Nurturing a Self-Help Group: One Professional’s Experience

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Abstract
In April 1987, the parent of a child who was both learning disabled and intellectually gifted and talented and a professional educator (the author) founded Parents of Gifted and Learning-Disabled Students of Northern Virginia, a self-help group for people who were dealing with the challenges posed by such children. The article begins with a background explaining the need for such a group followed by a history of the group and a description of how it functioned. It then details ways in which the author and the group interacted over the course of 5 years. A major component of this interaction was the members’ partnering in a research study with the author—a process now known as participatory action research (PAR)—and the outcomes of that partnership.

Keywords
self-help group, participatory action research, parent self-help group, professional–self-help group relationship, special education, experiential knowledge

Prior to my involvement with Parents of GT/LD (simultaneously intellectually gifted and talented/learning disabled) Students of Northern Virginia, I had heard of groups like Alcoholics Anonymous for years. I had also known members or several self-help groups. However, it was the rapid proliferation of books, articles, groups, and activities related to self-help which caught my interest in the late 1980s. Self-help appeared to be an effective and popular means of enabling people to do many things, from teaching themselves skills to dealing with serious physical and/or emotional problems.

I began to read more about the movement and to talk to people engaged in various self-help activities. I soon realized that elements of self-help were basic to some of my own activities, including networking with fellow graduate students, teaching myself to use computers, and participating in church action groups and professional problem-solving groups. As I became aware of these underlying elements and of my own positive feelings about them, I wondered whether I could consciously incorporate them into my role as an educator as well.

Background: The Population and the Need for Support
I am a special education teacher who has worked in the public schools of several states since 1972; at the time of my involvement with this self-help group, I was teaching in a middle school in Fairfax County, Virginia. Over the years, my students had manifested many kinds of disabilities, including mental retardation, emotional disorders, learning disabilities, autism, and chronic physical problems and illnesses. During class time, my student and I have worked on improving academic skills, interpersonal relationships and social skills, self-esteem, and independent living skills. But our time together is a small percentage of their days and especially of their years and lives, and that time was spent in an artificial environment controlled by me. I felt that many of my students needed more help than I could provide in that setting, even when my efforts were supplemented by those of the school counselors—who spent even less time with the students in even more contrived settings.

My feelings were reinforced in most of the conferences I had with parents. During those times, they voiced frustrations that sprang from the bureaucratic procedures which are an integral part of the legally mandated public school special education programs. Parents and older students were often unhappy with the lack of understanding they perceived on the part of both school staff and “normal” students, a lack they often blamed on ignorance and disinterest on the part of these others. I had expected these types of comments based on my own experiences in schools. But they went much...
further and described problems that surfaced at home and in the community—problems of which I was largely unaware. Parents straightforwardly informed me that they had very serious problems in addition to those related to their children’s performance at school: difficulty understanding and/or explaining students’ problems to others, difficulty handling some of their students’ behaviors at home or sometimes in public, tension in interactions between family members, inability to see a productive or happy future for their children, and anger at schools that seemed to want them to somehow “fix” their children. They often disparaged school staff for not having answers they needed.

One group of students seemed particularly afflicted by the demands and callousness of school personnel and their peers. This group was comprised of intelligently gifted (GT) students who had been diagnosed with either learning disabilities (LD) or emotional disturbances (ED) or both. For convenience, I will refer to this combination of giftedness and disability as the GT/LD syndrome. These conditions are “invisible handicaps” that seem more difficult for people without disabilities to understand or to accept than conditions such as cerebral palsy or Down syndrome. As these problems have no obvious outward physical manifestations and no easily identifiable causes, other people often regard GT/LD students as lazy, unmotivated, or out-of-control rather than as individuals whose mental makeup and processes differ and whose feelings of self-worth and competence are constantly undermined. By the time they reach secondary school, many of these students have acquired habits and behaviors which further interfere with their acceptance by “normal” people.

Examples of students with the GT/LD syndrome are easily found in the school environments in which I have taught. I recall an eighth grader who had been diagnosed as having an attention deficit disorder (ADD) and who was so easily distracted that he could not maintain his focus on an academic task for more than a few minutes. His curiosity was insatiable; his command of trivia, amazing. Having traveled abroad, he could describe other countries and customs and peoples vividly—and empathize with those in poorer areas of the world. What he could not do was follow a string of oral directions, remember where he had left his notebook or to bring it to class with him, sit quietly, or work independently for any length of time. His impatience with the tedium of writing resulted in undone or “forgotten” homework, particularly with math assignments which required him to show all his work. His impulsivity led to many referrals to the principal’s office for “talking out” or for teasing other students. At one point, his mother confided to me that she had told her coworkers to tell school personnel that she was unavailable when they called because she could not bear any more complaints about situations over which she had no control.

