Effective Steps to Creating Parent/Teacher Partnerships in Special Education

Danielle Jeanne Bundy
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MASTER OF ARTS IN EDUCATION

Danielle Jeanne Bundy

Effective Steps to Creating Parent/Teacher Partnerships in Special Education

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Effective Steps to Creating Parent/Teacher Partnerships in Special Education

Danielle Jeanne Bundy

Submitted in partial fulfillment of the requirements for the degree of Master of Arts in Education

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CERTIFICATE OF APPROVAL

This is to certify that the Action Research Final Project of

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Has been approved by the Review Committee, and fulfills the requirements for the
Master of Arts in Education Degree

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ABSTRACT

Effective Steps to Creating Parent/Teacher Partnerships in Special Education

Danielle Jeanne Bundy

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Leadership Application Project (EDC 585)
Action Research (EDC 587) Final Project

While the value of the parent/teacher partnership is universally accepted, it is not always easy to promote or maintain. The purpose of this study was to identify the effective steps to creating parent/teacher partnerships in special education, in order to plan a curriculum that was more responsive to children's needs. For the purpose of this study a multi-method qualitative approach was used, which included participant observation, questionnaires, and analysis of field notes. The results of this study revealed a complex set of issues related to interactions between parents and special education professionals within the school setting which included: (a) Listen to us, (b) develop effective communication between parents and professionals, (c) increase knowledge about various disabilities, (d) demonstrate sensitivity, and (f) improve the IEP process. The research delineates, from the parents' perspective, specific courses of action that special educators can take to facilitate more sensitive and productive communication and decision-making partnerships.
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Introduction

Increasing the involvement of parents in the education of their children is a national goal for policy makers in both general and special education. One of the National Education Goals states that, “By the year 2006, every school will promote partnerships that will increase parental involvement and participation in promoting the social, emotional, and academic growth of children” (National Education Goals Panel, 1994). In the Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Congress emphasized the rights of parents to participate in decisions about their children’s education based on the belief that “strengthening the role of parents and ensuring the families of such children have meaningful opportunities to participate in the education of their children at school and at home” can improve the education of children with disabilities (Section 601(c)(5)(B)).

Many researchers, practitioners, and policymakers have documented the importance of parent involvement. A significant body of research (Olmstead & Rubin, 1983) indicates that when parents participate in their children’s education, the result is an increase in student achievement and an improvement of students’ attitudes. Increased attendance, fewer discipline problems, and higher aspirations also have been correlated with an increase in parent involvement. The positive effects of increased parental involvement have been known for some time (Henderson & Berla, 1994). Epstein (1983) reported that when teachers were committed to increasing parent partnerships, the parents “... felt that they [the parents] should help their children at home; ... understood more about what their child was being taught in school; ... were more positive about the teacher's interpersonal skills, and rated the teacher higher in overall teaching ability...”
This change in parents’ perceptions is true even after socioeconomic status and students ability are taken into account (Epstein, 1983; Eagle, 1989).

Active participation and family-centered practices is recommended rather than passive participation. Federal law mandates collaboration between special educators and families. These rights are codified as procedural safeguards embedded in various aspects of IDEA. Schools must include families as members of the Individualized Education Program (IEP) team; provide prior notice for identification, evaluation, or the provision of free and appropriate public education (FAPE); and offer mediation when disputes cannot be resolved amicably.

The purpose of this study is to identify the effective steps to creating parent/teacher partnerships in special education, in order to plan a curriculum that is more responsive to children’s needs and promotes working with parents on an open and equal basis. Also, bi-directional information sharing between parents and teachers has been established in order for teachers to provide parents with relevant, accurate and up to date information so that they can make informed decisions and parents in turn can offer their knowledge about their children and family situation so that the information base can be used in decision making. For the purpose of this study partnership is characterized by common aims, mutual respect, negotiation and flexibility (Pruitt, 1998).

Perhaps the most salient characteristic of families who have a child with a disability is not always being seen as full partners in their education or, as Hobbes (2003) states, “true experts on their children (p.16).” On the contrary, in the early years of special education parents were frequently seen as the cause of their child’s disability (Turnbull & Turnbull, 1998). Their voices were often muted by professionals who were
more interested in assigning blame than listening to their hopes, fears, and dreams—or
taking their advice (Stearns, 1999).

Previous exposure to persons with disabilities can help teachers and parents
reconstruct their ideas and expectations about children with disabilities. People who
relate often to others with disabilities are more likely to focus on the person as a whole
rather than on the disability (D’Alonzo, Giordano, & Vanleeuwen, 1997). The experience
parents gain from providing for their children with disabilities has been demonstrated as
having an impact on their values and beliefs. For example, some mothers of children with
disabilities place a greater value on their children’s physical development, and others
may prioritize academics or social skills depending on the nature and severity of the
disability. It is important to recognize the individuality of families and the uniqueness of
each child’s needs (Case, 2001).

As Cochran (1993) strongly argues, teachers should take a look at the contexts in
which they work and comprehend the communities from an insider perspective. Teachers
need to find ways to be learners who confront and evaluate their personal assumptions,
understand the values and practices of families and communities that are different from
their own, and create pedagogy that honors and respects those cultures.

**Literature Review**

This literature review includes a summary of several empirical and longitudinal
research studies published between 1980 and May 2003. This review is divided into
sections summarizing research in seven areas: Supporting teacher-parent relationships,
factors that have an effect on effective relationships, at-home activities, comprehensive
parent involvement efforts, effects of parent involvement, working with minority families, efficacy beliefs of parents and teachers, communication, and an effective model for building collaboration.

**Supporting Teacher-Parent Relationships**

Teachers, through their interactions with parents, play a major role in encouraging parents to support learning at home. Ames (1995) found that parents' overall evaluation of the teacher, their sense of comfort with the school, and their reported involvement in school activities was higher when parents received frequent and effective communications from teachers. When communication is continual, varied, and covered both classroom content and individual information about their own child, parents are more likely to take part in suggested activities. The degree of teacher enthusiasm for a particular strategy designed to increase parents' involvement also is important (Bauch, 1994). Teachers who eagerly pursue a strategy find they are better able to engage parents in activities than teachers who "go along" with an administrative mandate. Since teacher pre-service education does not provide extensive opportunities to develop the skills needed to communicate with and engage parents, schools that wish to promote parent involvement must craft opportunities for teachers to become adept at sharing information with parents and suggesting ways in which the parents can assist their children (Rich, 1993; Epstein, 1992). Schools must create an environment where teacher input on implementation of parent involvement strategies is sought out and encouraged.
Factors That Have an Effect on Effective Relationships

There are a number of factors that affect a teacher’s ability to develop a smooth parent–teacher partnership. Some of these factors pose problems and the challenge is how to develop an effective working relationship in spite of the problems that may be present. The factors include: (1) the degree of match between teacher’s and parent’s culture and values; (2) societal forces at work on family and school; and (3) how teachers and parents view their roles.

The Degree of Match Between Teachers’ and Parents’ Culture and Values

In today’s mobile world, it is less likely that parents and teachers will hold beliefs and values that are closely matched, compared to previous generations. In earlier times teachers lived in the communities with families, and there was a ‘natural bridge’ between family and school (Hymes, 1974). Now parents and teachers share the community less frequently. Teachers do not have the same sense of belonging to the community that they did when they lived in the same town. Teachers often come from a socioeconomic class, race or ethnic group that is different from that of the children they teach (Keyes, 1980). Differences in these realms are associated with different interactional styles and language systems, as well as values and present challenges to developing effective partnerships (Galinsky, 1990; Henry, 1996; Coleman, 1997; Langdon & Novak, 1998; Burke, 1999).

Teachers’ own backgrounds are a key factor in how they relate to parents (Strum, 1977; Solity, 1995). A classroom teacher’s experience highlights the influence of background and the challenges to recreating a bridge. Participating in a teacher group discussion of intercultural communication, a teacher wrote (as if realizing it for the first time):
Culture means more than holidays and food; it includes all of the subtle patterns of communication, verbal and non-verbal that people use every day. I noticed how easily I valued cultural diversity in the abstract or in the form of occasional holidays yet, how readily I rejected cultural differences when they appeared in the form of parents’ different approaches to child rearing. (Strum, 1997, p. 34)

She goes on to write about the group’s reflection:

We realized that unexamined values, beliefs and patterns of interaction learned when we were children exert a powerful influence on our communication and care giving routines. Our sincere intentions didn’t prevent us from rejecting parents’ diverse values when they challenged our own cherished beliefs. We were often unable to set aside our own cultural values long enough to listen to parents. (Strum, 1997, p. 35)

From the parents’ perspective, some of the factors that influence a degree of openness include: (1) cultural beliefs related to the authoritative position of teachers that prevent parents from expressing their concerns; (2) a lack of education that may cause parents to be intimidated in interactions with teachers; (3) language differences that may result in parents feeling uncomfortable if no one speaks their language; and (4) different socioeconomic levels that may result in child-rearing practices and values that conflict with those of the teachers (Greenberg, 1989; Keyes, 1995).
If there is a consistent match between teacher and family culture and values, the probabilities are greater for developing effective professional skills in working with parents over time. In contrast, the greater the discontinuities, the more effort that is needed to promote a partnership (Lightfoot, 1978, p. 10).

Societal Forces at Work on Families and Schools

The breadth of changes in society is well documented. Among these changes are the increasing reliance on technology, the changing nature of work, a more diverse population, and a more service-oriented society. For the purpose of this paper, the concern is how such forces affect schools and families. As we think about building bridges to support parent–teacher partnerships, it is critical to keep these forces in mind.

In addition to what was at one time the ‘traditional’ two-parent family, we now have two-parent working families, single-parent families, adoptive families, remarried or blended families, to cite just a few of the new family constellations. Family roles have also become more flexible and fluid. Mothers may function in what was once the traditional role of fathers; fathers may function as homemakers, and children may perform some parental functions for siblings. Thus the school does not necessarily have access to one continuing adult to speak for the family. Sometimes it is one parent; other times it is a different parent from a blended family; and at still other times, it may be a sister, brother, or aunt—making effective communication a real challenge.

As far back as 1950 it was understood that parents and teachers had multiple responsibilities and pressing time demands:
As we work with parents it is especially important that we not forget the complexities of family life. When we see a tired youngster coming to school we may want to shake the parents and make them read a good article about children’s need for sleep. It is easy to forget—or maybe we never knew—that at home three children sleep in one bed while mother and father sleep in the same room with them. We put pressure on parents to come to school meetings as if these were the only true important events of the day. But parents, even very good parents who care deeply for their children have shopping to do, floors to scrub, hair that must be washed and often have tired feet and aching backs ... You have to avoid the error of seeing life only from the school’s side as if homes simply flowed along smoothly with no problems of their own. The closer you move to parents the more realistic your expectations become ... Each family has their private story of how it lives its present days. (Hymes, 1974, pp. 5, 17)

Twenty-nine years later, the responsibilities and times demands are still present:

But whether parents can perform effectively in their child-rearing roles within the family depends on role demands, stresses, and supports emanating from other settings. As we shall see, parents’ evaluations of their own capacity to function, as well as their view of their child, are related to such external factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends or neighbors who can help out in large and small emergencies, the quality of health, social services, and neighborhood safety. (Bronfenbrenner, 1979, p. 7)
Both parents and teachers experience job stress. For parents, the number of hours they work, the amount of job autonomy and job demands, and relationships with supervisors affect their other relationships. For teachers, the job stress also is affected by the number of hours worked, schedules, amount of autonomy, role ambiguity, physical demands of the job and clarity of the program (Galinsky, 1988). Teaching is physically and emotionally exhausting, and reaching out to parents is sometimes viewed as one more burdensome task. So, in fact, both parties in the relationship are buffeted by strains and tensions in their worlds.

How Teachers and Parents View Their Roles

More than half a century ago, Willard Waller (1932) observed that parents and teachers are ‘natural enemies’. The basis of his argument was that parents and teachers maintain qualitatively different relationships with the same child, especially in regard to affective bonds and spheres of responsibility and as a consequence want different things for the child. (Powell, 1989, p. 20)

In the last 50 years, however, there have been changes in how schools and families have viewed each other. Because of a developing awareness of the importance of the bridge between home and school, schools have reached out to families and families have pressed to be heard in schools. Laws have also been enforced in an attempt to secure parent involvement.

Educators have described and defined the differences in the roles and spheres of responsibility of teachers and parents (Getzels, 1974; Katz, 1984). Figure 1 depicts the framework developed by Katz (1984).
Figure 1 describes the distinctions in parent and teacher roles. In Katz’s model, the teacher’s role is specific to schooling while the parent’s is universal in all aspects of the child’s life. Teachers are responsible for all the children for a specific period confined to the school setting and therefore the teacher’s role is more objective, detached and rational, using insights, techniques and abilities to support each child. The teachers’ role is shaped by professional knowledge about ‘all children’. Parental relationships, on the other hand, are shaped by their own child for whom they are responsible 24 hours a day and are likely to demonstrate intense partiality, attachment and even irrationality in their interactions about their own child (Katz, 1984). Given the difference in roles it is critical to look for the meeting points as partnerships are developed.

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Influences on How the Parent and Teacher Role are Enacted

Confusion results when teacher and parent roles become ambiguous. The first challenge is to make public some of the parameters of the role enactment patterns. The second challenge is to figure out how to use those parameters to create effective parent–teacher partnerships. Therefore it is essential to look at some of the forces that influence how the roles are enacted.
Parents’ role construction

How parents view their role in relation to school also affects the parent/teacher relationships. Parents’ role construction may be described as parent-focused, school-focused and/or partnership-focused. In the parent-focused construct, parents consider that they have primary responsibility for their children’s educational outcome. In the school-focused construct, parents feel that the school is primarily responsible for the children’s educational outcome, and in the partnership-focused construct, parents believe that teacher and parent working together are responsible (Reed et al., 2000). It seems apparent that how parents interact will vary based upon the construct the parent holds. This interaction may also vary culturally.

Roles for parents at the school are varied. In one study (Ortner, 1994), parents increased their volunteer efforts at the school and had higher attendance levels at parent/teacher conferences if they received a home visit from the school welcoming committee, which included one parent and one staff person from the school.

Several research studies examined the impact on achievement when parents participate in decision-making roles in the educational program. Gillum (1977) studied adoption of reading programs in three elementary districts. Each district shared information about the new program with parents. However, the district that involved parents in decisions about implementation of the program and strategies for reinforcement at home had significantly higher reading scores. Bromley (1972) found that when Head Start parents participated in program decision-making, they were motivated to increase their own learning. This active leadership role brought about a
higher level of involvement than did a strategy that stressed home visits at which parents were given examples of learning activities they might do with their children.

*Teachers’ role construction*

Teachers’ role construction has developed primarily outside the formal education arena and is less clearly documented in the literature but evident in the field. Teachers may view their role as parent-focused, school-focused and/or partnership-focused. The parent-focused view evolved out of the parent-cooperative movement (Sumson, 1999). In that movement teachers and parents worked side by side empowering parents and giving the parents teaching roles. This view is most prevalent in early childhood programs. The school-focused role reflects teachers who believe that in an effective separation of roles and functions between home and school. This view is more typical in elementary schools and intensifies the older the child gets. The partnership-focused perspective, where family and school work cooperatively, is a more recent construct, evolving as the literature began to point to the significant benefits that accrue to children, parents and teachers as a result of the partnership (Henry, 1996). Like the parents, how the teachers interact will vary based upon the beliefs the teachers hold.

