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I Never Knew I Could Stand Up to the System: Families' Perspectives on Pursuing Inclusive Education

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The purpose of this study was to investigate the experiences encountered by parents committed to inclusive education for their children with disabilities. In-depth interviews of nine study participants were analyzed to identify common themes related to their experiences and perceptions. Results revealed that parents desired inclusive education, because they viewed it as a fundamental right for their children. Most importantly, findings indicated that parents employed numerous strategies to obtain inclusive education for their children, often seeking assistance from the courts and media. These findings suggest the need for meaningful family and school collaboration.

DESCRIPTORS: ethnographic research, parent-professional relations, parents, placement

The emergence of full inclusion as a conceptual framework for educating children with disabilities has generated considerable attention. Several important initiatives regarding the education of children with and without disabilities have been observed nationally including expanded federal funding opportunities and the National Association of State Boards of Education report (1992) outlining specific directives for promoting inclusive education. Originally, inclusive education emerged from ethical issues and civil rights arguments (Brown et al., 1989; Lipsky & Gartner, 1989; Stainback, Stainback, & Forest, 1989). Current discussions of inclusive education have moved beyond the philosophical and ethical questions and now focus on ways to support children with disabilities in natural environments (Giangreco & Putman, 1991; Salisbury, Palombaro, & Hollowood, 1993; Stainback & Stainback, 1992). Biklen (1992) points out that successful inclusive schools consider how to include children with disabilities in their home school instead of asking why.

Despite the existence of policy statements and other initiatives in support of inclusive education for students with disabilities, there is a sharp contrast between the optimism emerging from the national discussion of inclusion and what is (or is not) occurring regionally. In New York State (NYS), for example, there have been several efforts to promote inclusive education including federal- and state-funded projects, numerous state and local conferences, parent association advocacy, and professional organization activities. However, there are still many factors that limit the accessibility of inclusive education.

According to Advocates for Children (1992), school districts in New York State have one of the lowest rates of general education placements for students with disabilities in the country. For example, in New York State, 7.0% of the students with disabilities between the ages of 6 and 21 years are served in general education classrooms in NYS, which is far below the national average of 32% (U.S. Department of Education, 1992). Additionally, children with disabilities ages 3 to 5 were served almost three times more often in special education rather than in general education placements across NYS (U.S. Department of Education, 1992). New York was ranked second to last nationally in providing inclusive education according to a recent report on inclusion for students with mental retardation (Association for Retarded Citizens [ARC], 1992). Thus, although efforts are being made to promote inclusive education in NYS, inclusive placements are not available readily to parents who desire this option for their children.

The systemic changes needed for inclusive education are complex and time-consuming. There are few options available to parents who desire inclusive education while state and local policies are reconsidered and revised. The significance of this problem is highlighted by data indicating that when parents of children with disabilities in NYS were asked which placement

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they would choose for their child, the most frequent response was a general education class (NYS Commission on Quality of Care for the Mentally Disabled, 1990). It is difficult to expect a parent to wait until state policies and procedures change, particularly when barriers to change tend to be financial and political. Advocates for Children (1992) suggest that several statutes and regulations in NYS contribute to the lack of available inclusive educational opportunities. They further assert that the primary barrier to educating children with disabilities in general education environments is a funding formula in which financial rewards for segregated placements far outweigh the financial incentives for inclusive placements.

Many parents in NYS are not waiting passively for policy changes to access class placements in general education for their children; they actively are pursuing these placements. Whether or not these parents are immediately successful in securing inclusive education or facilitating long-term policy change, their experiences are critical to understanding the process of change. As a means of learning from parents' experiences, this study describes perspectives of a small number of parents from one state who sought inclusive education for their children with disabilities.

Method

The purpose of this investigation was to examine critically the experiences encountered by parents interested in inclusive education for their children with disabilities. Qualitative methods were used to gather data about parents' experiences and perspectives. These methods were selected because the nature of this study requires an approach to research that produces rich and descriptive data derived from the study participants' own frames of reference (Bogdan & Biklen, 1992).