Another young man had an IQ score of 147 on the Wechsler Intelligence Scale for Children, carried on adult-level conversations about topics in philosophy and science, and he wrote computer programs for his own enjoyment. He hated written assignments, though, because he had so much difficulty in composing a sentence and in spelling even simple words. His difficulties with visual-motor tasks resulted in nearly illegible handwriting and in returned papers covered with the teacher’s blood-red ink. His teachers constantly sent notes home about his lack of homework and unwillingness to complete even simple worksheets; his grades on tests were often in the single digits. The year I met him, he had been “written up” twice for throwing pens at teachers who were insisting that he concentrate on his work. His sophisticated vocabulary and sharp sense of the ridiculous combined to make his sarcasm and insulting remarks both memorable and definitely beyond the pale of acceptability in a classroom.

Then there was an eighth-grade girl who earned As and Bs in all her class except math. After 8 years of schooling, she had not learned her multiplication tables, reversed numbers in simple addition and subtraction problems, and confused signs indicating which arithmetic operation she should use. She sometimes complained that the numbers seemed to “dance around” on the page. She had failed every general education math class since the third grade. She preferred a period sent in the girls’ bathroom or even one spent in the principal’s office to one in the math classroom. Some days she just stayed home.

Finally, I worked with a teen who could remember almost anything he heard, could play four different musical instruments, and did an outstanding job as the master of ceremonies for all class productions—But he would not read fluently. When asked to read aloud, he had to “sound out” almost every word letter by letter; when asked to read silently, he stared out the window. He hid his discomfiture by taking on the role of the class clown. His knack for mimicry and his refusal to desist upon request eventually led to enough office visits for a referral to the program for students with emotional problems.

In a one-on-one situation or even in a small class geared to their strengths, these youngsters could be delightful, hard-working students. In large general education classes of 26 or more, they were problems. Teachers trying to cope with their needs were also responsible for covering the prescribed curriculum for all the other students and for maintaining classroom discipline. Those teachers felt that they did not have the time, training, or support to deal effectively with such students—a feeling that was reinforced by a special education paradigm which for years had removed “special” students from general education classes for part of all of the day so they could receive help from experts trained in disabilities.

These special education programs resulted from federal legislation. In 1975, the Education for All Handicapped Children Act mandated a free, appropriate public education for all students with disabilities. Since then, it has been revised and renamed as the Individuals With Disabilities Education Act (IDEA); the latest revision was in 2004. This
act requires local education agencies receiving federal monies to comply with laws, which require them to identify students with disabilities and provide them with education services specific to their abilities and needs. To do that, public school systems have had to develop special education programs based on a continuum of services ranging from residential treatment to monitoring student progress. Previous to that legislation, it was estimated that only about one in five students with disabilities received services in public schools; many of them—particularly the more severely involved—either stayed home or were serviced in separate facilities. After 1975, many of students were provided services in “pull-out” programs such as tutoring or in special classes in their school districts; over the years, there has been an increasing emphasis on serving special education students in the general education setting with their peers to the maximum extent possible—again increasing the expectations and demands on general education teachers.

Special education was also usually responsible for developing programs for gifted students at the elementary and middle school levels; at the high school level, advanced students were usually provided services through honors courses and/or advanced placement (AP) classes.

Although students, such as I have described, may meet the criteria for both the special education and the gifted (GT) programs, often they have encountered problems in obtaining the legally prescribed appropriate education for three reasons: (a) Their LD problems interfere with their academic performance to the point that they are not considered for GT programs; (b) their intellectual abilities mask their disabilities so that their problems are blamed upon factors such as lack of motivation or laziness; and/or (c) the interaction of their disabilities and their giftedness results in needs which are not met in either a LD or a GT program, especially when the special education staff has training in only one of the areas. The last instance has largely to do with social and self-esteem issues of students who are intelligent enough to realize their problems and frustrated by their inability to resolve them.

At this time, my students were assigned to me one class period a day for remediation in their weakest areas and for assistance with their other classwork. During the rest of the day, they attended general education classes in which they were expected to complete the same assignments and follow the same rules as their peers. They did not participate in the classes or activities provided for GT students. They avoided most of the extracurricular activities at the school, including clubs, dances, and sports; sometimes they were excluded from those activities because of grade averages or inappropriate behavior. As I talked with parents, I realized that, for the most part, they also were uninvolved in community-based activities (scouts, church youth groups, etc.) and rarely had close friends for sleepovers, shopping, movies, and so forth. They generally preferred the company of adults to that of their age mates, probably because of their above-average mental abilities and because adults were more accepting of them as persons.

I considered beginning a group for parents, but I had serious reservations about taking such a step. First of all, I worried about the time commitment. Furthermore, my previous experiences with parent groups had been uninspiring: After a meeting or two, they often quit coming or came sporadically. Meanwhile, anyone involved in organizing the meetings spent hours and energy trying to recruit members, to get reliable volunteers to undertake some of the “housekeeping” tasks, to provide appropriate information, and to handle disputes and unhappy people who came to meetings only to vent their feelings.