*At-Home Activities*

Another focus of parental involvement efforts is the home. Several programs (Yap & Enoki, 1994) try to help parents improve their parenting skills so that children come to school better prepared. Others (Goldenberg, 1987; Scott-Jones, 1987) offer parents instruction on at-home activities to support learning. Stearns and Peterson (1973) found
that when parents of young children tutored their children, student performance improved. When parents learn to teach their own children, they not only give the children new skills, but also build their feelings of competence. This increased confidence, in turn, motivates the children to perform better.

**Comprehensive Parent Involvement Efforts**

How comprehensive do efforts to involve parents have to be? Broad-based, comprehensive approaches have their supporters (Seeley, 1993; Gordon, 1979). Morrison (1994) found that a mixture of informal and formal activities work well. Parents can become engaged through social and recreational activities. Once engaged, they are more likely to work with their children on school-related activities and view themselves as involved in their child's education. It is also essential for schools to provide supports such as childcare and transportation. Seeley (1993) argues for a different model of schooling—one in which parent involvement is a necessity. What is needed is a persistence of effort and a reorganization of budgets and roles to reflect the importance of parent involvement.

While some programs have adopted extensive comprehensive efforts to increase parental participation, relatively simple efforts also have effects. Walberg, Bole, and Waxman (1980) found that children of parents who adhered to school contracts made greater gains. These contracts signed by the principal, teacher, parent, and child stipulated that parents would provide a special place at home to do school work, talk with their child daily about school events, and pay attention to their child's academic progress and compliment any gains.
Effects of Parent Involvement

There appears to be a relationship between the age of the child and the forms of parental involvement. Greater efforts to involve parents are seen at the preschool and primary levels. Efforts here focus on assisting in the classroom and reading to children at home. Teachers of young children are the most frequent users of parent involvement techniques (Epstein, 1987).

At the middle and high school levels, parent involvement practices decline (Lucas & Lusthaus, 1978). Hollifield (1994) presents a number of reasons why this is so. The adolescent has a developmental need for autonomy and greater responsibility. Families often live further from the high school and are less able to spend time there. The organization of the secondary schools is more complex and teachers have contact with larger numbers of students. Few high schools make any one teacher responsible for a small group of students. Information on student progress involves contacting four or five individuals.

At the secondary level, what parents do at home seems to have the greatest impact. Keith, Reimers, Fehremenn, Pottebaum, and Aubey (1986) found that key strategies to follow at the secondary level were limiting recreational TV viewing and emphasizing the completion of homework assignments. Hollifield (1994) noted that parents of high school students are rarely guided to conduct discussions with their teenage children about important school decisions or plans for the future.

Research also suggests a correlation between parent involvement and dropout rates. Rumberger, Ghatak, Poulos, Ritter, and Dornbusch (1990) found that students who drop out reported that their parents rarely attended school events or helped with
homework. These parents were more likely to respond to poor grades with punishment. These high school students rarely consulted their parents when making educational decisions.

Rumberger et al. (1990) also noted a disparity between what teachers feel must be done and what they are able to do themselves. While nine out of ten secondary teachers feel parent involvement remains important at the high school level, only three out of ten feel that it is their responsibility to involve parents. Increasing communication between home and school and providing guidance to parents for discussions with their children about planning for the future were viewed as positive strategies. High school teachers, however, reported that they lack the time to pursue any of these strategies. Brian (1994) reports that parents of high school students feel more uncertain about what is happening in their children's lives than they did during elementary school. Despite their need for autonomy, Brian finds that teens are less resistant to the idea of parent involvement than is commonly believed. Key here is the notion that parental efforts have been seen as support rather than control.

**Working With Diverse* Families**

Often parents of diverse backgrounds are seen as less involved in their children's education. Many factors contribute to differences in the ways parents relate to school and how they view appropriate levels of involvement (Ritter, Mont-Reynaud, & Dornbusch, 1993), such as a history of bad experiences with schools, a general lack of trust of institutions, a traditional deference to education, a tendency to equate teachers' questioning with displays of disrespect, and the lack of English language skills. School

*a group of people who differ racially from a larger group of which it is a part*
staff must be sure not to equate unfamiliarity with the curriculum and procedures of the school with a lack of caring about their children's education.

It is important for schools and teachers to develop attitudes and policies that are reflective of, and sensitive to, the community they serve. When they do (Zelazo, 1995), more parents become involved in ways that are recognized by the school as being engaged in the schooling process. However, before parents can be involved, they must feel comfortable with the staff and school. Goldenberg (1987) noted that when teachers sent home suggestions of things parents could do to support word-recognition skills, Hispanic parents responded favorably. Often what is interpreted, as a lack of interest or caring is, instead, a cultural predisposition to interpret help at home with interference and disrespect for the teacher. Once parents became aware of the need to help their children at home and were given a set of strategies to follow, they were quite willing to help. Scott-Jones' (1987) study of African-American families with first graders found that better outcomes occurred when home learning and school-related activities were integrated into the flow of pleasant, play activities and were not formal or intentional. Parents' efforts to support their children's learning work best when the parent is able to respond to activities initiated by the child.

Chavkin and Williams (1993) studied the attitudes and practices of parents from diverse backgrounds regarding the issue of involvement in their children's education and found that parents are concerned about their children's education and want to take an active role. Parents in the study expressed the highest level of comfort with coming to school events and/or working with their children at home on learning activities.
One key to involving all parents is creating an atmosphere in which teachers, administrators, and families all are seen as valuing parental involvement (Dauber & Epstein, 1989). Schools that are serious about developing partnerships with parents can provide information to parents about different ways they can be involved and understand the barriers that keep parents from being more active (Chavkin & Williams, 1993). The literature indicates that work needs to be done at the school and district level to develop policies and practices that encourage involvement at the school and guide parents in how to help at home.

Teachers' and Parents' Efficacy Beliefs

In addition to how they construct their own understanding of role, teachers' and parents' sense of efficacy also influences what type of interactions they are likely to have (Reed et al., 2000). Research has shown us that teachers and parents with high efficacy levels are more likely to succeed in parent–teacher relationships (Greenwood, 1991; Garcia, 2000). On the one hand, teachers and parents who have had successful interactions with each other, observed or heard about others’ successes, and/or felt that efforts were worthwhile are more likely to have that personal sense of efficacy (Hoover-Dempsey, 1995; Garcia, 2000). On the other hand, teachers and parents may have ‘leftover anxieties’ from earlier experiences with schools (Taylor, 1968, p. 272) that influence how effective they are likely to feel. Rebuilding the bridge for effective parent–teacher relationships may require different supports for those individuals.

From the parents’ perspective, most have little choice in choosing a school. Many feel powerless to influence schools and are threatened by the authority of the school. Some feel that running the schools should be ‘left up to the experts’ (Greenberg, 1989;
Greenwood & Hickman, 1991). Some resist or are reluctant to participate because they worry about their family’s privacy. Others find the school climate or school bureaucracy hard to deal with (Comer & Haynes, 1991; Henry, 1996). The lack of clarity about what to expect at meetings and conferences also poses a challenge for the relationship (Lortie, 1975; Keyes, 1979). For many apparently uninvolved parents, their school experience was not positive and they may now feel inadequate in the school settings (Brown, 1989).

From the teachers’ perspectives, some feel unappreciated by parents. They say that parents don’t come to conferences or meetings, don’t read the material they send home, and won’t volunteer for school activities. Some teachers feel that parents lack interest in what’s going on with their children. Others describe parents as adversarial, or apathetic, always a challenge (Greenberg, 1989; Hulsebosch & Logan, 1998). In both teachers’ and parents’ cases we don’t know whether their lack of a sense of efficacy occurs because they have an adversarial point of view or lack skills or because there is a cultural division.

*Teachers’ and parents’ expectations*

Different expectations on the part of teachers and parents may also affect the parent–teacher partnership. Often teachers and parents place different emphases on factors central to developing confidence in their relationship. For example, parents may emphasize teachers’ knowledge and skills. They want teachers to know and care about teaching, about their children, and about communicating with them. Teachers have more confidence in parents who have similar ideas and backgrounds about teaching issues and child-rearing practices, and who freely share important things about their children (Powell, 1998; Rich, 1998).
 Teachers' and parents' personal attributes

Closely related to roles and efficacy are personal attributes. According to the research, several characteristics appear to positively influence parent–teacher partnerships. The relationships are enhanced when teachers' personal attributes include: warmth, openness, sensitivity, flexibility, reliability and accessibility (Comer & Haynes, 1991; Swick, 1992). The partnerships are positively influenced when parents' personal attributes include: warmth, sensitivity, nurturance, the ability to listen, consistency, a positive self image, personal confidence and effective interpersonal skills (Swick, 1992). While both teachers and parents may lack some of the positive personal attributes, teachers who are armed with this knowledge may be more effective at bridging.

Teacher and Parent Communication

One of the categories of parent involvement identified by Epstein (1995) is communication. This communication includes teacher invitations, first meetings with parents, conferences, and adapting communication to meet the diverse needs of parents. Two aspects of communication; first meetings and teacher invitation, have special significance since they influence how roles will be enacted as partnerships develop. First meetings with parents, often the first personal connection that is made, set the tone for the subsequent relationship, making it critical to be aware of issues of cultural styles in conversation, space and eye contact. Research suggests that the teachers’ invitations to parents are also a critical factor in promoting more extensive parent involvement.
Effective Model for Building Collaboration

In recent years, parents of children with disabilities have been encouraged and supported to take a more active role regarding the evaluation, placement, and programming for their children with special needs by the law (IDEA), and by advocacy groups. Through the 70's, parent involvement in the education of children with disabilities escalated. The literature that chronicles the parent movement of the 1970's was extremely supportive of the "parents as partners" concept (Cooper & Edge, 1981; Kroth & Simpson, 1980. This goal continues through the present (Ammer & Lettleton, 1983; Collins, Collins, Botyris, & Deschler, 1991). The Individuals with Disabilities Education Act Amendments (IDEA) of 1997 Public Law 105-17, were signed by the President on June 4, 1997. In the individuals with disabilities education act amendments (IDEA) of 1997, Congress emphasized the rights of parents to participate in decisions about their children's education based on the belief that strengthening the role of parents and ensuring the families of such children have meaningful opportunities to participate in the education of their children at school and at home can improve the education of children with disabilities (IDEA, 1997).

For years, teachers have been complaining about the problem of non-support from parents of children and youth with special needs. While the teachers have been complaining, so too have the parents. Research indicates that positive results are minimized unless parents and teachers function as a team (Dolce, 1984).

It has been established that parental involvement and effectiveness in advocating for their child's educational program increases proportionate to the belief that their children will succeed in school (Lazar & Darlington, 1982). Collaboration of teachers and
parents can go a long way toward strengthening school and home ties (Silliman & Royston, 1990). While parents of children without disabilities have been involved in advocating for their children for several decades, the parent advocacy movement that combines all parents with children with or without special needs, has not, until recently, included families of children with disabilities. However, Parents of children with special needs have always led the fight for better services for their children. Parents have always been in the forefront of change, often nudging and encouraging the professionals along with them.

Parents of children and youth with special needs have been either reluctant or unable to lend support to school-based programs for their children, though documentation exists (Zeigler, 1987; Shapero & Forbes, 1981) that parent involvement programs are significantly correlated to student achievement. Kenneth Kamminga (1988) agrees "...the data are clear that the school’s practices to inform and involve parents are more important than parent education, family size, marital status, ... in determining whether (inner city) parents get involved with their children’s education in elementary school and stay involved through middle school."

Regardless of whether their child has a disability, parents often view their child’s special needs as an expression of their own value systems. They may believe that school staff that does not understand the origins of their child’s needs has singled out their child. Or, they may feel embarrassed by their child’s behaviors. Friesen & Huff (1990) explain, "... because they have often been held responsible and even blamed for their child’s problems, family members have been reluctant to identify themselves, to speak out, and to demand the services and accommodations that their children need (p. 42)."
Compounding factors contributing to the lack of advocacy by parents for their children across systems include a) the emotional and physical stress of parenting a child with special needs, b) worry related to treatments costs, and c) the stigma associated with disabilities (Karasik & Samuels, 1990). Parents, however, do not want sympathy. They want empathy (Stewart, 1980). They also want to be recognized as valued contributors to their child’s success. Parent(s) have assumed a more active role regarding the evaluation, placement, and programming of their children with special needs (Mlynek, Hannah, & Hamlin, 1982). In fact, Morrison and Holtapeck (1991) stated, “Parent involvement is the key to success (p.21).” The teacher must realize that the parent(s) of children and youth with disabilities have undergone a great deal of disappointment and frustration, and that they too, would like to see evidence of partnership, communication and academic success (Kauffman, 1989).

While many teachers may doubt whether certain parents are willing or able to be involved in helping their children, Ziegler (1987), found that those who take the initiative in reaching out to families do not seem to be overcome by perceived obstacles, but have instead been able to work successfully with parents of all backgrounds.

Enhancing communication and promoting shared activities between schools and parents or parent groups is a goal that many teachers would consider important. Reilly, Turnage, & Donahue (1986), addressed the need for consistency in the communication process between all parties as an aid in the educational arena. Promotion of parental involvement through open door policies (i.e., offering weekly or monthly passes to families, rather than requiring them to “check-in” at the principal’s office each time they
visit the school) and dialogues such as mutual, shared comments, are all elements of the communication process (Gulley, Matthias, & Zobari, 1991).

One effective model of building parent/teacher communication is through a parent-teacher support or self-help group. Such groups have been in existence for parents of children with disabilities for decades, and can provide parents with needed information, support, and a forum for discussion of primary concerns (Twilling & Brock, 1990). The more specific the focus of the parent/teacher support group, the more likely it is to attract participants (Sczymczak, 1991).

**Methodology**

**Multi-Method Qualitative Approach**

No two families are alike. Despite some commonalties based on socioeconomic, cultural, and linguistic characteristics, or similarities in the nature of severity of their child’s disability, each family has a unique set of needs, wants, capabilities, and dreams for their children. Some children live in traditional, two parent households. Others live in nontraditional families with single parents, or in foster, adoptive, or blended families and culture plays a unique role in the interpretation of what constitutes a family. In order to create individualized educational programming, it is important to understand and value the uniqueness of each family member that a teacher works with.

The purpose of this study is to identify the effective steps to creating parent/teacher partnerships in special education, in order to plan a curriculum that is more responsive to children’s needs and to promote working with parents on an open and equal basis. Also, bi-directional information sharing between parents and teachers is
established in order for teachers to provide parents with relevant, accurate and up to date information in order to make informed decisions. Parents in turn can then offer their knowledge about their family situation so that the information base can be used in decision making.

In order to evaluate and interpret the effective steps to creating parent/teacher partnerships in special education, a multi-method qualitative approach is used. Qualitative methodology provides the researcher with a way to gather a broad range and a variety of types of data and allows for the study of the interrelationships among the data (Stainback, 1988). The data tend to provide a holistic understanding of the topic of study, which makes qualitative methodology particularly appropriate for educational research.