Study Participants and Setting

This study involved nine parents from New York City and surrounding suburbs who desired inclusive education for their children with disabilities. All participants lived within a 60-mile radius of New York City. Prospective study participants were identified through several means. Two of the parents were known to one of the authors through a local chapter of an advocacy organization, The Association for Persons with Severe Handicaps (TASH). The relationships between the parents and the author can be characterized as casual, and contacts were limited to conferences, meetings, and infrequent telephone calls. Another parent previously had asked one of the authors to be an advocate on her behalf in the pursuit of an inclusive education program for her child by attending individualized education plan (IEP) meetings. A colleague of both authors who had served as an advisor to parents in their pursuit of inclusive education suggested one parent for the study. Two additional parents were identified as ardent advocates of inclusion by one of the parents mentioned above.

Additional study participants were identified at a meeting for parents on inclusive education held by a local child advocacy organization. One of the authors attended this meeting and asked for volunteers to participate in the study. Eight parents responded by returning a form distributed by the author. After the meeting, the researchers contacted these eight parents by telephone. Among other questions, parents were asked to indicate on a 10-point scale the degree to which they were committed to inclusive education for their child (i.e., 1 indicating no commitment and 10 indicating a very strong commitment). Three parents with a strong commitment toward inclusion were selected to participate in this investigation. Thus, a total of nine parents who were very highly interested in inclusive education for their children had been selected.

Although the sample size was small, an effort was made to recruit parents from a variety of backgrounds (e.g., geographic area, ethnicity, socioeconomic status) reflecting the demographic diversity of New York. It was not the intent to exclude fathers; however, it was generally mothers who agreed to participate in this study. All but one of the study participants worked outside of the home. Two thirds of the participants had completed some college; the remaining one third had received high school diplomas. All but one of the participants were married at the time of the study. Respondents were not asked directly to report socioeconomic status (SES) because of the sensitive nature of this information; however, SES was inferred from parent(s) occupation. Approximately one half of the sample lived in New York City and one half lived in suburban communities outside of the city.

Study participants' children ranged in age, ability, and educational placement. Children ranged in age from 5 to 19 years and were of diverse racial cultural backgrounds. Five of the nine children spent some or all of the school day in special education classes. The remaining four children were placed in full time general education classes. Three of the general education placements (two full-time and one half-time) were not with same-aged peers. In two placements, the age difference was 2 years and in one placement the age difference was 1 year. Demographic data on study participants and their children are shown in Table 1.

Data Collection

Given that parents' pursuit of inclusive education was the primary interest, semistructured in-depth interviews were employed to gather comparable data across study participants. This provided the basis for understanding the viewpoints of participants without restricting those views by pre-established rating scales

Table 1
Demographic Data of Study Participants and their Children

Participant name[a]	Parent					Child				
	Occupation		Education		Geo area	Age	Background[b]	Disability considered	Siblings & ages	Educational placement
	Mother	Father	Mother	Father						
Eva	self-employed	food service director	HS diploma	HS diploma	urban	5	Greek/German American	moderate	brother 8 brother 13 brother 15	general ed kindergarten (full time)
Martha	special education advocate	gov't bond broker	2 yrs college	2 yrs college	suburban	19	Caucasian	severe	sister 15 brother 22	spec ed HS (50%) supported employment (50%)
Millie	housewife	CPA	college degree	graduate degree	suburban	6	Caucasian	severe	none	spec ed kindergarten (full time)
Barbara	college instructor	justice department	graduate degree	graduate degree	suburban	5	Arab American/ Caucasian	severe	sister 7	general ed kindergarten (full time)
Gina	church organist	sales manager	college degree	college degree	suburban	8	Caucasian	severe	sister 6	general ed 1st grade (full time)
Effie	secretary	—	some college	—	urban	8	Caribbean	severe	none	general ed 1st grade (50%) spec ed class (50%)
Lena	preschool social service worker	corrections officer	HS diploma	HS diploma	urban	7	Latin American/ German	moderate	sister 7 brother 9 sister 14 sister 18 brother 18	spec ed class (full time)
Sandra	registered nurse	school custodian	college degree	HS diploma	urban	12	African-American	moderate	none	general ed middle school classes (80%) special ed classes (20%)
Kim	clerical worker	military guard	HS diploma	HS diploma	suburban	7	Caucasian	moderate	brother 7	general ed 1st grade (full time

[a] All names throughout are pseudonyms.
[b] Description of background is presented as reported by participants.

or categories (Bogdan & Biklen, 1992; Stainback & Stainback, 1984). Thus, an informal forum was created for parents committed to inclusion to discuss freely their personal experiences and ideas.

