From the Beginning: What Educators and Parents of Children With Special Needs Do to Resolve Differences

Jeannette E. Newman

University of Pennsylvania, jeannettenewman22@gmail.com

Follow this and additional works at: http://repository.upenn.edu/edissertations

Part of the Educational Sociology Commons, Family, Life Course, and Society Commons, Other Education Commons, Other Educational Administration and Supervision Commons, Pre-Elementary, Early Childhood, Kindergarten Teacher Education Commons, Social Psychology and Interaction Commons, Special Education Administration Commons, and the Special Education and Teaching Commons

Recommended Citation

Abstract
How educators and parents of children with special needs resolve differences at the early stages of a dispute is vital to our understanding of how to avoid an escalation of conflict and irreparable damage to this important relationship. This study examines why some disputes between educators and parents resolved and others are not. Following the cases of nine children whose parents had a difference with the child’s educators, I focused specifically on what parents and educators do to try to resolve their differences. I interviewed parents and educators involved in disputes, observed meetings that centered on the differences the parents and educators were having and reviewed related documents. I found that educators who used a therapeutic approach and were highly informative in their work with parents were successful in resolving differences with parents. I also found that when educators apologized and promptly remedied oversights and serious social infractions, parents were appreciative and able to continue a positive relationship with the educators. Educators who failed to adequately address the concerns of parents about their child’s development and educational needs and future and who did not discuss alternative instructional approaches invited a pattern of misunderstanding and conflict. The central implication of these findings is that educators need to anticipate and prepare for issues and concerns that are endemic to the practice of early intervention. The capacity of educators to manage differences with parents must extend beyond the traditional approaches to conflict resolution and include an informed approach to the resolution of differences and data driven decisions about educational programs for young children. Further research that examines the competence, role and status of educators and how these factors relate to effective resolution of differences would further our understanding of the complex issues involved in dispute resolution.

Degree Type
Dissertation

Degree Name
Doctor of Philosophy (PhD)

Graduate Group
Education

First Advisor
Peter Kuriloff

Keywords
educators, parents, children, special needs, conflict resolution

Subject Categories
Educational Sociology | Family, Life Course, and Society | Other Education | Other Educational Administration and Supervision | Pre-Elementary, Early Childhood, Kindergarten Teacher Education | Social Psychology and Interaction | Special Education Administration | Special Education and Teaching

This dissertation is available at ScholarlyCommons: http://repository.upenn.edu/edissertations/1180
FROM THE BEGINNING: WHAT EDUCATORS AND PARENTS OF CHILDREN WITH SPECIAL NEEDS DO TO RESOLVE DIFFERENCES

Jeannette E. Newman

A DISSERTATION

in

Education

Presented to the Faculties of the University of Pennsylvania in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

2005

Supervisor of Dissertation

Graduate Group Chairperson
ACKNOWLEDGEMENTS

I am thankful to many who helped me in countless ways to complete this effort. I am forever grateful to Peter Kuriloff, my dissertation committee chair, who inspired me with his intellect and know-how and helped me with such grace. Thank you, Peter, for sticking with me so that I could realize my dream of being a scholar. I am very grateful to Steve Goldberg for his unfailing support and guidance and for his significant contribution to my understanding about conflict between parents and educators. I am also thankful for James Larkin’s astute critique and for helping me when I needed it most.

My husband and partner, Jon Tullis, is a wonderful blessing in my life. His love and unwavering commitment to help me in every way possible, sustained and comforted me throughout this dissertation. My very giving, always cooking and good-humored mother, Eve Chaichitz, helps raise our children and transcribed numerous interviews. Our dear friend, Mary Jo Bowman, also helps raise our children and transcribed interviews, both with great care. Our children, Jordan and Schyler, help me everyday to center on what is most important.

I am indebted to the parents who shared their stories, their heartache and their time with me. They have made me a better educator and have deepened my commitment to helping parents and educators realize effective partnerships. To the educators that spent time with me when they had a hundred other things to do, I know that you gave of yourselves and I thank each of you.
ABSTRACT

FROM THE BEGINNING: WHAT EDUCATORS AND PARENTS OF CHILDREN WITH SPECIAL NEEDS DO TO RESOLVE DIFFERENCES

Jeannette E. Newman
Peter Kuriloff

How educators and parents of children with special needs resolve differences at the early stages of a dispute is vital to our understanding of how to avoid an escalation of conflict and irreparable damage to this important relationship. This study examines why some disputes between educators and parents resolved and others are not. Following the cases of nine children whose parents had a difference with the child’s educators, I focused specifically on what parents and educators do to try to resolve their differences. I interviewed parents and educators involved in disputes, observed meetings that centered on the differences the parents and educators were having and reviewed related documents. I found that educators who used a therapeutic approach and were highly informative in their work with parents were successful in resolving differences with parents. I also found that when educators apologized and promptly remedied oversights and serious social infractions, parents were appreciative and able to continue a positive relationship with the educators. Educators who failed to adequately address the concerns of parents about their child’s development and educational needs and future and who did not discuss alternative instructional approaches invited a pattern of misunderstanding and conflict. The central implication of these findings is that educators need to
anticipate and prepare for issues and concerns that are endemic to the practice of early intervention. The capacity of educators to manage differences with parents must extend beyond the traditional approaches to conflict resolution and include an informed approach to the resolution of differences and data driven decisions about educational programs for young children. Further research that examines the competence, role and status of educators and how these factors relate to effective resolution of differences would further our understanding of the complex issues involved in dispute resolution.
# Table of Contents