Taylor and Bogdan (1984) point out several characteristics of qualitative research methodology that make it particularly appropriate for the study of parent/teacher partnerships; Qualitative research is inductive, that is, researchers develop concepts, insights, and understandings from patterns in the data, and follow a flexible research design. People, settings, and groups are not reduced to variables, but are viewed as a whole. In qualitative research, all perspectives are valuable, and the methods used are humanistic. Additionally, qualitative research methods emphasize validity. They are designed to ensure a close fit between the data and what people actually say and do. Finally, qualitative research is a craft; the researcher a craftsman. There are guidelines to be followed, but never rules.

The interactive nature of the study made it an ideal candidate for qualitative research methodology. Many elements were examined and analyzed in order to determine the success of effective parent/teacher partnerships in special education. The participatory
nature of the qualitative research methods employed rendered the research process a meaningful end in itself. In addition, it provided a vehicle for social inquiry. Participants in the qualitative study took an active role in the course of the research. Their intimate involvement in the processes as well as the outcomes of the research project made qualitative methodology a socially valid and useful tool. Participants in the qualitative study were empowered by their participation in the research process. The following descriptions of the methodologies implicated in the study illustrate the interactive and participatory nature of qualitative research, and give insight into intrinsic benefits of qualitative methodology.

All participants were asked to sign a consent form, and the standard regulations with regard to the use of human subjects in experimental research were used. Open-ended informal interview, questionnaire, and participant observations were the methods of data collection implicated in this study. Perceptions, trends and patterns that arose from the data collection processes were clustered into categories, arranged according to prevailing themes, and interpreted using the constant comparative method described by Lincoln and Guba (1985).

Participants

Participants included three fourth-and fifth-grade students, aged 10-11 years, and their families. The students were served by the special education department 21% to more than 61% of their school day. These students had one of the following disabilities: autism, emotional and/or behavioral disabilities (EBD), and multiple disabilities. The three students and their families were selected based on the following three criteria:
1. Student and family come from one of the following chosen home settings:
   a. Two-parent family home
   b. Single-parent family home
   c. Adoptive family home
2. Strong and trusting relationship between family and teacher
3. Parents' informed consent

The three families chosen were the Cory* family, the Robinson family and the Gulsvig family. The Cory family is an adoptive family. Peter was adopted from Russia. Peter is a fifth grade student who is labeled with fetal alcohol syndrome (FAS) and emotional/behavior disorder (EBD). Peter spent more than 61% of his day in a special education classroom. He has two older siblings, a brother and a sister who has epilepsy. During the study, Peter was hospitalized for attempting suicide. Due to extreme stress on the family, Peter was moved to Newstead, a group home for children with EBD. Newstead had six residents and a live-out staff of ten.

The Robinson family is a single-parent home made up of Kenny, and older sister, a younger brother, and his mom, who is divorced. He has never met his father. Mom has a boyfriend who has lived in the house for three years. Kenny calls him his stepfather. He is a fifth grade student with Autism. Due to a car accident at age two, Kenny is unable to walk. He spent 30% of his day in a special education classroom. During the study, Kenny’s mother felt intolerable stress taking care of Kenny on her own and placed him in Heathfields, an established group home of six residents, all having Autism, and a live-out staff of ten.

*Cory, Robinson, and Gulsvig are pseudonyms given to families to ensure privacy.
The third family is the Gulsvig family which is a two-parent home. Mark is a fourth grade student with severe multiple disabilities. He had muscular dystrophy and severe mental impairments. Mark spent more than 61% of his school day in a special education classroom. Mark has an older sister named Rebecca. All of these students have extensive needs.

These families were chosen because I have developed a strong, trusting relationship with each family through home visits, meetings, celebrations, and through daily communication either by phone, e-mail, or notes.

Setting

The study population came from a suburban public elementary school with a student population that is predominantly white (70%) from a middle-class socioeconomic background (22% free and reduced-price lunch). The school contains two special education classrooms (one for students with serious emotional disturbances and one for students who need pull-out instruction) and 26 general education classrooms. The observations for the study took place outside of school in each of the families' homes. The families live within the district. When two of the students moved to alternative living placements, consent was given by the institutions and by the families for observations to be completed at Newstead and Heathfields. When referring to these two institutions, the term surrogate parents is used.

Procedure

Prior to the home visits, the families were asked to complete a questionnaire that requested information on caregivers' perceptions of the most urgent needs of their
children and on their own requirements for information or skills to meet those needs. The questions were open-ended. Participating families were informed of, and consented to, the use of their responses in the study. The responses to the questions were placed on index cards. The following are a list of questions that appeared on the questionnaire:

1. How do you prefer to communicate (i.e., phone calls, notes, daily communication between caregiver and teacher, or face-to-face meetings)?
2. What are your child’s strengths and needs?
3. What are your concerns regarding your child’s educational program and what are your suggestions for improvement?
4. How can the teacher be more sensitive to the needs of your family?
5. What are your child’s most urgent needs and how can the teacher meet those needs?
6. What information or skills do you (parent/caregiver) need to assist or meet your child’s needs?

Home visits, which included participant observation, were conducted with each family once or twice a week for three to six weeks. Because participant observations took place over an extended period of time I was able to develop a more intimate and informed relationship with the informants, generally in more natural environments than those in which experiments and surveys are conducted (Cohen & Manion, 1980). I dictated field notes onto audio tape after each observation and were later transcribed and analyzed. The field notes included observations of the family, their daily functions, struggles, and successes.
During the first home visit, an informal interview was conducted with the parent(s). Parent(s) were asked to describe their living situation, they were also asked to describe their roles and the stresses and problems they encountered.

Data Analysis

The main purpose of the data analysis was to identify themes and issues that were grounded in the data being collected (Glasser and Strauss, 1967, p.46). The responses of the families to the question “How can educators be more sensitive to the needs of your family?” was examined to determine the issues that families identified as critical in their interactions with special education teachers and was used as the primary unit of analysis from the questionnaire. The responses were categorized inductively and the field notes were analyzed using the constant comparative method described by Lincoln and Guba (1985). Glaser and Strauss (cited in Lincoln & Guba, 1985, p. 339) described the constant comparison method as following four distinct stages:

1. comparing incidents applicable to each category,
2. integrating categories and their properties,
3. delimiting the theory, and
4. writing the theory.

The analysis follows these guidelines closely. According to Goetz and LeCompte (1981) this method "combines inductive category coding with a simultaneous comparison of all social incidents observed (p. 58). As social phenomena are recorded and classified, they are also compared across categories. Thus, hypothesis generation (relationship discovery) begins with the analysis of initial observations. This process undergoes continuous refinement throughout the data collection and analysis process, continuously
feeding back into the process of category coding. "As events are constantly compared with previous events, new topological dimension, as well as new relationships, may be discovered" (Goetz & LeCompte, p. 58).

**Categorizing Data Bits**

According to Bruner, Goodnow, and Austin (1972), "To categorize is to render discriminably different things equivalent, to group the objects and events and people around us into classes, and to respond to them in terms of their class membership rather than their uniqueness" (p. 16). The act of categorizing enables us to reduce the complexity of our environment, give direction for activity, identify the objects of the world, reduce the need for constant learning, and allow for ordering and relating classes of events. At the perceptual level, categorizing consists of the process of identification, "a 'fit' between the properties of a stimulus input and the specifications of a category. . . . An object of a certain color, size, shape, and texture is seen as an apple." (Bruner, Goodnow, & Austin, p. 176).

Categories, created when a researcher groups or clusters the data, become the basis for the organization and conceptualization of that data (Dey, 1993). "Categorizing is therefore a crucial element in the process of analysis" (Dey, p. 112). Content analysis, or analyzing the content of interviews and observations, is the process of identifying, coding, and categorizing the primary patterns in the data (Patton, 1990). "The qualitative analyst's effort at uncovering patterns, themes, and categories is a creative process that requires making carefully considered judgments about what is really significant and meaningful in the data" (Patton, p. 406).
Inductive analysis (Patton, 1990) means that the patterns, themes, and categories of analysis "emerge out of the data rather than being imposed on them prior to data collection and analysis" (p. 390). According to Dey (1993), a natural creation of categories occurs with "the process of finding a focus for the analysis, and reading and annotating the data" (p. 99). These categories, while related to an appropriate analytic context, must also be rooted in relevant empirical material: "The analyst moves back and forth between the logical construction and the actual data in a search for meaningful patterns" (Patton, p. 411). The meaning of a category is "bound up on the one hand with the bits of data to which it is assigned, and on the other hand with the ideas it expresses" (Dey, p. 102).

Several resources are particularly useful to the process of category generation: "inferences from the data, initial or emergent research questions, substantive, policy and theoretical issues, and imagination, intuition and previous knowledge" (Dey, 1993, p. 100). To utilize those resources optimally, the researcher should become thoroughly familiar with the data, be sensitive to the context of the data, be prepared to extend, change and discard categories, consider connections and avoid needless overlaps, record the criteria on which category decisions are to be taken, and consider alternative ways of categorizing and interpreting data (Dey, p. 100).

According to Lincoln & Guba (1985), the essential task of categorizing is to bring together into temporary categories those data bits that apparently relate to the same content. It is then important to "devise rules that describe category properties and that can, ultimately, be used to justify the inclusion of each data bit that remains assigned to
the category as well as to provide a basis for later tests of replicability" (p. 347). The researcher must also render the category set internally consistent.

Comparing Data

Categories must be meaningful both internally, in relation to the data understood in context, and externally, in relation to the data understood through comparison (Dey, 1993). When a particular category is adopted, a comparison is already implied.

To compare observations (Dey, 1993), we must be able to identify bits of data which can be related for the purposes of comparison. In principle, data is organized by grouping like with like: data bits with data bits. After the bits are separated into piles, each bit is compared within each pile. Data requiring further differentiation, will be divided up into separate "sub-piles." We could then compare observations within each pile or sub-pile, looking for similarities or differences within the data. We could also look for patterns or variations in the data by making comparisons between the different piles or sub-piles. However, things are not simply "alike or related - they are alike or related in some respect or another. Distinctions are always conceptual as well as empirical - they reflect some criterion or criteria in terms of which observations are distinguished and compared" (Dey, p. 96).

The constant comparative analysis was used to look for statements and signs of behavior that occur over time during the study. The process of constant comparison "stimulates thought that leads to both descriptive and explanatory categories" (Lincoln & Guba, 1985, p. 341).
Refining Categories

The meaning of the category evolves during the analysis, as more and more decisions are made about which bits of data can or cannot be assigned to the category (Dey, 1993). The fit between data and categories—the process of developing categories—is one of continuous refinement. "Flexibility is required to accommodate fresh observations and new directions in the analysis" (Dey, p. 111).

During the course of the analysis (Dey, 1993), the criteria for including and excluding observations, rather vague in the beginning, become more precise. The research must continually attempt to define and redefine categories by specifying and changing the criteria used for assigning them to the data. In so doing, one must recognize that any definitions developed in the beginning will probably be quite general and contingent in character. "In defining categories, therefore, we have to be both attentive and tentative - attentive to the data, and tentative in our conceptualizations of them" (p. 102).

The researcher hoped to develop a more intimate and informed relationship with the families, which would further the exploration in creating effective partnerships. The data was collected to gain insight into how to develop effective steps to creating partnerships with parent/teachers in special education. The information was used to plan a more individualized learning program that addresses the unique needs of each of the students and was the basis for the action plan.
Research Findings

The analysis of the data revealed four main themes which predominated in the interviews and observations - isolation, fear and suspicion, community facilities, and school contact.

The analysis of the questionnaire data had shown how interpersonal relationships and patterns of influence occurred between individuals at home, at school, and in the community. Specifically, the results of this study revealed a complex set of issues related to interactions between parents and special education professionals within the school setting. Themes emerging in the data: (a) Listen to us, (b) develop effective communication between parents and professionals, (c) increase knowledge about various disabilities, (d) demonstrate sensitivity, and (f) improve the IEP process. The following section will discuss each theme in turn.

Isolation

Perhaps the most obvious difference between the situation of the biological parents and the surrogate parents are the fact that caring for a child with a disability does not isolate the surrogate parents in any way from their friends, family, or interests outside their jobs. The stresses of 'being alone' simply do not apply. At the end of each shift, the surrogate parents return to an 'outside life'. Future commitments are in their own hands. Mary explained:

"Some days you go home and your head is throbbing from the noise. It's nice just to sit in the quiet and think things out. My family soon gets me going again though - wanting a meal."
In contrast to the biological parents, there was the knowledge that if the physical or mental strain of the work became too great, or ambitions changed, they could leave.

Isolation appeared to be woven through every aspect of the life of the Gulsvig family. The ways in which Mark caused his family to be isolated were many. The time he took up was enormous and the mental energy even greater. Both parents agreed that there was little else in their lives. When he was at school they spent their time caring for the house and tackling the vast amount of laundry, mainly generated by their son continuously soiling his clothing and bedding. There was also the baking for his special diet, which they did to try to offset some of the cost of caring for him.

Both Mr. and Mrs. Gulsvig thought that while most children took up a tremendous amount of time initially this decreased as they grew up. Ultimately parents were able to resume a separate life again and take up old friendships, hobbies and careers. This would not be possible in their case and the isolation appeared to be deepening. Mrs. Gulsvig explains:

Rebecca [their daughter] grew away from us; she went through the stages and sort of separated herself from us. With Mark it has just got worse. If you’ve a mentally handicapped child you’ve got no space in your life.

Apart from the physical workload of looking after Mark when one parent coped alone in order that the other could go out "It was difficult to switch off from the anxiety." Taking Mark out anywhere beyond walking distance was difficult as they did not have their own transportation and if they tried to take him on a bus he screamed and they received complaints from other passengers.
To them it seemed that few people had any real knowledge of how caring for Mark had changed their lives. Some friends did still call on them, but rarely offered any practical support or real understanding. The needs of a child with profound and multiple learning difficulties and complex behaviors are outside the experience of most people. However, such visits from friends were welcomed if not relied upon. The acceptance of their situation was also an isolating factor. Their awareness of the present and likely future quality of their lives left them stripped of any pretense that they were an average family. Relating to other families was harder because of this realization.

They were worried about their daughter, who had very few friends in the neighborhood. No one ever called for her at home despite the fact that she was a popular girl at school. The pain they felt on their daughter's behalf appeared much harder to cope with than their own. Mr. Gulsvig felt that "Rebecca's got to find a way around it. We don't know how to help her, but we'll try... Rebecca knows we'll support her. She knows we love her." Mr. Gulsvig said "We don't think we've done too badly with Rebecca." He considered that despite their problems and bleak outlook on life "she still has lots of fun and laughter at home."

The other two sets of biological parents interviewed had their children living in group homes. They felt that the situation created for their other children meant that the decision had to be made and faced up to. They all agreed that the activities in which they now participated from hobbies to holidays had previously been severely restricted. Their other children had received insufficient time and interest and had few friends. Each family felt that while they were able to cope with short-term commitment to their child
with a disability during regular home visits, the physical and mental stresses and strains of full-time care were beyond their capabilities.

The community homes were both situated in expensive residential housing areas. They were separated from their nearest neighbors by extensive grounds. There was little, if any, interaction between the staff and children in the homes and the local residents, which apparently suited both parties. As stressed previously, the surrogate parents had lives beyond the community homes in which they worked. The children in the homes were also much less isolated than Mark. There was a range of activities in which they could participate and few difficulties over raising the necessary funding. Swimming, horse riding, and trips to the beach were readily taken. Transportation was not a problem as each establishment had its own vehicles. Often, extra helpers were taken on to assist with special trips or for school holidays. Yet, the children in the group homes were isolated to the home in which they lived.