Although themes and questions generally emerge during qualitative research, an initial set of questions was used to facilitate discussions as well as to provide researchers with consistency and flexibility across interviews (e.g., modifying questions, changing order of questions, asking follow-up questions). Specifically, parents were asked to discuss (a) how their child's educational placement came about, (b) how they were defining inclusion, (c) what their experiences were in pursuing inclusive education, and (d) how the process of pursuing inclusion affected them.

Each of the nine study participants was contacted via phone by one of the two investigators and a meeting time and place was established according to parent convenience. All the parents were interviewed individually by one of the authors. Each interview lasted from 60 to 120 minutes. Six of the parents were interviewed at home. Two of these six parents met with the researchers for their interviews at one of the other parent's home rather than in their own homes. Two parents were interviewed at restaurants, and one parent chose to be interviewed at her place of employment. One interview was conducted per study participant, although some parents were also contacted by telephone for additional information or clarification.

Interviews began with a brief introduction by the interviewer in which the purpose of the study, confidentiality, and consent for the interview to be tape-recorded were addressed. Interviewers posed open-ended questions using the protocol stated above. Parents were encouraged to speak freely and openly about their perspectives, experiences, and ideas regarding inclusive education in their communities. At the end of the interview, background information was collected on each of the study participants.

Data Analysis

Because data analysis in qualitative research is an ongoing process, the researchers separately as well as jointly noted themes and questions that emerged during data collection. Thus, efforts were made to understand the data so that the integrity and richness of participants' stories would be preserved.

All completed interviews were transcribed from the audio-taped version and read by both researchers who individually noted questions, themes, and comments on each transcript. Meetings between the researchers were held to re-read, review, and discuss each transcript. Detailed written accounts of these meetings were kept to assist in understanding specific concepts or schemes. A set of coding categories was developed to reflect emerging themes, interpretations, and concepts (Bogdan & Biklen, 1992; Taylor & Bogdan, 1984). Because this was a continuous process, categories often had to be redefined or collapsed with other categories to better reflect emerging themes. For example, it was noted initially that most of the parents described specific strategies used to pursue inclusive education from which emerged the theme "accessing inclusive education." Within this theme, several topics (e.g., legal channels, key people, media coverage) were identified and later merged into one category (i.e., negotiating the system) to enhance the organization and clarity of the data.

To verify the accuracy of the data, which were derived from a single interview with each parent, a draft of the present article was sent to each study participant for comment and review. Initially, six of the nine study participants replied to this request for feedback. These parents unanimously responded favorably to the article and provided positive comments about the accuracy of the data and results. The parents who did not respond initially to the request for feedback were later contacted by telephone. All three of these parents expressed their strong satisfaction with the article. Only one of these parents requested specific changes pertaining to the wording of the demographic information. Thus, unanimous approval of the article's content and tone was obtained.

Results

This section provides findings gathered from one semistructured interview with each of the nine parents from the New York area who participated in this study. Results of the analysis are discussed in terms of the following themes that emerged: (a) the meaning of inclusion to parents, (b) accessing inclusive education, and (c) personal transformations. Although these parents do not necessarily represent all parents' experiences, their stories were somewhat similar and have something to contribute to professional understanding.

The Meaning of Inclusion to Parents

A sense of belonging. To understand parents' experiences seeking inclusive education for their children, it was first necessary to examine what inclusion means to them. Several different beliefs were expressed, yet these ideas individually contributed to a unified framework for defining inclusive education. Consistent in each parent's view of inclusion were themes such as a sense of belonging, being part of the group, and not being separate. Inclusion was characterized by one parent as "just being part of regular life as much as possible from birth on through life." Actual visions of what inclusion would look like also emerged:

> So I picture him sitting in a group at one of those tables with, with maybe four other, five other children around him. And I picture them laughing and learning together.

In addition, parents regarded discrimination as the antithesis of inclusion. Inclusion meant the opportunity to participate in real life events and "not being excluded from anything, from any life activity based on the fact that a child has a disability." In other words, a disability should not exclude a child from participation in any activity or event he or she would naturally be involved in if the disability had not been present. Parents expressed frustration about sending their child with disabilities to a different school than the one attended by siblings. Additionally, this deprived children of interaction with neighborhood children.