At the same time, I was pursuing a doctorate at George Mason University and had constructed my program of study to include networking and self-help groups. Through one of my sociology courses, I met Dr. Thomasina Borkman, who consented to be my advisor. With her help, I completed an independent study that involved interviews with representatives of 10 self-help groups in the Washington, D.C., area (Schubert & Borkman, 1991). These interactions with self-help group members made me even more aware of the efficacy of self-help groups. I toyed with the idea of trying to start such a group for the parent of GT/LD students, but I hesitated because of the amount of commitment entailed and because the literature on professionals’ relationships with self-helpers was rather negative.

**Relationships Between Professionals and Self-Helpers**

Relationships between professionals and self-helpers in the late 1980s and early 1990s were often problematic. Professionals, especially those who have never experienced the focus problem of the group, usually become involved with self-help groups for two reasons: to conduct research and/or to facilitate the group by providing support and expertise to the participants. The professionals view themselves as benefactors willing to donate time, resources, and professional knowledge to people who need them. Self-helpers, especially those who feel their needs have not been met by these experts in their professional capacities, sometimes respond favorably to these laudable intentions. Often, however, they responded with hostility, discomfort, and suspicion.

These less-than-positive responses are not unfounded: Research and case studies show that professional involvement is not always beneficial. For example, Kutchins and Kutchins (1982) described the evolution of a self-help group with professional contributions that was designed for Black teenage gang members. First, it gained an executive board comprised of professionals, such as judges. Next, a professionally trained counselor became the group’s leader. Then the group obtained funding from agencies which demanded that the group conform to their rules and procedures. The end
result was a large new building which housed a new staff to provide professional services for delinquent youths. Lost in the process were many of the components of self-help, especially personal empowerment and responsibility for one’s own decisions and actions.

Kleinman, Mantell, and Alexander (1976) reported that cancer patients in a group called CanCervive gave up autonomy, egalitarianism, spontaneity, and feelings of self-worth in return for the legitimacy of being affiliated with professionals. The professionals, however, felt that their counseling expertise, control, and power were constantly being questioned by group members. Balgopal, Ephross, and Vassial (1986) noted that professionals felt uncomfortable working with self-help groups because they lacked clear-cut roles in those groups, had difficulty with the zeal and self-motivating qualities of the members, questioned unconventional value premises underlying self-help, doubted that the groups could be as effective as professionally led groups, and only tentatively accepted the groups because of fear of losing control over the delivery of services to those people.

Despite these concerns, however, professionals continue to be both interested in and involved with self-help groups. Toseland and Hacker (1982) reported that 56% of the groups they surveyed were begun by professionals, including social workers, reverends and priests, teachers, psychologists, nurses, and physicians. Seventy-two percent of these groups had one or more professionals as current members. Yoak and Chesler (1985) similarly found that 52% of the groups they studied were led either by a professional or co-led by a professional and a nonprofessional self-helper. In addition to articles such as these, much of the available literature on self-help is devoted to research that involved professionals and self-help groups (e.g., Mack & Berman, 1988; Silverman, 1976; Storer, Frate, Johnson, & Greenberg, 1987) and to publications that described ways in which professionals may assist self-help groups (e.g., Gartner & Riessman, 1982; Gitterman, 1989; Powell, 1987, 1990; van der Avort & van Harderden, 1985).

Starting the Group

Although my interest in beginning a parent group continued to grow, I took no action until I received a telephone call from a stranger named Sally Reeves. She called at the urging of mutual friends who were aware of our shared interest in children who were both gifted intellectually and learning disabled. That telephone call established a partnership that lasted until Sally and her family moved out of Virginia about 2½ years later. During our time together, we focused on finding ways in which to assist students identified as GT/LD and their families.

She was an ideal partner for this task. As a parent, she coped daily with the effects of the GT/LD syndrome. She had researched legal aspects of special education and was a constant advocate for her child in the school setting. She actively participated in several parent groups, including one for parents of GT/LD children in the neighboring state of Maryland. Her background as a nurse and her experience with other children made her knowledgeable of medical conditions (such as ADD and allergies) often associated with the GT/LD syndrome. She tirelessly pursued information and resources for herself and the group and undertook the responsibility for many of the organizational tasks—including serving as president and librarian. Her charismatic personality and personal interest in others drew members and encouraged people to volunteer for various tasks.

I came to the group from a different perspective as a special education teacher with both a master’s of education and an educational specialist degree. Having had taught at elementary, secondary, and college levels, I knew how schools functioned, what problems and challenges special education students face, and potential solutions to some of those problems. At the time, I was the head of the special education department in a middle school and was knowledgeable of local school policy and procedures as well as state and federal legal requirements. Rearing two “normal” sons of my own made me realize how much more strenuous and stressful parenting a child with special needs could be, and I had resolved to make myself available to anyone trying to support such a child. As an educator, I had participated in school-sponsored parent–teacher groups and in professional organizations. In addition, I had an ongoing interest in the benefits of self-help groups and some knowledge of how they functioned.