THE RESEARCH PROBLEM AND ITS SIGNIFICANCE ............................................. 1
REVIEW OF THE LITERATURE ........................................................................ 4
IDEA 2004: An Ongoing Effort to Legislate Increased Parent Involvement ...... 5
Parent Involvement in Regular Education...................................................... 9
Legal Remedies for Resolving Conflict ......................................................... 15
Contributing Factors to Parent and Educator Conflict .................................. 20
Models to Avoid Conflict ............................................................................. 22
Stress and Adjustment ................................................................................... 26
METHOD ....................................................................................................... 28
  Research Design ........................................................................................ 28
  Participants ............................................................................................... 29
  Data Collection ......................................................................................... 32
  Data Analysis .......................................................................................... 36
RESULTS ....................................................................................................... 37
  Where Conflicts Emerge ........................................................................... 37
    Parents' Varying Levels of Satisfaction with the Early Intervention System 40
    When a Child is not Making Progress ...................................................... 45
    Pressures on Parents: Time, Acceptance and Perception ......................... 65
    Child is Not Getting the Services on the IEP ............................................ 91
    Educators Make Unprofessional or Insensitive Remarks to Parents .......... 94
    Parents as Experts ................................................................................ 96
    Friction Points That Are Endemic to Early Intervention ......................... 103
A Context of Limitations .............................................................................. 106
  When a Child Needs More Service and Early Intervention is Unwilling to
    Provide .................................................................................................. 109
  Early Intervention Splits Hairs: Service is On the IEP but Early Intervention
    Doesn't Want to Pay ............................................................................. 126
  Enactment of a Constraint Driven Ideology ................................................. 130
DISCUSSION ................................................................................................. 141
  Why Some Differences are Resolved ......................................................... 141
  Why Some Differences are Not Resolved .................................................. 142
  When Parents Pursue Mediation or Due Process ........................................ 144
  Resolving Differences: Implications for Educators .................................... 145
    Joint Negotiation Training ....................................................................... 145
    Anticipate and Prepare for Conflict ....................................................... 146
    Improve Educators Capacity to Manage Differences ............................... 151
    Need for Data Driven Decisions ............................................................ 152
Appendix A: Glossary ................................................................................... 157
Appendix B: Consents .................................................................................. 159
BIBLIOGRAPHY ........................................................................................... 166
THE RESEARCH PROBLEM AND ITS SIGNIFICANCE

Educators and parents of children with special needs often have differences of opinion concerning a child's educational status and program. These disagreements may be about any number of issues including: the child's diagnosis, the manner in which evaluations are conducted, the recommended educational placement, the type and frequency of therapies (e.g., speech, physical, and occupational therapies), the content and specificity of the child's goals, the instructional approaches used or not used by the teacher, or the level of services that the school will support. Legislation has attempted to provide a framework for the resolution of these issues. Yet in the area of special education, there is considerable dissatisfaction with the legal remedy of due process as well as mediation, an alternative form of dispute resolution. An additional opportunity for educators and parents to informally resolve disputes is now mandated in the recent reauthorization of the Individual with Disabilities Education Act (2004), known as the IDEA. Effective July 2005, educational agencies will be required to convene a "preliminary meeting" with the parent within 15 days of receiving a parent's request for a due process hearing, unless both parties agree to waive the preliminary meeting or agree to pursue mediation. This study looks at how parents and educators go about addressing and possibly resolving their differences themselves from the very beginning of a conflict, prior to a "preliminary meeting" and prior to intervention by a mediator, hearing officer, or judge.
A parent's concern or dissatisfaction with an aspect of the education her child receives is often communicated to the child's teacher, a designated parent liaison or a supervisor (e.g., principal or director). Other parties may be involved depending on the nature of the child's needs and how the school is structured. It is during these initial attempts at local resolution that the tone of the relationship is set, the parties are interacting with each other directly and most significantly for the purposes of this study, corrective action may be taken by the educators involved.

In many instances, disputes between parents and educators of children who receive early intervention or special education services never reach mediation or a due process hearing. When differences occur, many of them are resolved or otherwise do not escalate to these more formalized methods of dispute resolution. Yet, we do not know how and why parents and educators work out their differences at the early stages of a dispute and at the local level, without resorting to a formal system of dispute resolution.

In this research, I explore three questions:

Why are some disputes between parents and educators resolved and others are not?

In those cases where they are resolved, how and why do parents and educators commonly work out their differences?

In those cases where they are not resolved, what issues or events cause parents to pursue mediation or due process?
In order to ask and answer these questions, I examine what happens at the local level between parents and educators in their encounters with one another over a difference. I use a case study approach to “focus deeply and specifically” (Lawrence-Lightfoot, 2003) on these questions. This approach allows for a full elaboration of the process that parents and educators undertake in their efforts to resolve their differences. I examine the nature of the disputes in an effort to understand the underlying social, political and economic influences that come into play as well as the manner in which the disputes are handled by the parents and educators. And I look at the reasons why parents may be dissatisfied yet are unwilling or unable to take further action.

