far greater challenges

What I will pursue in the future will be:

- Continuing to play and go frequently (*note: from a focus person who joined a cribbage group as part of the project*)
- Encouraging my daughter's group home to help initiate having people visit my daughter and trying new venues for her

- Ways for my son to be more involved in our community
- My daughter is taking a tap class with typical teens. She has been installed as a preschool Sunday school teaching assistant (3-4 yr. olds.) and I observed her playing in the nursery with one of the kids after church last week. A job in the community after she graduates from transition.
- Will continue to look for suitable activities to try to get my son involved in. The key is staying committed and following through. Right now, my "to do" list is to have my son volunteer at the local senior care facility
- Continue to contact community members for social interactions
- Try to find more community activity and encourage my son to call up friends for activities
- Meet-up that I had connected through the B.C.F. and Belonging Project. This project has shaped the prospect going forward.
- Continuing to reach out to others to help my son in community events. -Continue to encourage my son to reach out to others.
- The use of the participant's DD waiver funds for a Personal Support person - Finding a group home for her as her cognitive abilities decline, I will periodically review the variety of activities ideas which I have learned of in this group and see what may suit her. I expect to keep in mind all of the great ideas which have come up to pull from in the future!
- Continue seeking opportunities for friendship for my daughter
- Put some of these ideas into practice
- Jaycees and other Meetup Options

- Continuing to push the social interaction and hopefully, eventually friendships will develop for my daughter. What should be pursued is this should be implemented and mandated to include this in all schools starting early. Maybe the ARC should pursue this for their young adult age group
- Encouraging a couple of new people to be friends-trying to find groups that will "adopt" my child
- Groups live meetup.com; Music related activities; Continuing to pursue the friends he has now; Trying to figure out how to add to that group