That interest coupled with both Sally’s and my previous interactions with other parent groups coalesced into determination to start a new group. Our past experiences had shown us that groups focusing upon giftedness or upon disability would not adequately address the issues and concerns raised by the GT/LD syndrome and would not provide a forum or a platform for discussing promising practices, ideas, or solutions. Groups sponsored or led by professionals tended to be centered on topics which interested the professionals or to promote services which they offered. Finally, groups sponsored by schools and professionals generally dealt with school-related topics, while the effects of the syndrome were diffuse and affected almost every aspect of the lives of these individuals and their families.

The only parent group that seemed to match our ideas was the parent group in Maryland, so we used it as a model for logistical considerations such as meeting format, registration, recordkeeping, and so on. We also used suggestions from its members for potential speakers and program topics, and we copied their ideas for building a library of reference materials and inviting teachers of members’ children to meetings. We published a newsletter that included telephone numbers of people willing to answer questions. Later, panels of parents and of students were created to do presentations at the meetings of other organizations, including the parent–teacher organizations of local schools.
Our backgrounds and choice of model led to several decisions. First, we felt that the group should be run by and for parents rather than by professionals who would ordinarily provide direct services to our students. Parents would set the tone and select program topics and/or formats for meetings based on their needs and preferences. If appropriate, professionals would be invited to speak at a meeting or to provide information and/or literature. Professionals, especially public school teachers, would be encouraged to come to meetings and to participate in them, but the officers of the group would be parents. This meant that I became a consultant/sponsor of the group, providing visible and tangible support, arranging meeting facilities, making myself available for questions related to the school system and special education, and so forth, but not serving in an official role.

Second, we felt every meeting should provide attendees opportunities to ask questions or just to talk about problems or concerns that were specific to their children or situation. Thus, as in the Maryland group, a portion of each meeting was devoted to sharing on an informal level: at a minimum, a ½ hr of “greet and meet” time before any planned program and another ½ hr or so of informal discussion afterward as we packed and straightened up the room. In addition, several meetings were either small-group discussions (usually based on children’s ages or grade levels) or parent (and later, student) panel discussions.

A third priority was the facilitation of communication among interested parties, whether or not they attended meetings. The number of individuals with the GT/LD syndrome is a small percentage of the total population, and these persons and their families lived throughout the northern Virginia area around Washington, D.C. To assist us in linking people looking for information with a person who might have that information, we asked everyone who attended a meeting to register, giving his or her name, the age(s) and grade level(s) of his or her child(ren), and an address and a telephone number. If someone called with a question which seemed best referred to someone else, we called the third party and asked whether he or she would be willing to speak with the original party. To the best of my knowledge, we had no refusals from third parties during the 5 years I was with the group.

As the group evolved, our telephone system was facilitated and complemented with print media. We established a newsletter that listed names and phone numbers of the group leaders and volunteers like myself who were willing to talk with callers. We also established a small library of books, pamphlets, articles, school district publications, circulars on summer programs, and handouts from presenters; these materials could be purchased at cost or borrowed for a month at a time. As the group met at the school where I taught, we stored these materials (as well as the refreshment supplies) in my classroom. Thus, people could contact me at the school for access to materials in the weeks between our meetings; they could also return materials using the interschool pony mail system. Finally, as I had easy access to the materials, I could add them and/or share them with other sources of parent assistance, such as the district’s parent assistance center.

But most of this came later. In April 1987, our group for parents of children who were simultaneously intellectually gifted and learning disabled met for the first time. Eighteen women sat in a circle, introduced themselves, and briefly described their reasons for attending. As the introductions proceeded, I realized that I was the lone educator in the group—Everyone else was there as a parent whose major concern seemed to be obtaining better education services for her child from the school district which employed me. Fortunately, the situation was not unexpected: These concerns were part of the reason I helped establish the group.

The group met only 3 times that spring. Out of those first three meetings came a list of potential and actual members, a meeting format, a list of potential programs, many questions, and a sense of having started a worthwhile journey with good companions.

**The First Year**

During the summer of 1987, Sally and I spent hours on the telephone. At that point, only the two of us were involved in the planning for the group, which did not even have an official name. Once the school year began, we soon were getting suggestions and physical assistance from volunteers, especially during the meetings, but at first, we essentially ran the meetings. As we had agreed, Sally acted as official spokesperson: she began the program portion of the meetings, introduced speakers, answered questions about the group, and so on. That first year, she even carted around our fledging library and shopped for refreshments. I encouraged people to register, made the arrangements to use the school’s library, arranged the furniture, made sure the room was left as we had found it, furnished audiovisual equipment, and encouraged my professional colleagues both to tell parents about the group and to attend meetings. Sally and I both constantly watched for articles and/or books which might be of interest to our group, made ourselves available to people seeking assistance, and searched for presenters who might have useful information for the group.

**A Typical Meeting**

Sally and I never planned the format for meetings—we simply continued as we began the first time. A schedule of a meeting would be something like this:

7:00 p.m.—Sally and I would arrive and begin to rearrange furniture, set up the registration and refreshment tables, and put out all the literature we had on hand. Others usually arrived about the same time, and they would usually volunteer to help or would start talking to someone about a child or about the group. Often
before the meeting began, several small groups would have formed based on a shared interest in some topic.