This research is an opportunity to develop a greater understanding of what is necessary to enact a relationship between parents and educators that is informative and helpful and promotes a real and meaningful partnership. My intent is to begin to construct a framework that will contribute to our knowledge about successful relationships between parents and educators. If we can develop approaches to partnering and problem solving that support rather than damage these relationships, then ultimately the educational needs of the child will be served.
REVIEW OF THE LITERATURE

The legislation that specifies what educators must do to involve parents in the important decisions about their child with special needs has been in place for nearly thirty years. The recent reauthorization in 2004 of the IDEA, gives educators specific instructions on how to involve parents in educational decisions, how to formally address disagreements between parents and educators, and what criteria must be met to justify a student’s exclusion from the regular education system and participation in special education. First in this review of the literature, I examine the key elements of IDEA of 2004 that pertain directly to parent involvement. Given the emphasis embodied in the pertinent legislation and resulting regulations on ensuring that children with special needs have more access to regular education, I review the literature on how teachers and schools typically support parent involvement. Since parents’ discontent with decisions about their child’s educational program sometimes leads to disputes requiring intervention by a third party, I then review pertinent research on participant’s satisfaction with due process and with mediation. I review approaches to conflict between parents and special educators that give some insight into approaches that have been proposed and used by educators and approaches that have been advanced in other arenas (e.g., business) that may hold promise for the management of conflict between parents and educators. Finally, I frame conflicts between educators and parents within the context of the difficult emotional adjustments that parents must make when they give birth to a child with a disability, when the child is diagnosed with developmental delays and
IDEA 2004: An Ongoing Effort to Legislate Increased Parent Involvement

In 1975, Congress enacted the Education for All Handicapped Children Act, commonly known as P.L. 94-142. This legislation gave parents the right to extensive procedural safeguards including written notice before any change of placement and the right to an independent educational evaluation at public expense. Section 504 of the Rehabilitation Act of 1973 is a civil rights law that offers some protections for school age children who have a physical or mental impairment that substantially limits a “major life activity” such as walking, seeing, hearing, speaking or learning. Children who receive special education services under IDEA, as P.L. 94-142 is now known, automatically receive protection under Section 504. These protections include the right to reasonable access and classroom accommodations and modifications. However, children who are eligible to receive protection under Section 504 are not necessarily eligible to receive services as prescribed in IDEA and Section 504 does not apply children under five years of age. The American with Disabilities Act (1990) offers additional protections to both children and adults who have a physical or mental impairment that substantially limits a major life activity. These protections require reasonable accommodations to ensure access to services, facilities and telecommunications.

From its inception P.L. 94-142, as well as the current version of the IDEA, required states to offer due process hearings to parents who object to a child’s
classification, evaluation, educational program or placement. The school district or LEA (Local Education Agency), on behalf of the state, is required to provide the family with information regarding their right to prior written notice, to independent evaluation, parental consent or refusal, access to educational records, opportunity to present complaints and to legal representation. The rights of parents to be represented by an attorney, to have the case heard by an impartial hearing officer, and to appeal the rendered decision are essential elements of “due process” and empower parents to dispute educational decisions that involve their child. In Pennsylvania, parents are allowed to request a pre-hearing conference before a formal due process request (Pennsylvania Administrative Regulations for Special Education Services and Programs, 2001). The pre-hearing conference is intended to provide an opportunity for the parent and school to try and resolve disagreements without proceeding on to a due process hearing. In the reauthorization of IDEA that will become effective in July of 2005, there is a new requirement for all states that adds “resolution sessions” and mandates educators to convene a “preliminary meeting” within 15 days of receiving a parental request for a due process hearing. The educational agency must resolve the issues that are the subject of the request for a due process hearing to the parents’ satisfaction within 30 days of the hearing request. If the complaint is not resolved within this time frame, then the parties may go to a hearing. The statute allows for this requirement to be waived in writing by both parties and to proceed directly to a due process hearing or alternatively, both parties may agree to use mediation.
In the 1997 version of the IDEA legislation, the rights of parents to play a significant role in the educational decisions that affect their children were expanded. The legislation sought to address increased concern about improved outcomes for children with special needs. The recent reauthorization of IDEA maintains the focus on outcomes for children:

- A commitment to include the child in the general curriculum while meeting the child’s special needs.
- The involvement of parents and students as partners with educators in the decisions that support and impact the child’s educational progress.

The legislative mandate of IDEA requires educators to start with the premise that each child should be part of the regular education system. If the full inclusion of the student presents challenges, educators must try to support the student in the regular education classroom and justify, in detail, the student’s participation in education that occurs in specialized settings (i.e., special education classes, resource rooms). The IDEA further stipulates the role of parents as team members and decision makers by requiring educators to obtain parental consent prior to the child’s receipt of special education and related services, to obtain prior to initial evaluations (unless the education agency obtains authority for evaluation from a due process proceeding in the case of a parent’s absence or refusal of consent) and maintains the parent’s right to receive regular progress reports.
Though it has been an option in a number of states for some time, the 1997 version of IDEA began to require states to offer mediation to parents involved in a dispute concerning a child’s special education. Parents who choose to bypass mediation and go right to a due process hearing may be asked to sit down with someone who will counsel them on the purported benefits of mediation and encourage them to use this process (Kuriloff & Goldberg, 1997).

But for the aforementioned changes, the legislation has consistently mandated parent and school district contact at specific points and intervals in the child’s education. There is some concern that these requirements have resulted in increased parent contact rather than increased parent involvement (Handler, 1986). Parent involvement, ostensibly, implies a collaboration among the parents and educators to develop and implement a mutually agreed upon plan of education for each child. Mandated contact requires active and complete documentation, which means more time spent on administration, notwithstanding a stated desire to decrease paperwork. Administrative requirements add to the burden of educational systems (Weatherly & Lipsky, 1977). The regulations that follow from IDEA 2004 detail highly prescriptive requirements and stringent timelines that most schools systems whether public or private, specialized or “regular” find difficult to manage. The clear expectation in the legislation, and increasingly in practice, is that “regular” educators will include children with special needs in “regular” classes and school activities. It is important then to examine how the regular education system deals with parent involvement.
Parent Involvement in Regular Education