> This should not be happening. So at that point I called up my director from public school and said, "I want her out of this school and I want her to be able to go to the same school her brother goes to. She knows the kids in the neighborhood." So to isolate Karen at school when all the [neighborhood] kids were who she would see outside of school didn't make sense.

Parents viewed the importance of being connected to meaningful experiences as natural and significant elements of childhood.

The justice of inclusion; the injustice of segregation. In defining inclusion, these parents naturally discussed the reasons underlying their commitment to it. Although different ideas were articulated about why inclusion is so important to parents, the message throughout parents' interviews focused on equal access and opportunity:

> Inclusive education should be a right for all children whether they're disabled or not. Just as it should be a right regardless of a child's economic status, social status or their ethnic background or religious background. Children are our future no matter what their make up is.
>
> I think anything you would not do with a typical kid you should not do with a child with a disability. You must have the same standards. I think society has a way of holding kids, or people with disabilities to a different standard.

Study participants felt it was unjust not to afford the same opportunities to their child with a disability as had been afforded to other children in the family without disabilities. Parents also felt strongly about the need for acceptance of their child by society:

> He shouldn't be segregated from the rest of the world because it can't be that way for his whole lifetime. And people have to accept him and realize he is part of the community and accept him for what he is and what he isn't. And I don't think segregating him or keeping him away from other children is going to be better for him or for the other children.

These concerns clearly reflect a belief in a fundamental liberty that grants *all* children the right to the same opportunities and experiences. Parents felt strongly that exercising such a right would benefit not only their children with disabilities and those children without disabilities, but would cultivate societal acceptance as well.

The right to choose. Although study participants felt very strongly about wanting inclusive education for their own children, they also acknowledged the importance of choice for all parents in making placement decisions:

> I would like if they [other parents] would see it my way, but the bottom line is they should have a choice and so should I.

Although these parents strongly advocated for inclusive education, they recognized that their preferences and beliefs may not be shared by all parents. Therefore, the need for options seemed to be a far more important issue for parents than the type of educational placement desired, because it provided a meaningful role in the decision-making process for *all* parents.

Accessing Inclusive Education

The journey for inclusion begins. Many of the nine parents first became aware of the concept of inclusion when the educational placement for their child was being reviewed or changed. It was generally a professional or another parent who raised the question, "Why doesn't your child go to your neighborhood school?" that planted the seed of the idea of inclusive education. Some parents learned of inclusion in other ways. Lena, whose child Jose was enrolled in a self-contained early childhood program from the age of 6 weeks, attended a conference on inclusion that changed her life. She left asking herself "What am I doing to my baby? . . . It's almost the end; he's going to graduate preschool soon." Only in one situation did the school district (which was involved in a federally funded project on inclusion) approach a parent to offer the option of a placement in general education.

Once parents learned about and embraced the idea of neighborhood schools, many of them embarked on a journey of self-education that prepared them for the advocacy roles they would later assume. Several parents received a copy of the inclusion video tape "Regular Lives" (generally from an advocate) and used the video tape as a learning tool to educate themselves, other parents, and their school districts. The more the study participants learned of inclusion, the more their commitment to it grew. For most of those interviewed, the path from concerned parent to advocate was gradual; it was not a conscious choice, but rather a reaction

to events they encountered in trying to secure what they believed was best for their child.

Negotiating the system: Making inclusion happen. With the exception of one parent in this investigation, a general education class was not offered to parents as a placement option by the school district. Thus, parents developed and used several elaborate strategies to obtain inclusive education for their children. Table 2 highlights the variety of strategies parents employed to pursue an inclusive placement for their child.

Most of the nine parents used multiple approaches, either successively or simultaneously. For example, Effie kept her son James out of school while obtaining assistance from various sources, including the press. Martha paid for private school placement while she negotiated for an inclusive setting in the local public school; she also started an after-school play group at this time so that her daughter would be able to interact with typical children.