7:30 p.m.—Sally would start the meeting by introducing us and then would follow-up with announcements of meetings of related groups, summer programs, new publications on the GT/LD syndrome, and so forth.

7:40 p.m.—Next she would introduce that night’s program. These programs varied in format a great deal depending on what the group’s needs or interests seemed to be at the time. Sometimes a professional—someone with personal experience with the syndrome—would speak. Other times, we had a panel made up of parents or students. Once in a while, we simply discussed the latest information on a topic of interest or set up small groups for informal discussion based on age of the children, topic of concern, and so on.

9:00 p.m.—If we had a speaker or any type of presentation, it would end so that parents could ask questions of the group, volunteer comments, or just chat with each other. Generally, we adjourned about 9:30 p.m., but the meeting was not really over. People would stay and talk as we straightened the library and even as we stood on the front porch (having vacated the building by 10:00 p.m. as required by the school). There were nights when a group of us were there until about 11:00 p.m.

The meetings provided members a chance to share their experiences, knowledge, and concerns in several ways. They could directly address either Sally or myself before or after a meeting. During those same time periods, they often sought out other parents who had children of the same age or who attended the same school. During a program or presentation, they interacted with the presenters by asking questions or volunteering information. They also had access to Sally and me and to each other through our telephone tree.

**Programs**

The programs that first year reflected members’ concerns with understanding the syndrome and with ensuring appropriate educational services for their children. Among the topics covered were the characteristics of the syndrome, legislation related to special education, special education placement procedures used in the school district, psychological and academic testing practices and results, appropriate summer activities for their children, and ways to deal with school-related problems such as homework, inflexible teachers, poor self-esteem, and lack of appropriate social skills.

The formal programs were done by professionals who routinely worked with people who were identified as GT and/or LD. Group members were willing to avail themselves of the expertise of those persons, but they were not a quiet or passive audience. They questioned and challenged presenters as well as agreed with and supported them.

Many people who attended our meetings were frustrated by their experiences with professionals, particularly those associated with public schools. They came to meetings to learn their legal rights, to understand the syndrome and its effects on academic performance, and to explore options which should be provided within the public school setting. Many parents wanted to discover better alternatives than those proposed by school personnel or to find ways to force educators to make accommodations for their children’s disabilities. Some came because they did not understand special education procedures or jargon well enough to make informed decisions about their children’s education. Some wanted to know what recourse they had if their schools refused those things which they believed their children needed and to which they were entitled under the law; a few frankly wanted to know which lawyers they should consult. Several came because they felt they were fighting a big problem alone despite legal requirements that their children should receive an appropriate education.

At first, people with questions or problems tended to consult Sally or someone from the registration list. However, after Sally had introduced me as a cofounder several times, after I had answered questions and clarified points during presentations, and after parents of some of my own students referred other parents to me, I found myself constantly talking to parents at meetings and/or by telephone. After a while I seemed to be the source of choice for parents whose children were being placed into special education programs for the first time, who did not understand special education programs for the first time, who did not understand special education jargon or test results, or who wanted to know what services other schools were providing for similar students.

The change in attitude toward me was reflected in the group’s gradual trend toward inviting other professionals—especially public school personnel—to meetings so that they might become more knowledgeable about the syndrome and about services and accommodations which were being made elsewhere in the school district. Private practitioners, such as parent advocates, educational therapists, tutors, and psychologists, were also invited and encouraged to come. Eventually, the group discussed about changing the group’s name (Parents of GT/LD Children of Northern Virginia) to one more inclusive and, hopefully, more inviting to professionals; however, the change was never made because members wanted to keep the group focused on parents. On the contrary, many parents did encourage professionals who worked with their children to attend by personally inviting them, sending them the group’s newsletter, and even paying the membership dues for them.

**The Second Year**

By the end of the first year, our mailing/registration list contained more than 60 names, our meetings were increasingly well attended, and the group had adopted an official name, Parents of GT/LD Children of Northern Virginia. Sally and I needed help. We recruited volunteers among the frequent attendees, drafted a slate of candidates for officers and committee
chairs, and presented that slate at our May meeting. The slate was unanimously approved.

In some ways, little changed. Sally remained president, but she had the support of the traditional executive board in addition to mine. Because our members came from many of the communities in Fairfax County (and a few from Maryland and Washington, D.C.) and because they were involved in many other family and community activities, the executive board meetings were poorly attended after the first two. Some important decisions were made at those two meetings, however. One of these was to continue the group procedures and meeting formats, including communication between meetings through the use of newsletters, telephone contacts, and so on. Another was the requirement that any person elected to leadership positions in the group had to be a parent.