Schools routinely attempt to direct and manage the involvement of parents in their children's education (McGrath & Kuriloff, 1999). A close look at the common approaches to parent involvement makes clear the underlying assumptions about the roles of parents and school professionals (Perry & Tannenbaum, 1992). The typology of parent involvement developed by Perry and Tannenbaum (1992) includes the "child-centered model" where the parents are encouraged to support learning activities for the child at home and to attend parent-teacher conferences. These activities are defined and initiated by the school. In the "collaboration model," the parent is guided to assist the school in some way, usually as a volunteer, as representative of an alliance and partnership between the school and the parent. In the "decisional participation model" parents serve on advisory committees and boards to help fulfill the school's intent to promote good public relations among the parent community. Lastly, in the "parent activist model" members of ad-hoc citizen groups, parent networks and organizations sustain a watchdog participation and criticism of school functions. Epstein (1990) also identifies five traditional types of parent involvement that schools articulate in an attempt to channel parent involvement. These are 1) the basic obligations of parents to make children ready for school, 2) school to home communications about programs and progress, 3) parent involvement and assistance at schools, activities and events, 4) parent assistance in home-based learning and 5) parent participation in governance and advocacy.
The call for parent involvement is endemic to schools (McGrath, 1997; Lareau, 1994). Participation by the majority of families in school related decisions is typically minimal. Parents who voice their disagreement with educators about their child’s education are often characterized negatively by educators. It is not surprising then that the common approaches of parent involvement that prevail in “regular education” are one of substantial exclusion and paradox by the school (Swap, 1993). Typically, traditional models of parent involvement serve to protect the school and teachers from interference by parents and to allow parents to participate in ways that the school personnel define. In effect, parents are not considered as equal partners in critical decisions involving their child’s education and acceptable communication goes in one direction: from school to home.

Despite evidence that parents and teachers agree on the need for parent involvement there is research that does not support the widespread view that teachers want more parent contact and greater parental involvement. In a survey about a teacher-parent relations high school teachers overwhelmingly said they did not want parent-initiated contact (Dornbusch & Glasgow, 1996). The teachers expressed resentment of parent-initiated contact. They welcomed contact when there was a problem and when they asked for the parent to come in for a conference. Such contacts operated in a context of teacher control, with parents asked to assist the teacher.

Both the manner in which parents participate in decisions that affect their children in regular education and the type of the communication that occurs between parents and teachers offer insights that go beyond quantitative empirical
work that equates increased parent involvement with improved student achievement (McGrath, 1997). Disparities among teachers and parents and among parents about how they define what it means to be involved with their child’s education, especially with regard to the division of responsibilities between parents and teachers need to be further analyzed and understood (Lareau, 1996).

In response to the trend to extol the virtues of increased parent involvement, Lareau counters:

Many family-school proponents have a flawed analysis. They do not consider systematic variations in families’ approaches to school among working class and lower class parents, especially the meaning attributed to being helpful, the number of serious conflicts in child rearing strategies, and the perceived power and threat of teachers in their lives (Lareau, 1996, p. 62).

A critical analysis of what is considered parent involvement demonstrates that parents are kept at a distance in most schools. There are a number of barriers to parent involvement including school norms that do not support partnerships, changing demographics (i.e., family relocation), limited resources to support parent involvement and lack of information about how to establish partnerships (Swap, 1993). The prevailing norm of minimizing conflict between parents and teachers and the failure of schools to deal with conflict in a positive and constructive manner are major barriers to collaboration. Conflict is discouraged and avoided by school personnel even if that conflict has the potential to result in creativity and growth (Epstein, 1985). This treatment of conflict is in keeping with the traditional model of school management that emphasizes hierarchy and individualism rather than dialogue and reciprocity.
Teachers are careful to not step beyond their bounds, and decision making about resources is often done by supervisors and administrators. Conversely, administrators are careful in their direction of teachers as professionals and may tread lightly in giving corrective feedback. Administrators are rewarded for keeping a lid on conflict and for preserving the status quo. Swap (1993) argues that this avoidance of conflict is especially problematic since parents inevitably introduce conflict into school and thereby create stress and defensiveness. To lessen parental contact and the accompanying “inevitable” conflict, schools have developed ways of avoiding conflict by bringing parents and teachers together for brief, ritualized encounters (e.g., open-houses, parent-teacher conferences).

Schools as they are traditionally managed do not seek or support parent involvement that is based on equal relationships, collaborative problem solving, regular self-evaluation, or open discussion of conflict. The result is an unsatisfying cycle in which most conflict (even normal, useful conflict) is driven underground: the conflicts that do emerge tend to be explosive, threatening and personalized: and the aftermath of these explosions reinforces the need for ritualized management of home-school relations (Swap, 1993, p.21).

In her study of parent-teacher conferences, Lawrence-Lightfoot (2003) points to the typical twice a year conference as fundamentally dissatisfying to parents and challenging to educators. Lawrence-Lightfoot suggests that parent-teacher conferences would be more productive if at the outset of every school year teacher and administrators educated parents about:

- How to make their dialogues with teachers more productive.
- How to prepare for and what to expect during these encounters.
- What to listen for and good questions to ask.
• The aspects of school life in which they should not be involved
  (Lawrence-Lightfoot, 2003, p. 231).