All of the biological parents described the difficulties, which echoed through the Gulsvig family, that they had experienced prior to their children being admitted into residential care. Mrs. Cory explains:

I rarely go out. It is hard enough getting to the grocery store when you have one kid who is having seizures and people are staring, and the other kid telling strangers that he wanted to kill himself. It is not worth public humiliation just to go out. I would rather stay home.
They also expressed concern about the way the behavior of the child with a disability had isolated their other children from neighbors, friends, and boyfriends. Mrs. Robinson elaborates:

My oldest daughter, don’t get me wrong, has many friends at school. After school, she will go to a friend’s house, but she never brings friends home. My daughter has never had a boyfriend. I think boys are scared of her brother. I just want to tell them that Autism is not contagious.

Two parents were also aware that their anxieties over their child had caused them to cut themselves off from others. Mr. Cory explains:

We are very aware that our personal insecurities keep us from making connections with others. We are worried what people think of us, that we are bad parents, that we don’t know how to take care of our children. We have a right to feel this way. Past experiences dictate that we are being scrutinized by our neighbors, friends, relatives, and even strangers.

However, the parents of the children in both community homes were no longer isolated in the way Mr. and Mrs. Gulsvig were. The two mothers had returned to their careers. All of the fathers worked and all of the couples enjoyed a social life, although this ceased during the occasional visits home of their child with the disability. Mrs. Robinson said:
I have a new job at an elderly home. I couldn't work before because I was always being called away from my job to deal with Kenny. Now I have a steady income. I just got engaged and I am getting married in less than six months. Kenny is very important in my life. Kenny comes home once or twice a month. When he comes home, we enjoy a quiet weekend with him at home. It is too stressing to take him out on any adventures, besides, he goes out on outings at his group home.

**Fear and suspicion**

Children with disabilities appear to generate fear and prejudice among the general public, particularly when their behavior is unusual or bizarre. Mr. and Mrs. Gulsvig described:

When we are out in the local community, people stared and were rude to us when Mark did odd things. Shopping at the local grocery store was often a nightmare because Mark was extremely noisy or ill tempered and would hit the side of his head. If he managed to reach stacked shelves he would knock items to the floor or eat his way through the packaging to get to the food. People were either insulting about their handling of Mark or offered inappropriate advice.

Mr. and Mrs. Gulsvig repeated many times that attempts over the years at forming good relationships with neighbors were hardly worth the effort. Mrs. Gulsvig pointed out that she had given up trying "to explain to neighbors and relatives that mental handicap was not infectious." Mark's most difficult behavior to control was his continuous
screaming which, while reducing, could go on for hours at any time of day or night. This particularly caused tensions with neighbors. Mrs. Gulsvig explained:

The man across the back, his wife is a friend - ha! He had to go into another bedroom one night, in front of the house because he had to go to work in the morning. It's hard for us to keep on apologizing, when that's what our life is like every night. No one cares a jot unless it puts them out. How could they know how bad things are... or would they even care.

The Gulsvig family felt that they were unwelcome and an inconvenience to others. The community homes, due to their physical location and the reduced need for local contact - for example, food was delivered in bulk - rarely encountered the rudeness given out to the Gulsvig family. Crying and temper outbursts were seldom heard by neighbors because the gardens separated the homes from their houses. The transportation owned by the homes meant that the children were rarely seen entering or leaving the building and in any case spent less time there than Mark did in his house. There were no daily encounters on route to the shops and no need to explain the children's behaviors and apologize for instructions on the lives of others.

When they took the children out into the community the competence of the surrogate parents was not challenged. There had apparently never been any criticism of the way they coped with the children when they behaved in bizarre ways in public - for example, at the local park; Jill said, "People know that we are employed as live-out workers to do this job and that we know how to handle them." They did, however,
occasionally feel embarrassed when the children behaved badly, but thought that passers
by were generally kind and just ignored the behavior if asked to do so.

The biological parents of the children in the community homes had also
experienced problems arising from neighbors' suspicions. Kenny's mother found that
babysitters were not prepared to baby-sit for a child with Autism. Even longstanding
friends, who regularly sat for her other children before Kenny was born, were frightened
in case he woke up. Another mother, whose daughter experienced epileptic seizures,
stated how these fits could arouse terror in some people who made no attempt to hide
their feelings, "People would just stare at you or protect their children or pets. You can't
take too much of that, it just makes you so upset." Kenny's mother felt similarly, "I
simply didn't take him out if I didn't feel up to all that."

The data reflected how little the general public knows about caring for children
with disabilities. It raised haunting questions regarding how communities could become
more understanding and what role special educators might play. The data also suggested
that people are supportive of those caring for children with disabilities when they have
chosen to do it as a vocation, but not when they have to do so through family
commitment.

Community facilities

In the community where the Gulsvig family lived the services provided were not
grounded to help them meet Mark's needs. They related the problems that they had
experienced getting medical attention for Mark. If he needed the doctor, they had to wait
with him in the waiting room at the clinic, which caused problems with other patients.
The family dentist refused to treat him. Mrs. Gulsvig explained that even when Mark was
hospitalized for pneumonia the nursing staff complained that they were unable to cope with him. They insisted that Mrs. Gulsvig stay with him at all times in order to contain him. She felt that that was particularly unacceptable because of Rebecca. Eventually Mr. and Mrs. Gulsvig discharged Mark themselves and cared for him at home.

The situation seemed little improved regarding the relationship with the support services. Mr. and Mrs. Gulsvig felt that, if anything, their dealings with the support services had increased rather than alleviated the stress of their situation. They spoke of how initially they were not informed of allowances available to them and how often after finding their way through the maze of forms they always seemed to be the exception to the rules. They had particularly wished for a mobility allowance, but because Mark could walk they were ineligible despite the fact that traveling public transportation inevitably brought on a bout of screaming. Rather bitterly Mr. Gulsvig claimed:

We see the support service as us supporting them. We give them the information they need - we hope it will help someone else; if they get the right form that is. We hope that we are hardened to it now.

The described how they were assigned a community nurse whom they rarely saw, he continues:

They do no good anyway. They have a good gossip and go. We had a visit from a speech therapist once. She spent an hour talking about nuclear disarmament and
then left. We just laughed. That's all you can do. We think they come because they need someone to talk to.

In contrast, the local community services offered more to the community homes than to the Gulsvig family. The local swimming pool made lifting apparatus and an attendant available when the staff took their children swimming. The assigned doctor paid a weekly visit to the homes to check on the health of the children. This removed the stress experienced by Mr. and Mrs. Gulsvig of trying to keep a distraught child amused in a waiting room for up to an hour. Perhaps the most obvious difference in terms of community facilities was in relation to social services provision. The necessary facilities were provided at both the community homes. Here were modern lifting aids, laundry facilities and access to the medical and psychological services. Staff considered that there were no unnecessary delays experienced when claiming benefits on the children's behalf.

Community facilities were little used by the biological parents when their children made short visits from their residential care. Kenny's mother described the difficulties of taking him out with her because the local shopping center had so many levels and steps. This made pushing a wheelchair and carrying shopping bags extremely difficult. Even the beaches around the lakes were hard to visit because it involved going up a steep hill. Peter's parents withdrew from the community when Peter was at home because of his difficult behaviors. On the rare occasions when they took him out the whole family went along so that he was well accompanied.
Mr. and Mrs. Gulsvig both felt that the school was one of the few places where staff listened to them and tried to understand their circumstances. Mr. Gulsvig commented: "We trust the staff. They know Mark and what he’s like. They have him all day. They know we’re telling the truth." They were positive about the notion of partnership with the school and saw it as helping Mark and themselves. Mr. Gulsvig explains:

We need help too; it’s a new ball game to us. You might be able to help your normal kid with their math, but where do you start with mental disabilities? We need to be taught too. No one is going to do if for us, but if they’d just listen to us and not be afraid to approach us.

They considered that they had benefited already from a jointly planned feeding program for Mark that was carried out both at home and at school. They now felt that they needed some help in planning short- and long-term goals, possibly through regular meetings at the school. Regular visits were viewed as likely to help establish staff confidence in parents and trust between parents and the school. Mr. and Mrs. Gulsvig thought that seeing regularly what Mark could do at school would encourage them to try things out at home. Mrs. Gulsvig explains:

Sometimes, when I’ve been into school, I’ve seen staff handling Mark and getting him to do things that I know we couldn’t do. But they wouldn’t think to tell you these sort of things because they don’t know we can’t do it.
They felt that they were often excluded from his life at school, not deliberately, but because there was no definite policy to include them which was agreed and known about by staff and parents. They were concerned that without such a policy for partnership parents seeking greater involvement and understanding of staff teaching strategies could be misconstrued as parental criticism of school practices. Mr. Gulsvig notes:

We don't want to sound like we are criticizing your professionalism. We are very thankful for all the school does for us and the last thing we want to do is tell you how to do your job or question your practices.

Without exception, all of the biological parents wanted greater contact with the school. They were worried that because their children were living in a group home, they, as biological parents, were being excluded from school events and education planning. This was not the intention of course, and that point was emphasized to them. Despite the restricted opportunity for carrying out educational programs at home, they thought that if a particular approach was being taken at school and in the residential home, then they should know about it and maintain that approach during visits. Most parents also had specific questions about how to deal with difficult behaviors, which they thought could be addressed through regular meetings at school.

As suggested by Mittler and Mittler (1982), "parents need to be aware of the precise teaching methods and strategies being used by teachers and other professionals to achieve any particular goal (p. 84)." Most parents were unaware of the teaching
techniques being used with their children. They stated that they were often at a loss to deal with some problems. Mrs. Cory stated:

"The school was using a great technique to teach Peter to self-regulate his negative comments and he would come home talking about buttons. I had no idea what he was talking about. His negative comments are very frequent and intense at home and my husband and I would of liked to start the same strategy at home that was in place at school if we would of known about it.

They realized that their own, often desperate, measures occasionally resulted in conditions worsening. Mrs. Cory Continues:

"I try reading books and implementing techniques, but most are unsuccessful. My husband and I are very exhausted and when Peter begins telling us he is going to kill himself, us, school, and the world we sometimes overreact and say hurtful things to him. We just don't know how to change this behavior. And of course, when we say hurtful things, Peter's behavior escalates.

They wanted help from the school. They sometimes asked for it, but usually only when the situation had become unbearable. Mrs. Cory finishes:

"Peter's negative comments at home had become unbearable. It was like every comment out of his mouth was negative and usually involved hurting someone."
We got to a point when we considered taking him to the hospital to have him admitted. We finally called the school and asked his teacher to explain the strategy she was using at school to reduce this negative language. I just wish we would have known from the start what strategies were being used at school so that we could use them at home.

The surrogate parents varied in their range of qualifications and depth of experience. They included psychiatric nurses, general care assistants of many years experience and those who had attended short courses on working with children with disabilities. Staff from both group homes welcomed, "greater communication with the school and wished to work in partnership on educational programs." They stated, "we would like staff to visit the homes on a regular basis, but we accept that it is easier for us to visit the school." They were aware of the dangers of putting the children under too much pressure if they were expected to work all day at school and then repeat the work sessions at home. Jill explained that the group home wanted to "ensure a balance of expectations." Specifically the group home wanted to "set up a communication system between the home and the school to report any problems experienced, changes in behaviors, factors likely to affect the children in order to improve continuity and avoid confusion."

*Listen to us*

When asked the question, "What can educators do to be more sensitive to the needs of your family?" 100% of the parents who participated in this study stated that they wanted educators to listen to them. The overwhelming majority of the parents (80%)
recommended that educators should realize that parents know and understand their children; their contributions and suggestions are valuable and should be heard and respected. These beliefs are evident in the following statements made by parents.

Mrs. Gulsvig states:

It is an overwhelming experience to have a handicapped child. Sometimes I think parents get written off as being out of line with things. Teachers must remember that there is a lot of value to what the parents say—even though they are hysterical or not rational—because they really do know that child. They may not be coping well right now, but they do know best.

She continues: School staff need to listen and believe that the parents have input in their child's health and education. Some professionals believe that since they are the ones with the degree that they know everything and believe that the parents are inferior and don’t know what they are talking about. People who are teachers and have no special education kids of their own have no idea what we're going through.

Mrs. Cory shares, "I think the main thing a lot of times is just to be a good listener. Sometimes all it takes is somebody to listen to you. Not always to have a lot of answers like 'You should be doing this' or 'You need to do that.'"

Mr. Cory adds, "I guess just be understanding of what the parents have to go through, and listen to what we want, and need, and just have to say. Just be there."
Quality and quantity of communication between parents and professionals

To the question, "How can educators be more sensitive to the needs of you family?" 100% of parents responded that the quality of communication between parents and professionals should be improved. Several parents urged that educators use a more humane demeanor when discussing their children with them, interacting in an honest manner and treating them with dignity and respect. Other parents indicated that communication between parents and professionals should occur on a more frequent and consistent basis. Concern for the quality and quantity of communication is indicated in the following statements. Mr. Cory begins:

"Well, for one, communication could be better. Giving us an idea of what’s going on on a routine basis, basic notes to tell what they’re going to be working on." Mrs. Cory adds, "I think just make themselves available to us, so that we don’t feel like we are alone, and keeping in contact with each other is important, too. We need to communicate about what we are doing at home, and at school, or at the doctor’s, or whatever."

Others felt they were talked down to. Ms. Robinson explains:

Please don’t talk to me like I’m an idiot or assume that I know what you are talking about. Another thing is sometimes I get the feeling that the professionals are talking to each other and not me. It’s discouraging. Another thing I might say is that instead of telling me what you are going to do with my son, ask my opinion, give me some say in his education and placement. I don’t know what all my options are and it’s tough.
Mrs. Gulsvig adds to this, "Understand that while you may have my child in your classroom for 6 hours and are tired, I have him for the other 17 hours he is out of school. I may not always be full of energy, but I am human, so treat me the same way you would treat a friend. Speak to me in the tone and language that you like to be spoken to. I am no dummy, but I think we all can do without so much professional jargon."

Mr. Gulsvig finishes with, "I would say that the most important thing for a professional to do is to talk to the parents and not above the parents. It's very hard dealing with a person who is talking at you, but not to you."

Sensitivity to family needs

Almost 80% of parents who I interviewed suggested that educators should be more sensitive to the needs of their family. Of the parent responses in this category, 100% indicated that educators should realize that every family is different, should get to know the families in more depth, and should demonstrate the ability to see the family’s point of view, as exemplified in the following comments. Mr. Gulsvig shares:

Well, I think that having the information we may need to know about our child is a good thing, but expecting us to want to know everything you know, so that we can teach our child like you do, is asking too much. Don’t ask too much of parents. Take what they can give and don’t make them always feel like they should be doing more.

Mrs. Gulsvig adds: "Every family and every family's needs are different, so my biggest concern is that they take the time to get to know us and find out what our needs are. Once
they know our needs and know how they differ from the next family's. I think this is a definite starting point and a solid base." Others felt that family lifestyle and personal struggles and successes are also important factors when getting to know families. Mrs. Cory explains:

I think my biggest advice would be to get to know what the family lifestyle is because all families are different. And try to guide your advice and consultation as a teacher to fit that family and its needs.