I had expected to retire to the sidelines at this point so that the group would become more fully owned by the parents, but group leaders constantly found things for me to do. I found the meetings enjoyable, and I felt I could help people struggling with school-related issues. Furthermore, because my classroom was in the building, I was also prepared to continue logistical support—storing supplies, arranging for the meeting site and setting up furniture, and so on. I soon found that I was expected to participate in executive board meetings in an informal consultant role; although I could not and would not vote, I was asked for information and opinions and I was “encouraged” to volunteer for such diverse tasks as identifying program presenters, keeping the group updated on research, and nominating candidates for various positions.

I also supported the group in other ways. For example, I constantly tried to make other special education personnel aware of the group. I mentioned the group at school meetings when appropriate, encouraging my peers to attend meetings on special topics and to refer parents to the groups. I talked about the group to parents of students I taught. I gave my name and telephone numbers to the parent support center sponsored by the school district and to a parent advocacy group in the community. I added the group to the directory of self-help groups maintained by the self-help clearinghouse of the Washington metropolitan area. I made a point of meeting district personnel in charge of the gifted and the special education programs; when I heard they were jointly planning a summer curriculums committee on educational service for students who were GT and LD, I volunteered to be a part of it. I also created some fliers for meetings where we had well-known speakers and distributed them to parents and to other special education personnel in the district.

The Next 3 Years

At the end of our second full year, the executive board and I recruited another slate of officers. Sadly, Sally’s name was not on it because she and her family were moving out of state. The proposed slate was accepted, and the woman who had served as Sally’s vice-president became our new president.

The 1989-1990 school year varied from the previous one in two ways. First, the executive board faded away due to a lack of interest. Instead, the president and I and several other people began meeting for dinner at a restaurant near the school just before the meetings. This enabled us to plan, compare new information, and make whatever decisions were necessary. In the restaurant setting, all parliamentary-type procedures were abandoned. No formal votes were taken; indeed, our discussion often just came to a consensus. My role changed somewhat in that my comments carried as much weight as anyone else’s. Although my level of input was probably about the same, I more directly influenced the outcomes.

The second change was that the newsletters and telephone communication system became more prominent. Our meetings rarely had more than 30 attendees, but our mailing list to dues-paying members grew steadily. The newsletter became more frequent (at least once a month) and much more detailed in that they now contained summaries of meetings in addition to listings of relevant articles, summer programs, and telephone numbers. Anyone who registered at a meeting was sent one free newsletter; anyone who paid the US$10 dues was mailed each one as it was completed. Although I sometimes provided notes to assist in the writing of the summaries, the newsletter was written by the president and a committee member.

I was still introduced at every meeting as a founder of the group and as a professional in the school system. After a while, I found that at almost every meeting there was at least one parent who had come to meet me and/or talk with me about a child. In addition, because Sally was no longer available, I found I was getting telephone calls which probably would have gone to her in previous years. Unless those calls were related to some educational issue, I referred them to a parent on our list.

I also began to get calls from teachers of students whose parents had attended a meeting: most of those teachers were looking for more information about the syndrome or for suggestions for working with these students. This reinforced my position as a link between members of the group and members of the education profession.

I served the groups as a link in another way. Over the years, our group evolved into a drop-in group, which was held together by a faithful core who attended almost every meeting. Newcomers to the group often had the same questions and attitudes toward schools and professionals as old-timers had had when they first came. Those who had come to meetings for a while had worked through some of their problems and had become more educated about the syndrome, their rights, schools, and so on. While a topic for a meeting might be very important to a newcomer, it might be “old hat” for an old-timer. Therefore, old-timers often chose not to attend meetings...
that repeated information or did not address their needs in some way, although they usually chose to remain on the mailing list and would return for a new topic or if they felt the need for support. After 5 years, I was one of the three or four who still came to meetings and who had been with the group from the beginning. I believe, I was the only one who knew the history of the group and the rationale for its guidelines and format. Furthermore, as I was still teaching at the same school, I was also easy to find by anyone who wanted to contact the group.

My most valuable contribution to the group may have been my function as a thread of continuity. After my family and I left the area, the group continued for another year. After that time, the personnel at the school had no record of anyone asking to meet there, and the library materials disappeared. The group has apparently dissolved.

### Doing Research With the Group

Although my activities changed somewhat over the 5½ years I was with the group, basically my role as sponsor/consultant did not. In 1990, though, I added another dimension to my role by requesting that the group’s members become my partners in my doctoral research project (Schubert, 1991). I wanted to document how a group developed a body of experiential knowledge, how that knowledge was shared among members, and how it changed over time. My plan was to have key members assist me in designing a study that would yield these data as well as information that would be useful to the group in recruitment, maintaining membership, and planning.

Several members of the group were involved at every stage of this endeavor. First of all, they agreed that the best way to approach our task was to use a questionnaire so that we could access everyone on the mailing list instead of just those attending meetings. They had specific suggestions for some of the items: for example, they wanted to know why some people only came to one meeting, how many people were working with professionals in the private sector, and what other support groups parents had found helpful.