A significant barrier to parent involvement in the regular education setting is the lack of resources (especially time) allocated for building relationships among educators and parents. Epstein (1985) observed that parents will come to school activities, but with time so precious, they want to make sure that they are not wasting their time on activities where their involvement is not really wanted or valued, where their second-class status is underlined, or where they are not making a contribution to their child. When parents do not respond to traditional forms of outreach (e.g., parent association meetings, open houses, brief conferences at school) the assumption made by educators is that parents don’t care about their children or their schooling (Swap, 1993; McGrath & Kuriloff, 1999, 1999). The everyday obstacles of a multitude of demands and a lack of time are experienced both by educators and parents. Time is allocated for crises but not for developing meaningful partnerships (Ronzone, 1999; Kaltenbach, 1999).

Despite recommendations from a number of reports calling for improvements in education, few teacher preparation programs require parental involvement courses for their teacher candidates (Williams, 1992). Educators receive little or no training in how to meaningfully include parents in their child’s education.

Since most schools are and have been hierarchically rather than collaboratively organized and managed, and our professional institutions continue to prepare teachers for this model, it is not surprising that
hierarchical and authoritarian principles govern the schools’ relationships with parents as well.... The school-based norm of individualism affects home-school relationships. Strong connections between parents and educators run contrary to the normative value of individual self-sufficiency and dominant practice of administrative decision making and delegation (Swap, 1993, p.17).

Epstein (1985) asserts that typical pre-service and in-service training programs result in attitudes and practices designed to keep parents out of the learning process and out of the classroom. Parental involvement that is more than activities directed at parents is possible when educators learn to develop and sustain partnerships with parents based on mutual respect, trust and understanding (Williams, 1992). When teachers receive instruction in the design, implementation, and evaluation of practices to promote meaningful partnership they have the opportunity to learn about both the problems and potential of parent involvement (Epstein, 1985).

Lawrence-Lightfoot (2003) recommends that the development of teachers’ capacity to productively relate to the parents of students be an essential part of teacher training programs. As part of this core training, teachers would:

- Learn to value the authority and wisdom of parents and recognize the contributions that they can make to their child’s success in school.
- Develop an understanding of the “broad ecology” of education and the several institutions where children are socialized.
- Develop an appreciation of how students individually and collectively “navigate the terrain” between home and school.
• Develop strategies, tools, and skills for supporting productive dialogues with parents.
• Learn to listen to parents' perspectives on their children with patience, intent and respect (Lawrence-Lightfoot, 2003, p. 229-230).

The practice of educators known for their capacity to work well with families offers a number of approaches that may be far more effective and satisfying for both parents and educators. In her study, Lawrence-Lightfoot looked at educators known to be talented in their work with parents and shares some of their approaches. These include having the child present at the conference, regular communication with parents around child performance so that the data and discussion during the parent-teacher conference is substantive, parent training on topics important to parents, and using e-mail as a means of routine parent-teacher contact. These and other approaches may be tried and refined on a broader scale by teachers and schools that are interested in communicating effectively and building productive relationships with parents (Lawrence-Lightfoot, 2003).

Legal Remedies for Resolving Conflict

Discontent with Due Process in Special Education

Paradoxically, in an attempt to increase parent involvement the administrative burden imposed by IDEA (2004) compounds existing norms and decision-making practices of the educational bureaucracy. Parents who question
or complain about their child's education are typically seen as troublemakers who interfere with getting work done in the face of scarce resources and are viewed as obstacles to be overcome (Handler, 1986).

For many parents and educators, conflicts that are not promptly and satisfactorily resolved between the family, the teacher or the principal often escalate into an adversarial relationship and set the stage for dissatisfaction (Margolis, 1998). Though it is a crucial element in legislation to protect the rights of parents to pursue a legal remedy, due process in special education disputes is widely acknowledged as a process and experience that damages the sense of partnership between parents and educators (Goldberg & Kuriloff, 1991). At a federal level, there is a clear and stated commitment to using due process as a last resort.

Every effort should be made to resolve differences between parents and school staff through voluntary mediation or some other informal step, without resort to a due process hearing (IDEA Regulations, 1997).

The exhortation to avoid due process comes in recognition of nearly three decades of experience with the use of this adversarial procedure in an educational context. The problems with the application of the rule of law to special education are myriad:

- A prevailing attitude is that parents pursue due process because of failures in communication or (more likely) because they are malcontents or troublemakers.
• The exercise of procedural due process by parents is perceived as a challenge to educators: it is a hostile act.
• Professionals find it difficult to participate in meaningful shared decision making with parents.
• It is difficult to decide what is appropriate for an individual child who requires special education and to enforce a legal right when both the facts and standards are indeterminate (Handler, 1986).

The degree to which parents are disgruntled, feel bruised by an unfair system and dissatisfied with the promise of legal remedy is not an untold tale in regard to special education due process hearings. In fact, dissatisfaction among parents who pursue due process is substantial. In a study of parents and school officials who had participated in a due process hearing during a prior four year period, both parties were asked about their perceptions of fairness and their satisfaction with various aspects of the hearing (Goldberg & Kuriloff, 1991). On the whole, parents were very much dissatisfied with the hearing officer’s decision and felt that the hearings were unfair. In contrast, most of the school officials felt the hearings were fair and agreed with the accuracy of the decisions. However, both parent and school officials reported a substantial lack of satisfaction with the hearing in retrospect. Though it may not be true for all parents, the escalation of conflict that necessitates a due process hearing often has a negative impact on parents. Goldberg and Kuriloff (1991) reported some of the anecdotal comments made by parents during the interview process as testimony to the intensity of
emotion that accompanies the process. Parents used the terms “trauma,” “suffering,” “war,” “combat,” and “fighting” to describe their perception of the due process experience.