Mr. Cory adds, "They need to know anything and everything that I feel or that I have going on in my life. That includes personal things that might be a little hard to discuss. I still think especially with a special education child they need to the professionals need to know what is happening in that child's life, even away from school."

Characteristics of the family system are often heavily influenced by a family's cultural values and beliefs. For example, researchers have found that, in some cultures, the family unit includes extended family members or clans composed of several households of relatives with a commitment to a family-based support network, while other families tend to focus on the immediate family and utilize external support networks (Gonzalez-Alvarez, 1998; Joe & Malach, 1998). Knowledge and understanding of the variety of family structures and systems increase the professional's ability to respond to the family's needs. In turn, respect for the diverse systems of family
organization enhances a professional's effectiveness. We need to develop a personalized relationship with families.

*Increase knowledge about various disabilities*

Of the parents interviewed, 60% suggested that teachers need to have more knowledge about individual disabilities. The statements below characterize their perceptions.

Ms. Robinson felt that the "first step in teaching students with disabilities seems obvious. Treat them, simply, as students. After all, they come to school for the same reasons others do, and they bring with them the same range of intelligence and scholastic skills." Understandably, these truisms are more easily said than acted upon. Our best intentions often run into attitudes that can dramatically distort our relations with people who have disabilities. Ms. Robinson continues, "I think the main thing is to get as much true information about the type of disorder they're working with."

Other parents agreed. Mr. Cory explains, "Definitely seek out information and read pamphlets. I think that they need to be more educated on the disabilities." Mrs. Cory adds, "Sometimes I think regular education teachers need to get a better grasp."

Mrs. Cory felt that "regular education teachers need to design and teach appropriate curricula, assign work geared toward each student's ability, and grade papers and homework assignments." She also felt that "they needed to be involved in the students' behavioral and academic development, helping the students develop emotionally, feel comfortable in social situations, and be aware of socially acceptable behavior. She concluded: "Teachers need to remember that they are dealing, first and foremost, with students not with disabilities."
Improve the IEP process

The quality of interactions during IEP development and implementation was a concern discussed by 40% of the parents. Specifically, they made the following suggestions:

Mr. Cory suggests, "Just be more helpful at IEP meetings and stuff. A lot of us parents... know what our kids are entitled to. It would be nice if teachers would help us fight to get our kids what they need and what they deserve."

Mrs. Cory adds, "Read the IEP, I took my son to the school before school started, so he would know who his teachers were and could identify them. They hadn't even gotten his IEP, so they really didn’t know him. I'm asking, who would be responsible for adapting his curriculum and keeping track of that. And they're asking me, How much adaptation do you think he’ll need? I’m thinking, I don’t know; I'm not the teacher!"

Parents and caregivers had strong feelings about their child and services. They willingly shared information and provided me with insight into their personal lives, which included their daily successes and struggles in hopes to provide me with accurate information in creating effective steps to parent/teacher collaboration.

Discussion

Research clearly indicates that active parental involvement in the educational process benefits children both academically and socially (Henderson, 1988). In general, however, professionals in special education have not been successful in facilitating such involvement or in promoting collaboration as much as possible. Murphy (1989)
emphasized that ideally parents should function as equal members of the educational team, sources of values, determiners of priorities, and advocates. Although the value of such ideals appears obvious, many educators fail to understand the need to encourage parental participation. Pervasive attitudes and practices of those who provide special education services may be interpreted as fostering unsatisfactory levels of communication and collaboration.

Conversely, schools and school systems that are making positive strides do so by responding to the strengths, needs, and characteristics of families (D’Angelo & Adler, 1991). To facilitate such efforts, research and demonstration models regarding parent and family involvement have been generated by Epstein and her colleagues (Epstein & Dauber, 1991) and are widely accepted foundations for strengthening the partnerships between home and school. Epstein conceptualizes the following six types of parent involvement: (a) parenting (establishing supportive home environments), (b) communicating (designing effective forms of interactive communications), (c) volunteering (organizing parent help in the school environment), (d) learning at home (assisting families with homework and other related activities), (e) decision making (including parents in school decisions), and (f) collaborating with the community (integrating community resources to strengthen school programs).

Although all aspects of Epstein’s model are crucial to building strong partnerships between families and school, the results of the current study appear to further clarify interactive communication and decision-making roles within the context of special education. The parents in my study have sent a clear message regarding specific interactive stances that special educators must take if parents are to feel valued and
respected as partners. Although educators who wish to strengthen their partnerships with parents can take specific steps (Epstein, 1997), such as increasing communication with families, using parent networks, and learning to understand family views and parents' strengths in shared decision making, these steps will be successful only if grounded in the pragmatic input offered by the consumers they serve.

My research clearly indicates a discrepancy between the supports given and received by the biological parents and the surrogate parents. The biological parents spoke of a maze of paperwork to receive support services. They struggled to find appropriate health and dental care. Parents reported that information on programs for children with disabilities is rarely provided voluntarily. Yet, navigating the world of disability services and programs is bewildering. The surrogate parents spoke of having support services not only available, but the service providers come to the group homes to provide services.

My research also clearly depicts that the community in general feels that a person who chooses to work with children with disabilities is more knowledgeable and skilled than the biological parents. The biological parents spoke of how people in the community made remarks about their parenting or offered inappropriate advice. The surrogate parents spoke how at times they were embarrassed about a child's behavior, but never felt that the community looked at them in an incompetent manner.

Misconceptions about various disabling conditions abound in the general population and are related to the presence of socially disabling stereotyping as a cultural phenomenon. Significant levels of misconception have been demonstrated among the population regarding families and their children with disabilities. Public ignorance in these domains is thought to breed a climate ripe for discrimination, and studies have
shown that such discrimination does occur in the workplace and, perhaps more important, in the world of everyday discourse (Bayley, 1973; International League of Societies for Persons with Mental Handicap, 1978). Discrimination patterns are not uniform, however, and all disabling conditions are not alike in their susceptibility to discrimination.

My research delineates, from the parents’ perspective, specific courses of action that special educators can take to facilitate more sensitive and productive communication and decision-making partnerships. Each will be discussed in the following paragraphs.

Special educators must listen to parents’ contributions concerning their children’s needs, as well as family issues and concerns. As the one constant in their children’s lives, parents have valuable information to offer professionals. Although parents may lack professional training, they can still make good judgments regarding educational planning and instruction. Parents must feel that their contributions are heard and validated. Families want professionals to be supportive and nonjudgmental as they strive to deal with the day-to-day parenting of their children with special needs. Teachers are admonished to listen and consider all contributions without prejudice.

Special educators must determine concrete strategies to improve the quality and quantity of communication with families. Just as educators need to listen carefully, they also need to monitor their verbal and written interactions with families to ensure that communication is kept at a level of mutual respect. Parents request that educators speak to them as they would speak to an equal or a friend, rather than in a dominating manner, and without implying intolerance. In addition, regular communication from school, such as written notes, journals, informational meetings, and phone calls detailing successes as well as concerns, should be established. Educators must enable families to feel
comfortable in contacting the school with relevant information regarding home or related service situations that may affect student performance.

Special educators must be sensitive to the needs of the families, not just those of the students they serve. Parents encourage educators to "walk a mile in their shoes" and, as much as possible, to imagine how they might feel if they were parenting a child with special needs. Parents also exhort educators to recognize that every student they serve is a child in a unique family structure. By being aware of family issues, educators can be a key resource in tailoring school services as well as providing information about community services. Educators must monitor their advice and consultation to fit individual families and their needs while building their own knowledge of available supports.

Special educators must continue to increase their knowledge about disabilities. Educators should strive to be lifelong learners in the field. Parents ask that educators who are serving students diagnosed with disabilities with which they have limited or no familiarity seek additional information. By doing so, the educators are more adequately prepared to effectively address the complexities of those students' needs.

Special educators must improve the Individualized Education Plan process to be more receptive to family issues. Because the IEP process is the one mandated interaction between school and family, it must reflect to the fullest degree the potential for strong collaborative relationships. Parents ask that educators be responsive to them and regard their contributions as viable options for curricular and instructional services. Parents want to perceive themselves as equal partners in a team striving for the same goals. Educators
are encouraged to select service patterns and develop instructional goals collaboratively with families so as not to give the impression that the family has no recourse.

Educators must be willing to acknowledge that parents should have equitable, collaborative roles because they possess critical information about their children, without which the educational process cannot be complete. Parents know their children better than anyone else; they can represent them in a way no one else can, advocating for what they feel and know is best (Goodall & Bruder, 1986). Unless their message is recognized, internalized, and acted on, true collaboration based on the total picture of the child and family cannot be realized.

Clearly there are restrictions on how far schools can develop the notion of partnership. The time a teacher has available for parents is already much in demand and in most special education classrooms there is no non-contact time. There must, therefore, be a commitment from senior management to enable teachers to participate in sessions with parents. As suggested previously, deeper involvement with parents could prove stressful for staff and would certainly demand additional counseling skills for which training would be required. Teachers would also need to be more aware of the interrelated roles of the support services. This would assist in parents receiving timely and appropriate information on, for example, the allowances to which they are entitled.

The experience gained through carrying out the research and reflecting on the data was put into immediate use and has subsequently been added to. I feel very fortunate that the school I teach at has staff who recognize the value of, and are enthusiastic about, working with parents.
I have established close home-school links to ensure that support is provided for parents as soon as their children enters the school. Support is provided not only from staff, but from other parents. I also offer specific sessions to parents to address areas of need – for example, opportunities for parents and their children to use the pool and to access the sensory curriculum through the high school’s light/darkroom facilities and sound equipment.

Over the last twenty years research into home – school communication and relationships has steadily accumulated and given rise to an increasing number of articles and books providing advice on how to set up partnership schemes. Wells (1989) provides a useful overview of a review of the research findings on all aspects of parental involvement of parents in the education of pupils with disabilities. This could provide a useful starting point for teacher researchers looking for a way into surveying the literature in this area which at first can seem a daunting prospect. On a more practical note, the components of a theoretical model of parental involvement provided by Hornby (2001) could be used as a set of research questions to guide an evaluation of existing practice and to indicate the data that needs to be gathered to translate staff commitment to the principle of partnership into further action:

1. Information: how can maximum use be made of the information which parents can contribute?

2. Support: what efforts can be made to encourage parents to reinforce school programs at home?
3. Leadership: which parents would be willing and able to provide training for professionals or help in running parent support groups?

4. Communication: what can be done to promote effective communication with all the children’s parents?

5. Regular contacts: what are the best ways of maintaining regular contact with parents?

6. Education: which type of parent education programs should be organized?

7. Counseling: how can opportunities for counseling be made available to parents?

I believe that successful parent/teacher partnerships in special education are founded on the fundamental belief that such partnerships are an integral and indispensable component of a child’s educational program. True collaboration is a recognition that each partner has both something to teach and something to learn.

Future research should focus on the question of how to develop ethical guidelines for relationships between parents and professionals. Educators and families may appropriately engage, on the one hand, in an equal partnership to meet the needs of the child, and, on the other hand, they may be in a relationship where the educator provides support for intensive emotional challenges the family is facing, such as terminal illness of a child. How then to reach an appropriate ethical standard for practice? Future research should explore explicit parameters surrounding parents’ and professionals’ decisions about appropriate practices with each other. Future research might also explore and deconstruct the concept of
empowerment, and how do we let go of power and is there an unequal relinquish of power?
References


Self-Reflection

During the study, I felt torn between fulfilling the aims of the study and trying to respond to the immediate needs of the parents. For example, I felt selfish about wanting my research questions answered in order to achieve that end and bowing to the pressures of time, I addressed the research participants to my agenda again and again. To have allowed the interview conversation to digress might have resulted in conversation of more value to them. These difficulties were partly resolved at the conclusion of the study with the realization that the study itself had contributed to meeting some parents' needs by providing an opportunity simply to share problems.

One of the most difficult areas of the research was deciding on the use of time. Frequently, I felt I had insufficient time for observations, although the time that I allocated was generous and the observations generated more than sufficient data for the research. It probably takes a skilled researcher to be able to estimate the time required to meet with people and genuinely listen and explore their life. What I found most distressing was that when the observation had reached its anticipated length, or I had other commitments to go to, it was extremely difficult, when being trusted with details of parents' lives and problems, to terminate the discussion. The personal issues revealed in the conversations were extremely important to the parents and could not be rushed over or treated with anything less than respect.

Another difficulty to be overcome was that of readjustment to work in school after spending my evenings observing the families and surrogate families. I found it emotionally very draining to discuss with parents issues, such as the nursing of a child
involved in a tragic accident and worries about their survival, or to discuss with community home staff the admission of a new child who was covered from the shoulders to the knees in cigarette burns. It became increasingly hard to push this knowledge into the background of my consciousness in order to return to school and continue as normal. As the weeks progressed the content of my field notes became even more personal and intense. Inevitably the period of the research became a time when I questioned past assumptions and thought a great deal about the stresses experienced daily in the homes. It demonstrated how greater involvement with parents would put increased pressure on teachers and that this would have to be acknowledged and catered for by administrative staff. Also, if parents were to respond to the additional demands expected of them, then they must have more support from school.

During the observations the biological parents without exception raised very emotionally disturbing topics. If they had not chosen to do so, I suspect that I would have avoided raising them as I had no intention of adding unnecessarily to the stress that they were under. I discovered, for example, that for parents, who had decided to place their child in a group home, this decision still deeply troubled them and was raised time and time again in conversations. On several occasions parents became so deeply involved in such conversations between themselves that they forgot that I was present. It is doubtful whether any techniques of data collection could capture such moments adequately.

I found myself constantly questioning why this choice had to be so final and why part-time care arrangements were not available. Parents could then be reassured that time in care was all part of their children's education and managed by teaching staff with
whom partnerships could be forged. The heartbreaking choices which face such parents and their subsequent feelings of loss of rights appeared harsh and archaic.

As the home settings were so different, so were the ways in which I built up relationships with those involved in the research. The biological parents welcomed my interest in their situation. The sharing of concern for the children acted as a genuine bond. The conversations were regarded as an opportunity to tell someone "what it is really like." Relationships with parents appeared relaxed, friendly and increasingly characterized by trust and respect.

Relationships were fairly easy to build at the larger of the two group homes. At Heathfields, most of the staff had been there a long time and were very committed to it. Trust soon developed as we shared our knowledge and understanding of the children and their blessings and their difficulties. Information was soon readily exchanged. By the last few observations, regular future meetings between the school and the home were planned. A problem arising from this situation was that because I felt very aware of the work done by staff and sympathetic to their problems my data are not as detailed in key areas as they might have been. Assuming I knew the situation, I think that I may have failed to probe responses with vital questions that would have furnished clearer explanations. Although substantial information was also gained from Newstead, the smaller group home, the formation of working relationships was adversely affected by the lack of continuity of staff. Each time I visited I seemed to meet and observe different members of staff.