They also assisted in determining the content of the questionnaire by providing me material from which to formulate items based on qualitative analysis. They provided items such as notes from meetings, logs of telephone calls, newsletters, and information about conversations before and after programs at meetings. Furthermore, when I had difficulty in coding and categorizing the contents of my large accumulation of data, they listened to my description of the problem and brainstormed possible solutions with me. This activity led to a categorization system that worked.

Once a draft instrument had been constructed, several members offered to test it. Their critiques and suggestions led to revisions which in turn led to some of the most interesting findings of my study, especially those about the relationships between professionals and self-help group members. They also clarified some of the items which addressed demographic data relevant to their roles as group leaders.

Group members volunteered all this assistance—and more. When they learned I needed help with follow-up calls to potential respondents who had not returned their questionnaires, they divided up the list and called them. After a month’s time, they again called those who had not responded. I was impressed with their willingness to help me with a rather tedious task. I was also impressed that 181 people (73% of everyone registered as having attended at least one meeting) filled out and returned the eight-page questionnaire. Hindsight suggest that these activities made my volunteers feel more like full partners in the study, an observation supported by their comments at the time which indicated that they were happy to do something for me in return for some of the things I had done for them. Their participation seemed to put us on a more equal footing.

Once I had collected and analyzed the data, I shared it orally with some of the group’s old-timers and asked for their opinions. Then, after I wrote the final draft of the study, I shared the results with the leadership and with attendees at two meetings. I also presented the group with a copy of the final document.

Although I did not label my methodology at the time of the study, it fit a paradigm that is now known as participatory action research (PAR), a strategy which is increasingly valuable in research with self-help groups. PAR acknowledges that both individuals and groups create their own version of social reality based on their experiences, their values, their beliefs, their backgrounds, and so on—and that that social reality is both valid and valuable as a source of knowledge. A researcher using PAR respects those with whom she or he works as partners and shares decision making and information with them at every step. PAR is designed to benefit both the researcher and the group (Borkman & Schubert, 1994), as my research did in my study.

### Products of the Study

As mentioned earlier, participation in the study seemed to prompt a sense of partnership between group members and myself. The study also provided the group with insights into areas in which members had developed personal expertise in dealing with the GT/LD syndrome, ideas for future programming, information about aspects of the group deemed most beneficial, and ideas for recruiting and keeping members. The most popular section of the document, however, was Appendix A, a history of the group. After 5 years, only one officer had been with the group during its first 2 years, and only two of the group leaders had known Sally. In the course of the study, with the help of some old-timers (including Sally), I wrote the historical description of the group, which we photocopied and distributed to those requesting it.
My study was focused on the experiential knowledge that the group had and/or developed about ways to help GT/LD children and their families. With the assistance of the group’s members, I identified eight categories of this knowledge: understanding the GT/LD syndrome, concerns about their own GT/LD children, the impact of the syndrome on the family, concerns about getting appropriate help for children from their schools, concerns about getting help from private sources, concerns about ways to provide practical help for GT/LD children, benefits of belonging to the group, and a miscellaneous collection of items (Schubert, 1991; Schubert & Borkman, 1994). Once these categories were identified, I could look at how it differed from subgroup to subgroup—from that of newcomers to old-timers, for example—and how it changed over time.

I also came to understand how experiential knowledge empowered those who developed it. Group members felt comfortable sharing practical suggestions for dealing with the problem and for ways of obtaining appropriate educational services for children. In the study, some expressed their relief at not being the “only one” with a problem and/or that they had not realized how much they knew about the syndrome until they had a chance to talk to someone else. When conversing with a person who had a particularly frustrating issue, other parents could provide pragmatic suggestions and encouragement: “I know it’s hard, but you can do it. I did.” In addition, the validation of their knowledge by others in the group made it easier for parents to interact with professionals—both in the schools and in the private sector.

Another outcome of the study was the discovery that members of this particular group did not see all professionals in the same way. Those who specialized in areas of concern were viewed much more positively than were generalists in a given field. Thus, special education teachers were perceived as more helpful than general practitioners, and psychologists who worked specifically with students with ADD were more appreciated than others in the medical field. Parents wanted to consult with and work with professionals who actually had hands-on experience working with children with the kinds of difficulties their children had and who were open to a two-way sharing of knowledge. They were not interested in talking to researchers who only wanted to collect data, college personnel whose knowledge came from reading articles and books, presenters who assumed they could dispense absolutes, and so on. Those professionals who were invited to present at meetings were all people who were known to parents in the group with the exception of one nationally known expert in the field.

My experience with the group supported another finding about newcomers and old-timers: Group members who had come to meetings for a period of time tended to change their attitudes toward professionals, especially toward educators. Many newcomers came to meetings to discover ways to take action against their children’s schools because they were dissatisfied with the educational programs being provided. After attending some meetings, most of those parents became more aware of the ramifications of the syndrome (at home and in the community as well as at school), of their legal rights and avenues of recourse, of school policies and procedures, and or potential options they could pursue. Many of them turned to me or to other professionals for advice or for help understanding such things as special education procedures and jargon. Some of them began recruiting professionals as group members so that those professionals could become more knowledgeable of the syndrome. Those who did confront professionals reported that they were more prepared and felt that they had more support when they did so; they indicated they felt they were on a more equal footing with those professionals that they would have been without the group.