In education it appears that an adversarial framework such as our legal system provides sustains domination, encourages conflict, and supports hostility rather than reciprocity and empathy (Auerbach, 1983). One method of alternative dispute resolution that has been tried in the realm of special education is mediation.

**Mediation: A Flawed Alternative?**

The primary intent of mediation, as an alternative to due process, is to resolve conflict in a way that will preserve rather than destroy the relationship between parents and educators (Auerbach, 1983). Additional intents of mediation are to save the time and money that would be expended in a due process proceeding. Mediation gives the parties the opportunity to present and discuss their concerns with a trained and neutral third party facilitator and helps the parties to reach a settlement that is mutually agreeable (Moore, 2003).

Mediation is hailed as a preferable alternative to due process hearings (Osborne, 1996; Singer, 1990) and according to the IDEA (2004), each state must offer mediation to parents. Yet theoretical, pragmatic and empirical concerns about mediation have been raised. Even advocates of the use of alternative dispute resolution in special education cases acknowledge that parents, as individuals, are inherently less powerful than school systems thereby allowing for the possibility of coerced agreements and the surreptitious denial of...
assertion of individual rights (Handler, 1986). When used as a means to diffuse anger and to neutralize conflict, the fear is that mediation will accentuate the imbalance of power between parents as individuals and the bureaucracy, the school system.

The insights of a mediator experienced in special education disputes present a picture of mediation that is tangled and difficult. In her collaborative chapter with Patrick Davis, a mediator experienced in special education disputes, Sibley (1994) describes a scenario that is not atypical:

By the time a special education case comes to mediation, the parties have usually been in conflict for months, sometimes even years. Davis confronts people who feel frustrated and powerless, sometimes angry, and often tired of dealing with each other. All other conciliatory efforts have failed, and the parties have dug in their heels...mediation of special education disputes is made even more difficult by this personal history of disagreements and failed compromises (Sibley, 1994, p. 64).

There is more cause for concern about mediation as a viable solution to addressing conflict among parents and educators in the empirical literature. A recent study examined the degree to which parents and school officials perceive mediation as a fair process, are satisfied with the mediated agreements and the resulting implementation (Kuriloff & Goldberg, 1997). The study measured the parents' and school officials' long-term satisfaction by surveying those who had participated in mediation during the course of a one-year period. The lapse between the completion of the questionnaire and the mediation ranged from one to twenty months.

Both parents and school officials expressed a considerable lack of enthusiasm for mediation: participants were only mildly satisfied with mediation
and gave only a modest rating of their perception of the fairness of mediation as a procedure. Parents were more likely to rate mediation as a fairer process, and were more favorable about the resulting agreement and its implementation when they had an “effective advocate,” either an attorney or lay advocate representing them. This, as the authors point out, is a key component to procedural due process and therefore muddies the distinction between the differences in the formal and informal processes. The major finding of only a modicum of satisfaction with mediation as well as the data relating to the perceived positive impact of having an advocate, suggest that mediation may not be a significant improvement over due process hearings for an effective (“fair”) resolution of the dispute.

Contributing Factors to Parent and Educator Conflict

Lake and Billingsley (2000) interviewed parents, school administrators and mediators to identify the factors that contributed to the escalation and de-escalation of conflict. The parents, who were interviewed retrospectively, had all requested mediation or due process to address a conflict with educators. Lake and Billingsley found eight factors that escalated or de-escalated the development of conflict. These factors were: discrepant views of a child’s needs, lack of knowledge about service delivery and regulations and the difficulty in making good judgments, limited program options, fiscal constraints, devaluation concerns about dishonesty and withholding of information, demonstrations of power as resisting or making demands, limited or miscommunication, and intact or broken trust between parents and educators. These data suggest some areas
that parents, educators and administrators see as problematic and directly contributing to the escalation of conflict. The parents in Lake and Billingsley’s study spoke of reaching a “turning point” where they could no longer trust the educators to act in the interest of their child. The importance of communication, problem-solving and negotiation skills is highlighted as a primary approach to avoiding conflict and focusing on improved relationships.

The dominant models of parent involvement in education and the considerable failings of both due process and mediation suggests the value of exploring other options for how to successfully involve families in their child’s educational program. Within the field of mediation, transformative mediation is an alternative approach to mediation that promotes empowerment of the participants to make decisions and handles problems and provides an opportunity for disputants to recognize, understand and empathize with one another (Bush & Folger, 2005). Rather than agreements directed by a mediator based on the interests of the participants (Fisher & Ury, 1981), transformative mediation sees settlement as secondary to the possibility for participants to connect with each other around conflict and to therefore transform conflict and thus, the mindset of the people involved in the process (conflict). Theoretically, this approach to mediation may have potential for addressing the disputes in education where there is a tendency to dehumanize the children and parents who are in conflict with educators. However, the non-directive process, the uncertain nature of outcomes and the degree to which dehumanization serves the bureaucracy’s
efforts to conserve taxpayer dollars may be obstacles to the use of this approach in the educational context.

From within special education a few possibilities have been proposed as potential options to address conflict between parents and educators. As noted above, special education is governed by legislation that regulates the actions of educators. The prospects for effectively addressing conflict between parents and educators need to be examined within this regulated context.

Models to Avoid Conflict

_Having All Your Ducks in a Row_

One approach to avoid due process hearings is for educators to take greater responsibility for preventing and handling conflict with parents. Margolis (1998) provides considerable detail on where schools go wrong in not understanding their legal obligations and thereby failing to prevent or effectively resolve conflict between parents and school officials. He provides a litany of suggestions and approaches to be used by the team that develops or implements a child’s Individual Education Plan or IEP (see Appendix A for a glossary of terms) to minimize conflict with families. He urges school officials to:

- View disagreement as natural rather than indicative of quarrelsome or troublesome parents, to continuously and sensitively address the central but often hidden issues of distrust and fear, which form the core of conflict...and to engage in skilled, systematic problem-solving aimed at resolving differences (Margolis, 1998, p.234).