The weaker the relationship formed with research participants the easier it was to withdraw from the situation at the end of data collection. The more trusting and
supportive the relationship the more concerned I felt about ceasing my regular visits at the end of the research. Through my years of experience of teaching in special education, in order to carry out my work, I have had to develop a degree of perspective (not to be confused with insensitivity) to situations and families. This is forced on teachers who witness a terminal illness, and who have to come to terms with the occasional death of a child and the distress of parents. Inevitably, working closely with families over the period of my research that detachment gradually lessened. I found it was impossible not to become aware of and respond to the warmth and care displayed in all the parental homes which inevitably led to an emotional involvement with the children and their parents. This was especially the case in relation to the Gulsvig family whose strength, support for each other and care of Mark I came to admire. Such "going native" is obviously an important issue in research involving participant observation and one I had to come to terms with when considering how it might have influenced my data analysis.

I have learned that partnership between parents and professionals involves a full sharing of knowledge, skills and experiences in helping children with special education needs to develop as individuals. A commitment to partnership rests on the assumption that children will develop and learn better if parents and professionals are working together on a basis of equality than if either is working in isolation. Finally, I have learned that for a partnership to succeed there needs to be: mutual respect and recognition of the essential equality between parents and professionals, sharing of information and skills, sharing of feelings, sharing the process of decision making, and recognition of the individuality of families and the uniqueness of the family and child.
5. What are or could be sources of funding to support self-advocacy?

Now we get a pittance from the DD council ACT gets money from foundations we only get money from providers like when we do a conference we get sponsors. No money from Dept of Human Services DD council is mandated by federal law to give us money.

I would like to see DD council give more. I know they give other kinds of... I think we could further their mission a whole lot more than other things they do. I think my group has to lot better job of trying to get money from foundations. Groups see as social justice movement. I think we gotta have the freedom and the bigger vision and network to people sell themselves. We have to have funds to go to broad based movement.

6. How do you imagine the future of the self-advocacy movement in Minnesota?

Build the network and the idea that people feel like they are part of a bigger movement and that SA has a unified identity because a lot of people feel more ownership. It’s really hard to achieve these goals.

That people first isn’t John Cliff and ACT isn’t rick and mary kay and Gloria. I would love to know if I go away that I know that people first will keep going and the movement is bigger than a few key people. If MK left or Rick left ACT will keep going strong.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

What was said before about few people being in charge. People need to share power. Lack of common understanding of what we want to do and lack of stable resources so we can hire people and hire organizers to go out and do stuff. Sometimes lack of meaningful leadership by people with disabil. Kind of a token leadership.

8. What are the greatest opportunities for advancing self-advocacy?

We have lots of really passionate people and we have everywhere we go we meet more passionate people who get it and want to be part of it so that’s the biggest opportunity there. Obviously we have lots of issues and lots of cause for people with dis to come together and get strength from each other. Unfortuantley the issues are getting bigger with the Republicans in power.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Metro area and New Ulm... is a shining star
Strong leadership is a reason, people with DD support people in both areas have really strong leaders. Won’t let things die out.
10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Professional style like conferences where people are feeling they are involved in something important and I think create events that are participatory and ask people to talk to get a feel for getting organized talk to each other and building a group identity. I think those are the best training but as you know people don’t like to … they would probably like to sit and listen to people talk. The other thing creating events where people with DD have real leadership goals and they feel like it’s their event. Make sure it’s a high quality event without taking control.

11. How do people in the self-advocacy movement connect with each other?

Conferences is a really big one. We are trying to get together a statewide newsletter and we have a statewide website. We don’t have the resources to It’s a logical idea but we don’t have the resources to get it going. In a way that doesn’t depend on one or two people to keep it going. One of the ways people could connect. Hopefully issues in it that are interesting. For a lot of people connected ACTs Remembering with Dignity. People could id with that for awhile and connect around that. Issues that a lot of people understand and care about.
I talk to the U about we could have on a server at the U still unclear our web developer wants to get it ready to go up once we get it up I don’t think it will cost a lot to keep it up and going. We have an access to Act and Us both have a number 800 number where they can call us. Doesn’t get used much because we haven’t built that identity.
We tell people and mail it out to all the groups and when we do a common vision workshop we encourage people to stay connected and keep in touch. That the other big issue you hopefully heard about. For me and almost every support person SA is a real hard job when I first .. one part of a job was SA same at U I work on SA but I can’t work. I’m poin 1/5 FTE and .8 SA needs MK and Rick are fulltime SA people and at U they can’t afford to support only half time person it’s really going to take at least a half time person to make SA go. If we had financial support we could hire more and do more

We have 25 groups around the state all supported by people for different associations every group find. Some advisors work for ARC some for other providers and some get paid to support SA groups other are volunteers. We should have we have no control over any of them because.

12. Any other thoughts, concerns or suggestions?
I have lots of passion because I have a vision of what could be and I got a lot of frustrations too. 15 years I’ve been trying to get it going and stick with it. We are getting there.

National level kind of elite and hard to keep up on what they are doing or connect. They are a pol. organization. It’s hard to do a good job.
1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed.

Self determination top issue control over life and resources. AR C actively looking at effort. SA’s need to be supporting system to enhance self det. Choices we have to do this work with sa on public policy issues. They learn skills not good if no choices to control funding. Not being addressed as thorough as they could. MN. Behind now as we look at SD time to reinforce.

Number of things. General support for efforts, structure statewide. Growing number of PF groups organizing not PF in every country. Statewide infra structure. There are groups trying to develop this. ACT for example, number of ARC chapters involved. SW Mn. Eileen Erickson Organized before movement. Expanded greatly Now more groups. PF groups formed in central mn. And in Bemidji area. Hennepin Carver. ARC MN capacity staff working with sa’s workshops developed before with getting them involved in the pol. Process. PF central getting people reg. to vote in last election. Northland ARC in Duluth. 3 groups couples group and women’s group.

Arc Mower county active, SE has some things going on.

Past individuals in fact form committee this summer to look at all prog. And supports SA will fall under and will become part of service package SA will be part of. Pockets need to be addressed.

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

ACT, PF, they have done a lot of outreach in areas that there hasn’t been a lot of activity. ARC- PF central and ARC sw, ARC chapters in general. Why, because involving people with dis ingovernance and everything

Has been some collabs on conferences between people mentioned and providers to develop PF groups within company and agency. Hammer, Merrick corp. Inst. For community integration at the U. Couple sa paid staff, John Smith active in PF. Cliff Poetz always strong. Shows commitment including them as staff. Any more SA that you can name 9I asked this)
Chalie Applequist in Rochester
John Rishmiller varying level of involvement, some folks from act Gloria Katie rank, carol robinson had leadership role.

3  How would you describe the way the Minnesota self-advocacy movement is structured?
Trying to figure it out if there is a movement. Mike listed main org. How do they intereact and overlap is still unclear. Both agreed. I don’t have a sense myself of the structure aware of people doing things but not if there is a. A lot of parallel efforts going on don’t have a sense o how much they overlap

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?
ARC standpoint. Look at what has been successful here an put together a work plan. One step and the other is bringing key players together and look at efforts and see what can be done to improve them.
Key players. Look at list and see if we have left out people

Work group needs to Alliance for full part. Det. We really didn’t understand what was happening as a whole in Mn. This will will give us info. Growing out of meeting in sept we will have more of a work plan. One example: I should learn more about all these things, this is a great step this audit.
At sstate level I still don’t have clear perception of what is going on. Not as org. as ARC on this issue. WE are taking some steps to help organize.

Until people have contrl of resources it’s kind of a sham.

5. What are or could be sources of funding to support self-advocacy?

Need to survey our chapters and gather that info.
Mike” aware DD council provided funds to PF and ARC chaps to go to SA conferences and infol to help ACT do Common Visions.

Grants, we need to look and on-going activities. kkWithin kARC looking at other funding sources that might sustain us.
Heard talk in this state and maybe others, getting some of DHS budget to go to SA efforts.
Important to have more instit. Funding state hasn’t done anything in that area. Do search and see what other states are doing. Don’t see it as high priority in state now biven what’s going on.

DD council put above with organ. That support.
Partners in Policy making now going to SA
9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

In large part in some areas it's because of people not sure of all. True in SW mn. Lean in many Erickson years built a strong group not always people first but involved and connected in community. Can only speak for ARC, more effort to restart or start groups. Key individuals now we need to make it systematic. Some cases board members. Action clubs with Kiwanis clubs. Indiv and chap. Some effort also when people with dis. Took up the mantle

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Steve distanced form no comment
ACT has done things with common vision and leading change id qual. In self but other than things they do and flyers we do I know of things I don't have ocomment on them. No ideas of what might be effective.. wells run dry here.

Since DD council provide funding for SA eval forms to look at evals to see what's effective.

11. How do people in the self-advocacy movement connect with each other?
Through some chap just reg activites wheter workshops, picnics to bring them together, couples group, women's group, involved in chap active. With ARC or people first chap. Selling roses, car wash other activities. Day at capitol arc SW bring people up.

12. Any other thoughts, concerns or suggestions?
Laura Doyle - Department of Human Services 40 minutes

1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed.

A concern is that SA be able to speak for selves and we listen to them as opposed to suggesting what they ought to think. That need to be paid more attention to.

Probe: answer is the same. Respect of peoples feelings and abilities rather than assuming someone else can make decisions for them. Giving them opp. To be heard vs. manipulated. (Parent of person). Efforts made in Mn. For person center planning one step in right direction. System currently of case management so overburdened to achieve a more person cent approach is challenging for state and while we move in that direction consumer direction autonomy respect there is a challenge because of over burdened.

System of staff overburdents and reliance on government case management if we had really good care coordination system it could be more person centered and less directed by agencies.

SDet and SA what is the distenction. SD is a process and one of the essential elements is to speak for yourself SA...

There is a movement in Mn. Very affective groups

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

   - ACT and PF for DD
   - Access Press

Agencies support SA ARC DD concncil support and supportive to it but I wouldn’t want movement to be controlled by them. Arc has a lot of different interests but they were formed by parents and there is a paternalistic part of that need to know people mature and do have rights for autonomy and control sometimes organization s can be to pater. Need to protectovs. Need to set free.

   - Generally many agencies support and would like to see more promotion.

3. How would you describe the way the Minnesota self-advocacy movement is structured?

I don’t know!

They provide info see them at leg. Speaking on hot topics to leg. So there is a movement like a civil rights movement. Maybe not as strong but they are visible.

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?
A lot of things. Start with education and thought process around people with dis in general in the country. People more visible and changing over time. Still out of sight out of mind. A lot changing since more integration in schools but if look at Holocaust visible and people know what’s happened to Jews but no discussion in Germany to people with dis. Isn’t the exposure to what has happened worldwide even in the state so it’s too easy to forget without hist. reminder people forget there are issues. If I were a wealthy person and wanted to do something to help the movement I would have institute or museum like holocaust mus. Or symbols so it would be visible to people in this country so we never repeat those mistakes. So things we can do as far as ed. Our nation about all people esp. people with dis and keeping in public view will help create and continue sense of importance of protecting people also rights and autonomy over their lives.

People forget what is most important to us is also important to them. Create a sense of feeling.

5. What are or could be sources of funding to support self-advocacy?

Foundations, grants, you need a champion with money. Kennedy’s have taken on some of this but not totally in areas I like to see. You need champions money and power driven by it. Like bill gates. I can’t believe there aren’t people with folks in their families with money. Has to be private money.

I don’t know where they get funding assume dd council, arc, United way things like.

6. How do you imagine the future of the self-advocacy movement in Minnesota?

I think of it when we don’t need it anymore because we have respect for choice for others.

No way until you have exposure to it. I didn’t. When I had a child it was a steep learning process.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

Organization, money, people don’t see as a hot topic anymore deinst. So think all okay. Education big problem Public ed very bad. Not hot issues.

It was moving faster because it was a hot issue and we had terrible things happening in Mn with state hosp.

Barrier amt of public money in dis because people know in mn. We put more into dev. Dis services then any other state (dd waiver) we are compared to best or next to it so we can’t get better. All this spending is a barrier. We will never bet her.
8. What are the greatest opportunities for advancing self-advocacy?

One of the most expensive services we have is creation of mini gr home thorough waiver and it's most expensive form of service we have default move from inst. To mini gr homes thorough waiver. Fine for some but not for those with fewer needs it's not. Now recog of leaders that we spend a lot of money that not providing most integ IRE in mn. Who could live in more independent services. Big opp for SA to get behind the deininstitutionalizion of our waiver program. If they were interested in this as a topic they could approach the commissioner the div. director and people would be very interested in working with them on this topic. We are starting to get attention. Big opp to look at consumer controlled housing and indep. What we have now is so expensive so it's big opportunity.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Cities, region 10 in Rochester 10. I lived in SW mn. And pockets of sa down there but they may not have as much organization and power. More org. support in TC area. State laid out so sparsely populatied in certain areas.

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

I think training giving people tools is more effective. They are wonderful things all of us can use them. I know there have been some efforts.

11. How do people in the self-advocacy movement connect with each other?

It seems obvious that it is from communication and emails seeing people at capitol how effective or prolific are I can't comment. Appear it is

12. Any other thoughts, concerns or suggestions?
1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed?

One issue is a lot of people with dis don’t have much of a personal sense of empowerment. Have to keep doing things to help people get courage to speak out in everyday situations. There are really a lot of issues to the self-advocacy movement in Minnesota. Services are getting cut back. Personal care attendants staff you have to really fight to keep the services intact to help people have a good life. Finally the other big issue is give the public a positive view of who people with dis are. That they are good and strong people.

IS there a movement? I think there is but I think it’s very small and fledgling movement it’s kind of an elite group of people hard to break in to. It’s more of a click than a movement. The ACT board get up and work for years and years and I work with a group called People First and our board and leadership we don’t get new people like we need to. It’s hard to break in. The old guard is pretty strong. It’s the people on the ACT board. MK and Rick and me it’s hard to bring new people in and make sure they get ... people that have been around for awhile they SA is such a vital part of people’s lives it’s hard for people to move over. Great big part of their identity is they are part of act or PF and to think about moving over and letting other people take leadership is scary for people that’s a tough issue. It’s like the obvious answer is to make the movement bigger and take more projects but that takes time and resources. Have to have people organizing new projects.

Better for the 2 groups to merge that’s a big goal of mine. I kinda championed the PF we are kind of a leader. Now ACT is ... compared to us ACT is huge we need to work with that ... It seems like we are just about the same kind of work it would make it so much sense if we just combined put SA’s on the 2 boards but no one wants to give up. That would make my life a lot easier to combine and as we do that we gotta be really careful not to centralize power and really it’s ... it’s really hard to keep an organization grassroots really getting people on the same page and invite people to join in and be part of shaping the agenda.

You want to make an impact on issues and have a dynamite conference but at the same time the process is really important to get the platform ready to go. Putting the conference together really need to let it be done by self advocates and make sure they are making the important decisions and to help people make those decisions. It takes time more time than for a group of people who don’t have intellectual dis and that’s really easy... ACT is guilty and I am too because we have to get things done cause you want a high quality and all of a sudden your taking control away from people with DD and it’s really important that people with dis are running the meetings but a lot of times I don’t have time I don’t have time to prepare people to get them on board and a think about what
do we want to get out of this. The outcomes are important you want the impact and process you want to have it be grassroots.

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?
ACT People First, local ARC chapters, the DD council but they support SA but not very well and I think provider issues are support SA some of them do, some do great job.
DD they don’t get or understand the social movement part they want SA .. they don’t get the process part of it maybe they don’t really understand how important it is to really reach people and have a quality. A lot of people aren’t going to go to a one day workshop they need support. Takes a lot of time and the DD council they don’t get that process.