More than half of the parents in this study had to pursue legal channels after other efforts to negotiate with the school failed. This typically involved an impartial hearing as outlined in the provisions for due process in the Individuals with Disabilities Education Act (IDEA, formerly PL94-142) and section 504 of the Rehabilitation Act. For some parents, the threat of legal action spurred compromise; in other cases, more than one hearing was necessary. The outcomes of impartial hearings were not always favorable to the parents. For example, Martha lost her request to have her daughter's, Karen's, work study program continue throughout the year because the school felt Karen was functioning adequately without it. Martha reported that Karen was doing well, because Martha had arranged for and financed integrated work and recreational experiences for her daughter.

Eva recalled attending a meeting when her son was about to enter public school in which she inquired about an inclusive placement for him. She was told by the interdisciplinary team that inclusive placements did not exist, and that it was unlikely her request would be met. Eventually, she enlisted help:

Somebody from the preschool gave me the num-

Table 2
Summary of Strategies Used by Parents to Pursue Inclusive Education

Strategy	Illustrative comments
1. Became involved as a parent member of the Committee for Special Education (CSE).	"I did all of this because I knew I needed to know a lot about laws and I needed to get involved and I needed to know people that were able to make decisions."
2. Sought out key players in the school district	"I went to my (CSE) chairperson who I developed a rapport with over the course of the years."
	"I visited elementary schools and I finally found a principal that said 'yes we can do it'."
3. Pursued legal channels	"I went to mediation three times with our administrators because we wanted to exhaust every administrative process available to use."
	"I needed legal help at that point. I just couldn't do it alone."
	"And I just flat out refused, at one point in time . . . and that led me to my impartial hearing which was a very protracted hearing which lasted over 18 months, cost me a tremendous amount of money, and frustration."
4. Refused school district's recommendation for self contained class and:	
(a) kept child out of school	"The reason why I kept him out is because Ari is the kind of child even if he went to the special ed setting he would do well in there. He would fit in. He would probably progress. But not in the particular ways that I want him to."
(b) chose private segregated program over public school segregated program	"It wasn't what we ideally wanted. But it was better than the Board of Education was offering."
5. Agreed to a compromise with district	"So here I am just in a lurch. So I made up my mind to have him stay in first grade. In my mind the concession was to stay in first grade." [child to remain in regular education by repeating a grade]
	"It falls short, very short, of what I want for him, but I felt that it was better than none at all."
6. Sought media attention	"He got back into school, I believe because of this article. This article came out on Sunday. By the next day, at work, the Board of Ed called me up and said we want to talk with you."
7. Moved family to a new town	"We moved for several reasons, that [school/parent disputes] being one of them."

ber of a child advocacy organization—the person at the preschool should remain anonymous because she was going against the preschool. So I called and they assigned me to a lawyer and we fought the system.

After several attempts at negotiation with the district, Eva's lawyer called an impartial hearing that eventually led to an inclusive placement. This story is representative of many of the parents who tried to work with the school district before going to an impartial hearing.

Another parent commented on the emotional and political complexities of legal negotiations:

> You have to be real tough. And at the same time you have to be real nice. It's almost a passive aggressive thing. During mediation you have to be real nice because you have to be able to work with them after that. And you don't want to work with people who hate your guts.

This comment reflects a realization by parents that regardless of the outcome of legal action, there would be inevitable future interactions between themselves and the professionals.

One third of the parents sought and obtained media attention in their quest for inclusive education. In each case, journalists writing about changes in education were directed to these parents by professional organizations or individuals advocating for inclusion. Each article appeared in one of the widely read regional or national newspapers. Each parent was eager to cooperate with the reporter in the hope that community awareness would facilitate their efforts toward inclusive education. For both Effie and Eva, this proved partially true; they were contacted immediately by the schools, although they were less than satisfied with the placements offered.

Implementing inclusive education: Making it work. Study participants received a great deal of support in their pursuit of inclusion from a wide variety of people (e.g., advocates, lawyers, other parents). Once consensus for placement in an inclusive environment had been reached with the school district, the list of key players narrowed. Specific school personnel seemed to be responsible for providing initial endorsement of a general education placement while others were responsible for making the placement work. For example, it was reported consistently that the prerequisite for establishing an inclusive placement was securing the support of the school principal. It was the principal who served as gatekeeper by determining whether or not an inclusive education placement was going to be established. Without the initial support and approval of the building principal, inclusion did not occur.