Margolis (1998) advises that IEP teams must: listen to parent concern and fears, develop realistic and explicit goals and objectives for the student, frequently assess student progress and parent satisfaction with the program,
quickly respond to identified needs, design meetings to help parents understand and remember what is discussed, know the laws and regulations that pertain to special education, and avoid positional bargaining (i.e., win-lose power struggles). Among other recommendations, Margolis provides examples of the significant degree of specificity that he interprets IDEA to require of IEP goals and objectives and the measurement of student progress.

While exhaustive, it is unclear whether Margolis is modeling his recommendations on proven practices adopted by schools that have been successful in fostering cooperation and minimizing acrimony between educators and parents or whether he is enumerating points of vulnerability that leave schools open to criticism by lawyers and courts if they are inadequately or improperly addressed. Even more importantly, given the significant time involved in addressing all the recommendations for each child in special education, it may be that some, rather than all, of the practices that Margolis enumerates are more salient or meaningful for families in avoiding or addressing disagreement.

The importance of developing a realistic understanding of the issues that surround the implementation of a negotiated agreement has received recent attention in the corporate world (Ertel, 2004). This approach advises businesses to see the product of a negotiation as just the beginning of the effort to ensure that the parties involved actually realize what they are trying to create. In the context of schools and early intervention, what this may mean for parents and educators is a more thorough assessment and thoughtful discussion of the expectations and obstacles for implementation and recognition of the need to
maintain positive ongoing and workable relationships between children, parents and educators.

Communicative Conflict

Handler (1986) presents a model that was used in the 1980s in the Madison, Wisconsin School District that recognizes the substantive and contextual issues raised by active parent participation and disagreements between parents and educators. The salient dimensions of the Madison model are:

1) Special education is seen as part of general education. Parent interest, involvement and participation are considered an important part of the entire educational program.

2) A flexible and experimental approach to problem-solving and program implementation encourages negotiation and compromise on the part of both parents and educators. At the heart of the model is acknowledgement that our knowledge is incomplete and that educational, technological and medical advances occur often enough to merit incorporation into our existing frame of reference.

3) Rather than a negative, conflict between parents and educators is used to help communication. Each parent of a child who needs special education services is appointed a lay advocate to help the parent understand the school officials, to help the parent clearly communicate his or her position and to ensure that the parent knows his or her legal rights.
The role of the lay advocate is crucial to Madison’s model. One of the strengths noted in the Madison model is that the advocate operates within a context where the school wants a continuing, substantive relationship with parents and where all decisions are supposed to be individualized, flexible and experimental. The advocate is charged with the responsibility of fostering conflict that is both “aggressive and interpretive” and that furthers communication between the parents and the school officials (Handler, 1986). Though able to support families in the assertion of their rights the advocate’s focus is on being a skilled interpreter or communicator who helps to create a context for a venture that values participation, cooperative decision-making and experimentation: “Conflict is to produce communication and consensus, not the articulation of rights and duties. Procedural forms are to uncover shared ends, not adversarial positions” (Handler, 1986, p. 254).

Madison’s model produced very few due process cases. Handler (1986) attributes the relative absence of formal disputes to three factors: the use of a parent advocate to support communicative conflict between the parent and school, the district’s commitment to consider parents as part of the solution rather than the problem and that all decisions were viewed as experimental and flexible rather than as a win or lose proposition.

Alternative approaches to dispute resolution methods have received increased attention and use by educators in their efforts to resolve differences with parents (Singer, 1990). Interest-based negotiation (Fisher & Ury, 1981) that emphasizes interests rather than positions and seeks to develop win-win
solutions to problems is an approach that is encouraged by legal advocates (Goldberg, 2005; Wright & Wright, 2004). Dispute resolution workshops are periodically offered as training opportunities for educators in early intervention to develop awareness and skills around conflict management.

An approach that recommends the creation of "corporate capacity" for negotiating may have some applicability to education (Ertel, 1999). Within this model, corporations move away from a situational view of negotiation and use a more coordinated approach to organizing and managing negotiations. Rather than negotiation that depends on the personal judgment, timing and experience of the negotiator, this approach calls for a negotiation infrastructure that ensures that negotiators' priorities are and remain tightly linked to the company's priorities. The increasing control exercised by school systems and early intervention funders over what is negotiable by local educators is arguably a demonstration of this approach. However, there may be ample opportunity for educators at the local level to address conflicts with parents that are well below the threshold of due process concerns yet cause great angst and disruption.

Stress and Adjustment

The impact that a child with special needs has on a family can be comprehensive and traumatic (Hanson & Lynch, 2004). Parents can receive diagnoses or become aware of disabilities during the prenatal period, immediately after the child's birth, postpartum or at some time in the first few years of the child's life (Seligman, 1991). Pediatricians and psychologists who must deliver the news of a diagnosis of a developmental problem try to balance
hope with realistic expectations (Abrams & Goodman, 1998). In their research on the diagnostic conference, Abrams and Goodman (1998) found that pediatricians and psychologists try to soften the harshness of a diagnosis by using euphemisms, by hedging or being indirect in describing the impact of a diagnosis and by negotiating the level of severity of the diagnosis based on the parent’s reaction. Families of children with disabilities experience increased stress and care-giving requirements and must reorganize their expectations, roles, relationships, routines and priorities as a result (Hanson & Lynch, 2004; Singer & Irvin, 1989).