Maybe a handful of private individuals
Some providers are very key players. People First of New Ulm are good strong supports that is because partially because the provider agency gives all kinds of support and gives everyone support on thoughts and potentials.
That’s why it ‘s probably good to have a broad base.

There is it’s hard to support a self adv group with providers people are vulnerable .
My board I probably have way too much power I suggested they ought not do something they pretty much go by what I say and that’s big responsibility.
I can imagine how staff don’t listen we have to get a staff advisor who works in those group homes and say well what do you mean and well it’s not that bad. That only happens once in awhile.

3 How would you describe the way the Minnesota self-advocacy movement is structured?
I don’t think it’s what it needs to be. I think there are a few strong leaders set the agenda and another handful of people who follow that agenda and other groups don’t even know what’s going on and do their own thing and don’t really know part of the bigger...

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?
I think we need a mechanism to get communication between groups and we need support of local groups and groups all around the state to we need to give them something bigger to link onto. That’s going to take time we have to hire people to get out and be organizers and pull groups together and get people excited about it.

We need organizers it costs a lot to hire em and keep em going.
5. What are or could be sources of funding to support self-advocacy?

Now we get a pittance from the DD council ACT gets money from foundations we only get money from providers like when we do a conference we get sponsors. No money from Dept of Human Services DD council is mandated by federal law to give us money.

I would like to see DD council give more. I know they give other kinds of... I think we could further their mission a whole lot more than other things they do. I think my group has to lot better job of trying to get money from foundations. Groups see as social justice movement. I think we gotta have the freedom and the bigger vision and network to people sell themselves. We have to have funds to go to broad based movement.

6. How do you imagine the future of the self-advocacy movement in Minnesota?

Build the network and the idea that people feel like they are part of a bigger movement and that SA has a unified identity because a lot of people feel more ownership. It’s really hard to achieve these goals. That people first isn’t John Cliff and ACT isn’t rick and mary kay and Gloria. I would love to know if I go away that I know that people first will keep going and the movement is bigger than a few key people. If MK left or Rick left ACT will keep going strong.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

What was said before about few people being in charge. People need to share power. Lack of common understanding of what we want to do and lack of stable resources so we can hire people and hire organizers to go out and do stuff. Sometimes lack of meaningful leadership by people with disabil. Kind of a token leadership.

8. What are the greatest opportunities for advancing self-advocacy?

We have lots of really passionate people and we have everywhere we go we meet more passionate people who get it and want to be part of it so that’s the biggest opportunity there. Obviously we have lots of issues and lots of cause for people with dis to come together and get strength from each other. Unfortuantley the issues are getting bigger with the Republicans in power.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Metro area and New Ulm...is a shining star Strong leadership is a reason, people with DD support people in both areas have really strong leaders. Won’t let things die out.
Amy Hewitt Institute on Community Integration

1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed?

Systemic funding which doesn’t exist also the purse strings where funding is coming from now haphazard whoever the funder is controls the agenda or yanks money not always because of control but their source has expectations and if their sources not met Fundin now almost always grant related. Whose agenda is it. If SA want to get together and have fun we need to back off. Someone else driving the agenda. That model doesn’t work well. Counter intuitive to SA in an of itself. Challenge with money who controls and who. Minimal funding has existed and it is intermittent. ACT which rely on foundation money are separate entities. It’s confusing to people SA involved in both so efficiency problem. Have been attempts to merge but that becomes big thing does that take them away from their mission. But it’s confusing to funders, policy makers families.

Merge blended organization. Little FTE big effort. ACT and PF merging together. Differences

ACT niche of deve. Leaders and training and ed. Communities about civil rights movements more technical asst. and ed and training. PF more about grassroots cha[p level development. ACT more involved in policy and leg. action

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

Mary Kay, Cliff Poetz, Gloria Steinbring, John Smith

ACT and PF are organizations

ARM- ASsco of res resources of Mn. Statewide org. for res providers their members put resource at a local level to provide staff and places for sa to meet and support groups really trying to support local grassroots. Who gave money to state conf. half of org. are res. Providers. They are seen as big bad guys. are some honest well intended leaders who support local effort.

3. How would you describe the way the Minnesota self-advocacy movement is structured?

Not a well articulated movement in your face movement. Not on fingertips of everyday action of people working in the industry almost ancillary. Don’t know why but people try to seek to seek that perspective and include SA leaders on boards. From policy perspective not seen as a major movement. DHS doesn’t really know seek people out in a placating way. DHS would argue point but who you define as SA physical dis and intellectual.

Growing, it’s slow and steady what makes it hard is there isn’t systemic funding we watched this yr. when DD council pulled money from PF and all energy goes into trying to get money back. Slows down because of looking for funding. Progress over last 10 years but slow. No conf. before now 800 people.
I would try to build it into admin rates with Medicaid waiver tie to service delivery and keep the money pure. DhS could do if there was a champion.

Act and PF compliment each other and PF trying to figure things out statewide to organized some are adapt groups they form own things without affiliation. Groups all exist how do you bring them under an umbrella.

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?

Example of how in lives of those who work in field it's an after thought. Lg systems change grant in Ill. She works in workforce issues As more people are getting op. To direct own services individuals and fam. See how hared it is to direct services. They taking a lot of materiels for org. so approriate and useful for individuals. If we hadn’t been meeting with Mary Kay and you coming I wouldn’t have though of SA. Our worlds aren’t forced to be together and we hear and share perspectives. For MK it’s good to hear direct support systems are in big bad. No ongoing cont. major stakeholder meeting in MN. Even once a year. Advisory groups pop up but I don’t know any time where U said bring them all together where our worlds are forced to connect. This wouldn’t have come about if AFP thing wouldn’t have come about.

People don’t want to bother so why include them cause it will complicate things in terms of bringing SA in right away and that always being a first step. They also will ask to be paid and if I don’t have the money I don’t ask. It doesn’t occur to me. Pa has a good system they have state person who coordinate events for SA people call her all supports accommodations, notetakers one person organized it all. Great way to handle it.

Have to be planful materials have to be modified changed. logistics

5. What are or could be sources of funding to support self-advocacy?
I don’t know about ACT but PF here on-going center comm. Integ supports them. Cover john smith 25-50 percent and Cliff 11 hours a week. Core grant money and a place to have an office a lot of support printing etc. at least 10 years. We are hiring leaders and they are influencing work here. We have served as fiscal entry for PF.

DD council money comes with purse strings attached some because of their literal interpretation from funders. When they dish grant people have to produce what they are required. Their reporting back is ridiculous but without support or advice. I think they are gagged by their funders and literly interpret their funders. Pulled money and blamed on to grant advisory group. It was very demoralizing to self adv. Group. Give 30,000 and now only 15,000. A lot of work for that.

They could set aside a pocket of money. They don’t because sort of culturally something within that organization, ongoing systemic funding not something they see they should do. See self as more of seed money. I don’t know which SA are on the DD council if they don’t have sstrong internal person shoving it down our throat. That’s what happens
to us. We have to figure out for DD act to include topic around SA and programs in all 50 states like DD council. There are logistical problems, not all SA groups are official organizations. Many are connected to organizations. Other states who defines. Huge barriers to giving people with dis. Large pots of money.

ARCs now just trying to stay alive and they have purposefully tired to disengage because seen as a parent org, but most try to have SA on boards and support through own advocacy and provide staff but in terms of money no.

Committee what brought us together was the conference we were asked to id our priority areas and feed to natl group. If SABE hand’t pulled out it would not have been on top of list and direct care workforce issues ended up second.

6. How do you imagine the future of the self-advocacy movement in Minnesota?

It would be interesting to approach ARM-Remm owns arm if an ask could be made for an additional 10 percent to go to ACT.

In MN I think there will be one main group giving money out to local groups there is a common vision toward that. I’d like to think kSA would be more in face of policy makers at local and state level. I don’t see day at capitol things as effective getting more connected to local issues. Have to develop SA leaders. I don’t know with Physical dis groups and inter groups to see them come together.

All over country at a policy level it’s altruistic bring all together but it’s about budget cuts.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

Barriers, funding, trust and respect and that goes both ways assumptions that Mk talks about power and control and professionals if pretense is your bashing prof and organ. Some people can’t see civil rights movement so forget you your telling me your bad cause there are good and bad advisors if we could take a more collab. Approach. Our world’s don’t collide if they were forced to do so. We are huge and we have SA on board but what do they do and how does it influence my work no. Even within our org we can’t tell each other what we do to support SA.

8. What are the greatest opportunities for advancing self-advocacy?

Ripening from policy persp. At fed level and pressure exerted by SABE is a huge opportunity an dwe need to take it now.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Metro, region 10 rochester mainly urban. They are hugely progressive region fed waiver to do different monitoring they have
10. What do you see as the most effective way of training self-advocates? Probe:
What has been most effective at this point?

ACT great material matter of having resource of pulling people together and collaborating. The advisor thing is scary a lot of room in training advisors to be that to be adv and mentors and not paternalist. I’m not aware of efforts to train adv in systemic way or get them together to talk through things. Seen that happen not in exploitive way. Something need to happen there.

11. How do people in the self-advocacy movement connect with each other?

Conference has become huge in Minnesota. PF trying to create statewide structure that brings people together and hard if you don’t have access to technology and people to help you use. DHS had a TV system across state great way to bring people together. We are so far from thinking about using these systems.DHS hasn’t been doing much on anything.

12. Any other thoughts, concerns or suggestions?
SD and SA SD thing has become bastardized and about money in DD world we view it as budgets and being about to control that. Hard to sort that out because SD is about living own destiny and living own reality and you can do that with out controlling. With budgets parents still control money. Some is leaders in sd and not a rev. construct. So that is how people think about it controlling money. Need to look at SD as philosophy as all services and giving people opport to sd their day so SD and SA are different to me. SA standing up and speakin up for self and other in your situation.
1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed?

(OC. She was clearly talking from the perspective of ILC’s and didn’t know much about DD movement.)

Finding their own voice and being given the opportunities to do so. This is being addressed through people first. It’s an underground movement most people don’t really know about it.

Needs more publicity or public actions.

Not sure if there are efforts toward that in DD SA.

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

People First - they have local forums around the state reg. meetings.

Center for Independent Living are. Historically Mankato Center worked with dd other centers more limited with dd.

Not sure why that is but hasn’t been history for other ILC. Mankato does because they have waivered contracts. We have it as a goal to do outreach with dd to try to get them involved with our services. That is a goal for the next year. I’m not saying there are no people but not one of our biggest service bases.

With more probing she said, ARC is a key player. (she didn’t’ really know)

3. How would you describe the way the Minnesota self-advocacy movement is structured?

I don’t know if I know enough about it in terms of people with DD.

Other disability groups …. Going on very strongly throughout CIL in Mn all have conferences, classes, we have advocacy groups where we teach consumers how to be sa … I think going on inherently in a lot of different communities. Both rights issues and political issues.

Within our movement our involvement is limited with dd pop. I don’t have all the information on that. It’s sad, if there is more going on and I don’t know it would be a concern for me. I ‘m speaking what I know but historically we are advocacy organization… we must be consumer controlled so adv. Is a strong part of what we do.
Deaf culture limits to people coming together. Stero with hidden and ph dis and dd ..... 

8. What are the greatest opportunities for advancing self-advocacy?

I think just people getting in touch with CIL and local communities. We all have opportunity to serve people. People could be a part of and learn from. Giving more voice what issues they might be able to advocate on.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

This really related to ILC’s she didn’t know much about DD. I think adv. One of our core services going on in every center and it’s so diverse, we have ind groups and adv. Committee we do different things at different times of year we work on public issues and human rights issues. Consumer directed find something different. E grand forks Options works more on systems adv. Less service oriented. Don’t know within DD.

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Hands on adv training always best if they... we had an urgent cause when funding wiped out but it depends on their desires ongoingly. So many issues. Where their passion is focused they will be most inspired to act. Finding that info out with pop is critical. What are your needs? Trainings good and needs to start on personal level and develop. Basic skills basic level people have been denied these skills we have adults who don’t know what rights are we haven’t provided them.

I think it would be good to have one central program that people from all over could attend and receive a cert. something that would be lengthy so some high level skills are deve. And carry that back to their communities and become leaders. We need to train leaders from respective communities. To go back and work together on systems issues.

11. How do people in the self-advocacy movement connect with each other?

All the Centers there are committees forums, people first do a lot of this as well.

12. Any other thoughts, concerns or suggestions?

No that’s about it.
Colleen Wieck  DD Council

1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed

Where we see SA devel is thru providers. Linked with local arcs and growth in movement in day programs and res start sa groups within their orgs. Merrick sa committee she serves on 3 groups and 90 individ involved. Dakota communities stars progr. Growth occurring there. It may not be way Pf envisioned separate from an advisor. SA don’t have access to transp so meet at night at res. Providers realize this is the thing to do. If you’re a purist the org version was wasn’t attached to providers. I’m seeing.

Need to discuss you have ooks as if SA is going to be wedded to providers need to talk about. That is where money is. Providers have more assets to assign staff to be advisors we discover more and more sa groups out there they contact us. We have a chap but we say we aren’t on lists we see. If you want to see statewidness based on trasp. Needs it will be attached ot a provider.

If it is a statewide movement how else would you do it. There are advantages built in advisors, trasp. Dis wedded to provider interests is there a way to make sure training of adv allows chapters to do what they need to do.

In a sense mission structure phil and so forth. PA discovered no one knew other chap. Definition, locus of control, who is in control when a provider runs a sa and how do we assure the Pf advisors can benefit.

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?
ARC where it started, irving cliff, mel arc to ACT DD council funded activities way back St Paul ARC 80’s. DD council and now it’s gone to providers

Providers, ARC MN to every part of ARC—all over the state. ARC spread out Colleen timbers at Merrick
When they took performance contracting money metro based SA conferences. ACR homes Merrick. Went from state to local to regional arc’s
People First Mn. As non profit busy trying to get other SA’s groups organized

3. How would you describe the way the Minnesota self-advocacy movement is structured?

Local chapters first ,, areas have own structure in terms of what they do organize around providers community active. Merrick conferences, videos active legislatively. Dak community ARM conf. Varies based on location and advisor and if they have funding or not, if they have exta volunteers. Very localized and individualized. Those with more
monedy do more active. I don’t think state chap. Conference would be the unified factor, local and then state conf draws people together.

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?

Takes me back to debate about providers do we keep doing outreach to them saying this would be helpful as part of your mission. Do we approach Centers for Ind. Living.

It depends who can support it going back to first question. I think all ARC’s doing what they can do can’t think of one not involved.

School settings would be a market that is not tapped. Growth market especially transition age.

Need to discuss where it should go no congress it all becomes locally based.

Should it be centr or is it peer to peer.

People proud of what they do locally proud of tradition we do pol work, we do videos, comes from their agenda not top down.
Each area has a vehicle varies by agenda of local groups.

5. What are or could be sources of funding to support self-advocacy?

Providers, some paid by ARC, Some grants Bremer, from some foundations, United way must be, DD council for years so that is fed funds. ADD projects of national significance money. Neb read our waiver HCBW people can use money for SA training. MK said it was hard. We do have source but we haven’t figured out how to tap in to it.
Other states receive funds from DD division I think remembering with dig funds went thorough. Not aware if they have awarded a grant for SA.