> If we could get the principal to accept him, then the school district would put him into the home school. But that didn't work out because the principal wouldn't sign anything since his job was on the line. He wouldn't give his permission. The head of the district didn't want to hear anything about it. So we were practically back to square one.
>
> At first the principal at East Brook School was very supportive and she played a role by saying she would take Nina that first kindergarten school year which was a big step because a lot of principals wouldn't do it.
>
> And I went to see her [principal] and it was just her at the time. And I told her what I wanted and then she said to me "Well, what do you want from us as a program? How can we help Jose?"

Whereas the building principal was an initial and influential power in permitting inclusion to happen, the classroom teacher and/or consultant largely determined the success or failure of the experience.

> Well, the first thing the teacher said to me was "It's fine if he's in this class but I'm not trained for this and I have no intention of getting trained for it either." I would just describe her attitude as not welcoming for him. And I know that rubs off on the other kids.
>
> The only stickler we had was we had problems with the teacher. The teacher closed herself off completely to Ari. It's come down to the last few weeks of school where she has nothing at all to do with Ari except that she is present and he is present. She just sort of ignores him, like he's an invisible child.

A teacher's negative attitude can detract from an inclusive educational experience, and a teacher's positive outlook can enhance it.

> This was a really astute teacher. And the first thing she said to me was "I believe Timothy should be in a regular class."

In addition, parents recognized the value of a teacher's skill, competence, and educational vision.

> Well, the consultant has been great. She kind of does everything. She works with the teacher, she works with the children, she works with the aides, you know what I mean. She's really a very good coordinator. And we're lucky to have her because otherwise it wouldn't be going the way that it's going.
>
> One thing I noticed that they [teacher, aide, consultant] all have in common is that they really believe in his capacity to learn and they believe in his intelligence.

Efforts to establish inclusive education resembled a woven fabric with each thread systematically intertwining with others to produce a shared outcome. However, mere placement in a general education classroom did not automatically provide a truly inclusive experience for the child. Gina, who compromised with the district by agreeing to have her son placed in a general education class with younger students, remarked that he didn't seem to be a full member of the classroom.

> His desk is placed at the end of the row. I mean, he's with other kids but it's not like he's in the middle. His aide sits with him and he is very dependent on an aide.

Sandra, whose child attended general education classes at an elementary school, questioned why the school did not fully include her child in all classes with his typical peers, particularly the courses in which she knew him to excel.

> A few things he's not involved in. He doesn't go to regular phys. ed. He goes to adaptive phys. ed. At first there was a problem with computers and music which he is very, very good at. As you see, we have a piano and Jamal is very much into music. I sing, and there's a lot of music in our household, and I can't believe he can't go to music. And also computers -- he's a wiz at computers. So I said to [the program coordinator] "I can't believe that the two areas that he is thriving at, he's not able to attend."

Gina, Sandra, and others in this study raised pertinent questions about illogical class placements and educational practices. They recognized that for a general education placement to be successful, the child must be a full member of the class.

Personal Transformation

Parents' pursuit of inclusive education for their children tended to be a prolonged and challenging journey that for many had persisted over the course of several years. Study participants shared personal accounts about their quest.

> This is an emotional topic for me because it was a source of a lot of pain and agony and to tell you the truth this was worse, what the school district put me through, was worse than anything I've dealt with Paul. And we've been through quite a bit with Paul on every level medically—life and death. There are times that when Paul is quite sick and I wonder what's going to be.
>
> This probably affected me more than any one thing in my whole life. I just am getting teary because I always say it is a shame that I had to become a better person because of what is happening with her. I have certainly been responsible for spreading awareness [of inclusion], even among my own social group.

One of the most striking themes to emerge had to do with parents' ambivalent acceptance of their new roles as advocates. Because the schools did not offer the option of inclusive education or necessarily support parents in their pursuit, parents seemed to feel they had little choice but to learn how to advocate for their children. Many of the nine parents did not necessarily want to assume the advocacy role that was thrust upon them:

> I don't want that role either. Right now I'm devoting my life to extending myself and learning about the school system and learning about education. Learning some points of law, learning where to go, how to advocate. I don't want to do this. It's not necessary.
>
> Well, I think if I sit down and think about it I have to be a little angry because to me there are so many other problem situations that come up in life that you have to fight for.
>
> Sometimes it's a doctor, sometimes you have to fight for medication. To me it is a right. I should not, I shouldn't have to fight for this—it's his right.