Conclusion

My experiences with the group demonstrate that the relationship between a professional and a self-help group can be a positive experience for both parties. The sense of partnership that evolved between myself and group members was, I think the most vital element in the success of that relationship. That partnership was born as Sally and I collaborated to establish the group. Our experiences and expertise complemented each other’s, as did our personalities. Our mutual goals and priorities helped our focus on supporting the students and their families rather than on meeting personal needs or desires. This focus was maintained throughout the years I interacted with the group.

I demonstrated my commitment to that focus in the ways I served the group. I shared my professional expertise and experience with those who asked, but I did not force them on anyone. I volunteered time and logistical support. I physically moved furniture, carried boxes of books, and so forth. I found resources to share with members, and I found ways to share the group’s resources with others in the school and in the community. I recruited members from my professional colleagues as well as from the community. I served as a link between past and present and between information seekers and potential information holders. Finally, I was willing to trust the self-helpers to run the group because I knew the leaders had the same goals as I did, and, in many areas, they had more expertise.

I respected the expertise of the members. Their experiential knowledge had, after all, developed as they lived with the GT/LD syndrome and its effects 24 hr a day for years, whereas I really only dealt with it in the school setting. They were in truth the experts at living and constantly coping with the problem. Because I wanted to be more effective at helping my students, I came to the meetings ready to learn from these experts. I was somewhat surprised at how large the gaps in my knowledge of the effects of the syndrome were. I better understood the magnitude of the problem after listening to people discuss difficulties such as the lack of
understanding among extended family members, sibling competition for parent attention when one child has a disability, the quantity of time spent on homework, lack of friends for “normal” activities such as sleepovers, and the cost of medication and counseling. Through sharing their experiences with me, parents and students heightened my awareness of acceptable (and unacceptable) ways to assist them through simple techniques such as monitoring the education jargon in my language during a conference and being sure to call home with positive news about a child’s performance. I heard and read about advances in medical fields from material brought in my members. I gained insights for working with students in both the general education setting and in my classroom.

The relationship I shared with group members was enhanced when I asked them for assistance with my research, something that was obviously important to me. By consulting with them from the start and by incorporating their suggestions and efforts into my project, I again demonstrated my respect for them and my trust in their work. They were truly my partners in that undertaking; without them, the study would not have been as well done nor the results as meaningful.

Looking back at my time with this parent group, I have concluded that professionals can establish nurturing partnerships with self-help groups. To do that, however, they must assist in maintaining the focus of the group on the problem—not on their personal goals. They must respect the experiential knowledge of the members and the very real difficulties those members face on a daily basis. Finally, they have to trust the members to run the group, which may mean giving up control to people perceived as having serious weaknesses. Instead of leading the group—or worse, dictating to it—they need to find ways to facilitate its functioning, even if it involves such mundane tasks as rearranging furniture. To be successful at nurturing a group, professionals must recall what parents have to learn—to trust and let go.

Afterword

My family and I moved from Virginia to Texas in the summer of 1992. Now, more than 20 years later and thousands of miles away, I still reflect on that special group. Although I have continued to work with parents of special education students in many capacities, I have not had the opportunity to work with another group like that one. I believe that, because of the number of residents in Fairfax County and their generally middle-class status, there was a population of informed parents who had the time, energy, and confidence to take an active role in their children’s education. They were willing to invest their time in actively looking for resources to support their children and each other. The group also included people—mostly women—who were comfortable with being leaders and taking initiative.

The group members believed that they could influence other people and organizations within the community. They were looking for resources and support for themselves and for each other; they realized there was no quick fix that would make the problems go away and that simply assigning blame produced no results. They also realized that communicating and working with school personnel was more productive than assuming the school would handle school-related issues and that parents should handle the rest; they acknowledged that the syndrome affected all aspects of the child’s environment.

Except for the parents involved in Special Olympics, other parent groups with which I have had contact have tended to come together based on school-sponsored meetings with experts and/or have lasted only a short while. Parents in Kendall County, Texas, for example, have tried to begin groups dealing with dyslexia and with attention deficit disorder (ADD), but both groups relied heavily on professional input and neither lasted for more than a meeting or two.

And then there’s the Internet. Whereas in 1987 people had to actively seek out information and ways to share it, now parents and professionals can go online and gather more data than they can use. They can also communicate with each other and offer support that way. Although I appreciate the availability of the resources, I do miss the interpersonal interactions, the hugs and the handshakes, and even the tears. I believe that those interactions are one of the most valuable aspects of a self-help group, but it may be that people have to experience them before they can truly realize their value. Although the Internet can provide a plethora of information (and sometimes, misinformation), it cannot provide the type of specific, individualized support that came out of the experiential knowledge and caring attitudes of the group members.

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