Admin on DD in 2007 reauthorization won’t occur until then. Current comm. stays she understands and has met with ssa to figure out how to do this. Not every state has sa.
Hope is going to be them providing a stable source separate from all of us U DD council all of us.
Pat Morisssey

Got to think strategically.

Is there a conflict interest issue can money be given from state.
Performance indicators we have 75 we are bound by numbers. Nursing home only have 2. How will we prove money is spent ADD will do it otherwise.
Strategically we have to think of this so people don’t walk into the same indicators and we can maybe prevent problems and lose money to data collection rather than helping.
End result that all would be able to participate in able to exercise rights

6. How do you imagine the future of the self-advocacy movement in Minnesota?

Access to regardless of zipcode do you have access to the support training facilitation to exercise rights to take control of your life, exercise choices to be employed if that’s your choice, the number 1 issue, to control funding if possible, to be included and respected. Personal level future, next level is chapter future. That would be 1 step above this in some ways there is the structure that allows adv and others to assist people structure that enables all of first to happen and at state level that there is support and resources whether it be access to media, access to fed funds, publ website listserv. Critical voice of SA what are they saying so what can we do to facilitate that.

I think it’s growing in Mn. Growing because of SD public schools turning out grad. Whole new crowd of young adults who are sure I’m not going ot that day prog and not living in a group home. Clear because of the internet more people connected online and more aware and connected.

Far more adults and young adults speakers at events unknown people. Have own websites more assertive people, more action at legisature. Not the same group new emerging group, voting rights they are saying.

More commissions and committees including people on it. Whole new slew of people on it. More people applying for government appt. then before. Youth leadership we funded. By breaking down barriers of trad leadership org. (does this this beg the question of trad sa movements) Age segment too. This crowd wouldn’t go for teaching. We ;have a youth segment that’s different. It’s my choice Indiana took it.

I think the distinction is self det or self direaction, A lot of efforts going on outside of the Movement itself. Individuals taking on issues. If you want to call SA trad. PF then we have to call rest of it something else. Further more like small networks, not coalitions not trad crowds but more indiv. Pathways coming together on issue and then moving on, Family movement supporting this saying you come with me. There is growth in this area than trad. Way of chap.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

Transportation number one issue and DD people poor and underemployed or unemployed. Feels like we are under attack. Which doesn’t enable you to have the money to participate. Those needing most organization are poor. Trad chap may not involve younger people because they want ipods, job very different experiences.

Cultural outreach, fact we have so many in sped from minority cultures we aren’t reaching those pops.
8. What are the greatest opportunities for advancing self-advocacy?

Every person is great. All advisors and SA are terrific. We have so many more role models people who are spontaneous have more communication skills on higher level.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Metro high and Dultuth, Willmer Advisors make the difference and leadership themselves Individ with DD make it a priority a person works all the time the phones or make things happen. Merrick in metro they did the videos and DHS endorsing them. Finished new one YOU take the POWER. They didn’t’ choose merrick SA there say so they say to students in transition you pick where you go. That’s a good product.

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Not only formal training but also the coaching and facilitation. Formal training important especially where they participate versus lecture. Work as a team and make a pres. To county commissioner, bus exercise. Techniques we have learned whole other issue is enabling sa to train other sa to tell his story to others. Develop skills to develop speakers bureau. SA to SA’s you have to have the facilitation and counseling under it. Have to have the follow along get revved up so they can take power system to support them and a system that changes.

More surveys to figure that out what speaks to different people. Irving, ed Roberts Adult learning people underestimate what you can and can’t teach. People rise to the occasion, they can be a member of a team. Often isn’t they lead but we turn to them and say M... tell us about this. Assumptions prove to be false I have a lot of these stories. Figure out competencies and back up and figure how to enable them to participate in training. Multiple ways. And what is the learning style of person.

Every person with dis is a teacher to the rest of us.

11. How do people in the self-advocacy movement connect with each other?

Phone bills, internet, email conferences and they attend other gathering ARC MN convention. Chap to chap facilitators.

12. Any other thoughts, concerns or suggestions?

SD SA
It has eclipsed now became part of waiver. Multiple layers of confusion.
1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed?

No not a movement. There needs to be more work in whole arena. We have nec. People skills but people don't recognize that there is a self adv framework. I think there is but ther isn't. State doesn't recognize, local gov don't recog. Still want to keep... if movement why would we need to have a lot of programs because people would be self suff. Someone needs to work and help people understand the process. We've come far but still.

Funding is huge issue. Here we are in special session without anything like this on the agenda.

I think ACT is doing good job on public awareness they are only ones as far as I know doing training or work the movement. Do we bring in outside people to do this

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

Self advocates themselves by living on own standing up for rights being involved in org. having a voice.

I don't know of any but ACT who promote SA we can move in that direction having a state SA is the attitude but in long run it would benefit people. Like early intervention you can work up if you start early can be done from early on.

I don't knw what ARC does, I don't know dis law clinic, and asst. tech. Do people know about other efforts I don't hink so. We need to do more work in public education arena.

3 How would you describe the way the Minnesota self-advocacy movement is structured?
I don't think there is a structure from bottom up or top down cause I've never heard gov. talk about SA Leg needs to talk about it. IF there was I don't think org. would have to gravel for funds. Look at it from all people viewpoint all children all people.

I think we have a lot more to do in public awareness arena and that needs to grow and have a marketing tool and who to? Institutions, parents, schools, people. I think needs to be marketed to families. They will say no, it's fine where they are at now. I have cousin who has a storkein nursing home he clalled me, what canwe do I called rick. He set up and husband said no. He holds power and that's what happens to SA
who has the power. Only group in country someone still has to tell them how much money they can have.

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?  
Funding is the key. funding org. that do sa work. Doesn’t mean ACT has to be the only one. Why did we start this and why because SA felt their voice wasn’t at the table.  
Funding is the key.  

I think we need to promote SA themselves in anything they choose to do.

5. What are or could be sources of funding to support self-advocacy? 
Private and we haven’t touched on the business community. They need to take a look at what SA do. Grocery stores. Why can’t they come together to provide funding for SA for everything, for early intervention programs. Also philanthropic org. Bush, Bremer, can fund and the state and county and local governments. Once they recognize what org. have done with their money it can be on-going based on reputation of organization is. Outcomes tell them what you have done. As well as the business community.  

I think there needs to be more org. that promote SA or build it into their infrastructure. Shouldn’t be left to one. But then you get into competitiveness.

6. How do you imagine the future of the self-advocacy movement in Minnesota?  
I don’t because I don’t think they are funded to continue the work. We need to ensure that happens. Do we have lobby day at the capitol. We need to bend the ear. It isn’t just leg time to do it. That isn’t just the time you do it. It’s a process you have to work at to continue to be in the forefront at all times. Toot your horn and recognize what you have done. Has to be an on-going event you have to have a track record. Develop though staff, SA’s and has to happen all the time. One person can’t do this alone. That’s how you win elections, you hire lobby groups.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past? 
Public awareness, funding, outcomes what have we done. I don’t think it’s going to change. When you have someone in your family you start to care. You need to know what’s going on. I don’t. Attitudes of people need to change. Churches they control the dough… and attitudes.

8. What are the greatest opportunities for advancing self-advocacy? 
We have to look at history and find what we have done. Not the people but the whole movement of it. History present opportunities a lot. History wall goes everywhere an opportunity to understand where we come from.
With ADA recognizing natl things and being included in there. But do we have a natl. SA week. You can learn to standup for yourself and always have to be teaching that all the time.

Advocay should pervasive in all sectors.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not? Metro area because of demographics Southern Mn. New Ulm. They have done homework and are excited and promote is.

Where are the people of color in this movement.

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Think of curriculum and how you do it. Invite SA into the planning process. Act has a whole curricul and it’s a continutum. They need to go through a training

11. How do people in the self-advocacy movement connect with each other? By coming together through organizations through conferences, collabs. Not enough of this going on.

I think when we do public awarness we need to reach out to everyone child care providers, do they know anything about SA do we talk about disability, SA’s we don’t reach much of population that encounter people with dis.

12. Any other thoughts, concerns or suggestions? We need a revolution!!!!!!! I feel that.. how long to I have to do this it’s a life long experience cause when youleave you want it better leave a legacy for them to carry on.
Interview with David Johnson
Center for Community Integration

1. What do you see as the most important issues in the self-advocacy movement for persons with developmental disabilities in Minnesota? Probe: Are these issues being addressed?

Part of deve. A sense of organization how does adv evolve we have individuals ACT and PF are loose confederations they need some support in some sort of formal structure phone lines web capacity basic things. Too scotch taped a little money here and there. Needs leadership from standpoint of formality so they have someplace to go with their energy. ACT don’t speak for all of what’s going on but some.

Need strategic alignment where they make good decisions around sense of priority adv. For all things at all times on all issues. What most critical to them now. Target issues. They are very dispersed they are value based all that but need to move voice in direction of policy.

2. Among groups and individuals supporting self-advocacy to grow in Minnesota, who are the key players?

Oegan PF ACT, don’t see SABE. In Mn. We have adv. Affiliated to primary org like ARC org who are amenable to it. PF struggles in trying to establish affiliates is hard with no resource. ACT most formal otherwise loose. You see visitors to it DD council given funds but now you have it now you don’t. It’s random who is making decisions how and why. We have been visitors to it. John Smith. Hosted and sponsored people Events meetings here on Sat. not fixed in stone. Cliff Poetz brought on too he is a leader, John smith here. Quarter time for john, plus support costs, 10-15 hours week. New person quarter time. Convening is what they do. Support meeting transportation issues. Develop leadership John does and meetings and phone calls.

3. How would you describe the way the Minnesota self-advocacy movement is structured?

Not sure it’s movement in implying momentum. Indicators of body of people revealed by April meeting of 800 people. Nationally can see growth of SA. They have gained strength. In mn. Strong core who try to convene others around them I’m not as clear no no other identifiable people as spokespeople. Don’t see a structure. If it wasn’t for MK she has an anchor for them to respond to. Place to focus from....

Our sense around PF we contribute to sense of place and person John and Cliff, given it some structure.

4. In your opinion, what needs to happen in order to support the growth of self-advocacy?

Stability of a few things. Nice if there was (how to do in gov today) needs to be a commitment to advocacy. Gov and adv. Don’t get along so who is going to fund.. Nice to have 100000 a year to have a front and person who can go about business. I’ve seen...
parent adv. Grow because of like minded concerns about curing medical concerns.
Parallell with these guys. They formalized then and said they needed a voice. They were
ed. People. Expanded org. with membership, they appt. board. For these guys being so
loosely aligned it’s hard. Resources important as a focal point to begin thinking through
and mobilize people get announcement out. Consistency of meetings calling meetings,
letters. Need help and opportunities to define leadership what do they need to know to do
this. To pull this off they need external support, they aren’t people who can mobilize
people around don’t have political capital to move. Needs to be commitment somewhere
in state to do it. People say HS should but then they own. Could be corporately done.
Long way to go. Takes a champion to do that.
Need greater strength. They have a lot of concerns I agree with most and all, so loosely
structured with so little resources but they can’t lift the VOICE. We are in a climate now
where parent and indiv adv not highly valued.

Role of advisors, trying to engage voices and let consumers run the process but how do
we support and what does this mean. We are not trying to jump to immediate solutions
nor do we want to lead them to situation... needs to be interpreted through their vision
and what it means to them.

There are good leaders in group that can quickly think through things. Are people in
system now. A lot of pieces are in place at least 6-7 so in state now that have leadership
abilities. there is a core there now. Ability to convene is critical, get together, organize
Needs to be some community adv. Board requ. By law. Half have to be parents so’s they
need to have some key state people to sit down to talk. They need access. People in my
role, dhs colleen need to make a commitment to these groups
To talk through and say we are a state agency and be honest if it’s policy adv.

5. What are or could be sources of funding to support self-advocacy?
Foundations but usually short time funding. Notion of trying to id a champion, someone in
 corporate sector,. Metronic for example we work with starting with mentoring day science
math and tech. They took to next step and funded a staff member to facilitate internships
there and supported someone championed it. They put money on table consistently to help.
In economy like MN what we know, for this either ARC does it pol parameters around
that. Need sense of organization, is it ACT or do they carry baggage.

/To do what dd council did down to 15 thous. Not even helpful. Resources that are

sustainable.

To argue for funds, needs to be sense of direction and goals, there are but maybe 150
goals. I would want to have a group of advisors back me up. Neutral body that is
apolitical and could operate as fiscal agency U or ACT. Better to have access to
infrastructure. Who are my friends needs ot be mobilized. Who is on board and there are
people in state who have dd kids how do you get this out to awareness of this is strategic.
It means I network call bob bruinicks is it appropriate.
6. How do you imagine the future of the self-advocacy movement in Minnesota?

We are trying to do things here. In last year... more visibility should be seen. Here we have hired 4 all on ssi, I can’t solve all that but give them place with a voice. Doing that. Hunter writing use piece and also doing functional tasks, looking for board appts. for him. To say that DHS can’t create a voice for them is not right. Gov. won’t create opportunities. Create visibility and presence for people. The future has to be to move people into organizations where they can develop leadership roles. Defining ways to enhance organization needs to be stronger commitment.

7. What are the greatest barriers to advancing self-advocacy? Probe: What have the barriers been in the past?

Climate tougher now. Getting people’s attention is big barrier. Getting attention in a way of your message is your message but to get it across it has to be aligned with broader picture. Context issue. They talk about don’t get enough respect but what does that translate into. Have to think through this. SA have a hard time getting people’s attention. Because there is no infrastructure it can’t raise up. They can do private meetings at ACT Arc, do here but don’t really have opportunity to put selves out because they aren’t really part of something. Are we going to remain fearful of adv. For what it will do to change policy mission in an org. re-direct energy are we going to be fearful because it will say something we won’t want to do.. how do you create change first need general awareness among broader section of people. they can do but need friends tool Focus and direction.

8. What are the greatest opportunities for advancing self-advocacy?

Team thing we have been doing has been bringing people together

Strong people in mn who are sa’s people aligned as advisors mk Charlie, people at dd council, support around that Focus has to come. I get what sabe is about they are like black panthers, either plan was genceous or unfortunate. If it was just chester going out short fuse that’s unfortunate.

9. What areas of the state are most involved in self-advocacy? Why do you think some are active and some are not?

Metro

10. What do you see as the most effective way of training self-advocates? Probe: What has been most effective at this point?

Multiple things. Training leadership in the abstract. Needs to be well thought out. ID leaders or potential leaders. Need to be engaged in adv. Some level and have some focus. Can’t do in absence of context. Needs follow-up. Needs to be longitudinal issues to change. The reflection needs to be part of it. Needs to be viewed as a cadre invest in group as primary leaders who in turn help develop leaders on boards etc. find core group that can really go through intensive exercise over 2-3 years. Dev something initial, maybe organize in community around X and come in every few months and reflect and
not have you as adv. Solve it for me. What are strat. And leave with clear steps. And calling back and forth to see if things happen.

11. How do people in the self-advocacy movement connect with each other?

Have no clue loose.

12. Any other thoughts, concerns or suggestions?

SD and SA
SD is set of skills a state of being able to act
Adv. Is an act and intention to act
They are not that aligned. We define differently here.