Another parent expressed relief when she was no longer the sole advocate for her child since the consultant had assumed some of the responsibility.

> The consultant teacher . . . she's the one who's making it work now. And it's actually nice to have some of the pressure off me. I mean right now, they're fighting for an aide, not me.

Although parents discussed the frustration they experienced in their struggle to obtain a placement in general education, they also described the positive personal transformations that occurred. Parents developed a sense of purpose and awareness of their own strengths as a result of their advocacy efforts.

> I feel good about myself. I definitely do. I feel that I have made an impression on some people in the educational system even though they may not have agreed with me at the time. But I think I've made them stop and think.
>
> You're going against the system. I never knew I could even stand up to the system. I mean I wouldn't say boo to you. I mean I wanted to be liked and I would certainly never be adversarial for anything.

These parents reported a profound commitment to

educational equality for their child that led them to greater self-understanding. Although anger and frustration were present at times, these parents also tapped into a latent strength during their encounters with schools.

Discussion and Implications

This study provided some informative first-hand accounts of parents who sought inclusive educational placements for their children with disabilities. Although the children discussed in this investigation varied in ages and abilities, these parents all shared a similar perception of why education in an inclusive setting was the most appropriate for their children.

Although understanding the perspectives of these parents may be helpful in recognizing some of the experiences and challenges other parents may face when gaining access to inclusive education, the generalizability of these findings may be limited by several factors. First, the present study was based on the perspectives of only nine mothers. Second, the results were based solely on interview data; no other data were used to corroborate the information as reported by the participants. Third, although follow-up contacts were made to clarify and verify the information obtained, the data were derived primarily from a single interview with each of the participants. Perhaps different themes would have emerged with a larger sample and a more diverse data base.

In this study, parents of children with disabilities who advocate for inclusion seem to hold a vision for their children that is inconsistent with society's views. Their advocacy efforts reflect a commitment to the belief that all children deserve the opportunity to be full members of society. This includes, but is not limited to, membership within the family, community, neighborhood, and school environment.

The parents in the present study passionately articulated a vision for their children that reflected a social justice perspective. Although the critical issue of basic civil rights emerged, a more substantive issue that parents address is one of acceptance and membership. After all, what purpose do rights serve if they do not lead to acceptance, membership, and full participation?

In addition to advocating strongly for children's right to be included, parents acknowledged that they deserve the freedom to make decisions regarding the education of their children. Parents in this study recognized that although not all parents share the same educational goals, all parents should have an active and meaningful role in educational decisions if they so choose. Because not all families want or need the same things, parents should be the ones to determine *how* they participate in the process.

Although parental rights, including participation in their children's individual education plan, are protected by federal legislation, parents' opinions and concerns may not be accepted readily by school districts (Salisbury, 1992; Soodak & Erwin, in press). Because differences between parents and school personnel were not always easily resolved, parents in this investigation were forced to go outside the school for assistance. In fact, all but one of the parents had to pursue legal and other channels when barriers developed. The only parent who did not pursue assistance outside the schools had a child who participated in a federally funded project on inclusion.

The experiences of parents in the present study indicate that those passionately committed to inclusion may not await systems change passively. When faced with roadblocks, parents employed various strategies to obtain placements in general education for their children with disabilities. Some parents tried to enlist the help of influential administrators or tried to become part of the decision-making process. Those failing to obtain placements in this way used established mechanisms for resolving conflicts (i.e., initiating due process proceedings). Some parents in this investigation accepted compromises in the form of part-time general education placements or placements in classes with younger students. Some parents unwilling to accept less than a fully inclusive placement, refused to have their children attend public school and either paid for private schooling or kept their child out of school entirely. One family relocated to another town to escape conflict. Interestingly, one third of the parents interviewed tried to effect change by attracting media attention to the issue of inclusion. Clearly, these parents went to extraordinary lengths to achieve what they thought was best for their child.

Not only did the pursuit of inclusion involve an enormous amount of frustration, time, and energy, but the emotional impact this process had on parents deserves particular attention. Parents were often forced to assume advocacy roles they did not want or to acquiesce to decisions that they considered unfair or inappropriate. In either case, this was done at the parents' expense in emotional energy and financial cost.

What, then, made these parents engage in such a stressful process despite their admitted reluctance to become advocates? Although the present data do not permit definitive understanding of the unique characteristics, skills and/or propensities these parents possess that led them to engage is such activities, it is nevertheless important to note how they are similar to, as well as different from, other parents who may be equally passionate about their childrens' lives.

The similarities among the parents interviewed are considered first. Each mother had earned at least a high school degree and most had completed some college. Only one mother was not presently married; and only one was not employed outside of the home. Per-

haps education and work experience played a role in preparing them for the demands and stresses involved in advocating for change. Given that it was exclusively mothers who responded to the call for participation (and were the actors in the stories they told), it may be that mothers are more likely than fathers to become advocates. This hypothesis is supported tentatively by statements several mothers made about their husbands' hesitancy to challenge the decisions of professionals. However, it may be equally important to recognize that two-parent families were represented almost exclusively in this study, suggesting that the mothers might have been receiving the support they needed from husbands and families to engage in the struggle. In fact, the one single mother in this study had the help of her parents, who lived with her and her son.

Results of this study seem to suggest that a strong commitment to inclusive education crosses ethnic and racial boundaries and that this commitment can rally any parent into action. This suggestion seems to be contrary to findings of prior research that led Harry (1992) to characterize the participation of minority parents in education as indicative of a "pattern of passivity" (p. 101). However, as Harry explains, it may be that with education and support *all* parents can assume active roles in educational decisions.

The age and disability of the child seem to be unimportant in determining if parents actively pursue inclusive education. In this study, the children with disabilities ranged in age from 5 to 19 and were of no particular rank in birth order. However, one third of the children had no siblings, suggesting that parents of one child may be more likely to be involved actively in their child's education. Once again, the limited number of participants restricts interpretations; however, the present findings do suggest intriguing areas of further study.

Perhaps circumstance played a role in determining how aggressively parents advocated on the children's behalf. Parents were often thrust into advocacy positions for their children perhaps because they had little or no meaningful vote in the educational decision-making process. Biklen (1992) suggests that parents of children with disabilities experience anxiety and frustration when they disagree with professional recommendations, have limited accessibility to a range of options, are not given meaningful opportunity to participate in decisions, or are faced with situations that do not accommodate their children. Findings in this study are consistent with Biklen's research that suggests that the frustration parents describe is not about having a child with a disability, but rather how society, and in particular the educational system, treats individuals who have disabilities.

Given parents' experiences within the current educational system, developing partnerships between schools and families appears to be a necessary next step. The recognition that families are critical to the education of young children with disabilities is clearly reflected in federal legislation (e.g., Part H of the Individuals with Disabilities Education Act). Safer and Hamilton (1993) explain:

> Part H reflects not only a respect for families and what they know, but also an assumption that the family plays the key role in the development of the young child, and that the responsibility of the service system is to support that role. The needs of the family are as much a focus of Part H as are the needs of the child, and the family is given the authority to determine which services it will accept and which it will not. (p. 5)

Researchers and educators have acknowledged consistently the fundamental significance of partnerships between families and professionals in the education of infants, toddlers, and preschoolers with disabilities (Bailey, 1987; Bailey, McWilliam, Winton, & Simeonsson, 1992; Brown, Thurman, & Pearl, 1993; Turnbull & Turnbull, 1990). If elementary, middle, and high school personnel better understood the significance and implications of working collaboratively with parents, parents might feel like they are part of the system instead of outsiders looking in. Unfortunately, as shown in the present study, many parents are forced to seek powerful external forces in order to be heard. It is both unfair and unrealistic to expect parents to go to these lengths to effect change for their children.

In an effort to create more supportive and effective educational environments for children, school districts must reconsider their policies regarding families. One possibility for change is to conceptualize schools as communities—each with a unique collection of students, families, teachers, and administrators—who all play an integral part in the success or failure of the school. However, affording families consistent opportunity for meaningful involvement in their child's education will require the restructuring of school systems. Parent input is only meaningful in a school system that values parents as partners. This implies that parents should have the freedom and power to make shared decisions with professionals regarding educational placements and practices. Hopefully, parents will not have to "stand up to the system," but rather they will be seen as an integral and valued part of the system.

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