How parents adjust to the stress and demands of a child with special needs depends on a variety of factors, including perceptions, resources, cultural background and values and interactions with other family members (Hanson & Lynch, 2004). The conversations that parents and educators have about a young child’s development can be difficult and emotional, and often involve a discussion of what more can be done to meet the needs of the child (Featherstone, 1981). Starting at this very delicate place, and continuing on to discuss levels of service and approaches to instruction for a child, educators are engaged in very difficult conversations with parents. Yet, educators receive little or no training on how to handle these types of discussions (Stone, Patten & Heen, 1999; Arrow, 1995; Singer, 1990). In this research, I look at how parents and educators conduct these and other difficult conversations and the differences that arise in their efforts to meet the needs of the young child.
METHOD

Research Design

An attempt to resolve a difference is a process that is often emotional and trying for parents, challenging and uncomfortable for professionals, and operates in an educational environment of constrained resources and legal recourse. A close description of this process is well suited to a case study, in real time, of how parents and educators deal with and negotiate around what can be very difficult circumstances. Further, a close following of the attempts to resolve differences is particularly appropriate to this process since the issues involved and the strategies utilized are not always evident to the participants themselves. This study occurs in a context in which it is common for many of the parents and educators to be dealing with this type of conflict for the first time either because they are new as a parent of a child with special needs, new as a staff member in early intervention, or the circumstances are unique to the child.

In this research, I followed the participants as they tried to work out their differences. I interviewed parents and educators and sat in on IEP meetings. I interviewed parents and educators as they sort through their issues and concerns and formulate their perspective. I observed meetings between the parents and the educators to get a more complete picture of what happens as parents and educators meet together to work out their differences. The close following of how parents and educators try to work out their differences at the local level allows for a better understanding of the approaches that are
successful (or not) in averting heightened contention as well as the issues that are systemic and problematic.

Participants

The Programs

I conducted this research at two different early intervention (El) programs in Philadelphia. The programs are funded by the Department of Public Welfare through Mental Retardation Services and by Gladstone, Inc. who holds the MAWA (Mutually Agreed Upon Written Arrangement) for the Pennsylvania Department of Education. In the first program, approximately 250 children ages birth to five receive home and community-based services (i.e., “itinerant support”) at their respective pre-schools and daycares. Another fifty children with special needs are enrolled in a center-based program (i.e., in one of three inclusive pre-school classrooms or in one of two self-contained classrooms). In the second program, approximately 290 children ages birth to five receive home and community-based services. More than 100 children are enrolled in the center-based program. The second program has two inclusive classes and three self-contained classes.

During the course of my research the director of the first early intervention program retired and the new director was not interested in participating in the study. The new director had concerns about my asking parents about their differences with the educational team members. She felt that the research would highlight conflicts among parents and the educators and that this would have an adverse effect on the program and her efforts to establish herself as the new
director. I then obtained consent to conduct this research at a second early intervention program. I approached this second early intervention program for two reasons. First, the two programs are similar in size and scope. Second, I am familiar with the program and the staff and felt they would be willing to participate in this research. I have a working relationship with this program since I was the director of the program from 1992 to 1997 and have since worked with them as an administrative consultant. My work for them includes proposal writing, preparation for annual licensing and program expansion. I do not supervise personnel or manage any aspect of the program.

I also do consultative work for Mental Retardation Services (MRS) for the City of Philadelphia. This is a division of the Department of Public Welfare that funds and monitors early intervention services for children birth to three. The work that I do for MRS is mostly evaluation and systems work and I do not have any responsibility for or supervision of any aspect of services or providers. I disclosed my work with MRS at the outset of my interviews with both parents and educators.

I explained to all of the parents and educators with whom I spoke that I was there to conduct research, that I would interview and observe, and had no supervisory authority. At the outset of every interview I explained that I would not share information that I received from one person with another, that I would discuss the specifics of the situation only with my dissertation committee and that I would maintain confidentiality. To protect their privacy and anonymity, the names of the children, parents and educational programs in this study have been
changed to pseudonyms and the educators are referred to by their respective job title. (See Appendix B for consent forms).

The Parents

In the course of my research, I interviewed eight parents. The majority of parents whom I interviewed were female (i.e., seven were female, one was male). In all cases I interviewed only one, not both, parents of a child.

The Children

In this study, most of the differences between parents and educators concerned children between three and five years old. Two of the children were two years of age and seven children were three years old and above. The children were most often labeled as developmentally disabled (a function of the labeling system in early intervention) and presented a range of delays in the areas of speech and language, cognition, social-emotional and motor development. Of the nine children that were the focus of the differences among parents and educators, three were adopted and six lived with their biological parents. All of the children were eligible for early intervention and received a variety of early intervention services.

The Educators

I interviewed eighteen educators. For clarity, I refer to teachers (certified or not), teacher assistants, supervisors, directors, physical therapists, speech therapists, occupational therapists, social workers and psychologists as educators. I have used the category of “educators” to describe this myriad of professionals for two reasons. First, as a member of an early intervention team,
the role of these professionals is to address the developmental and educational needs of the child. This is consistent with the system’s effort to provide services that follow the regulations that govern early intervention and special education and to not offer services that are intended to improve a medical condition.

Second, in this research all professionals regardless of their discipline (e.g., teacher, psychologist, speech therapist, etc.,) struggled with differences with parents. Irrespective of their discipline, educators were challenged in their work with parents who expressed concerns or differences. For these reasons, I believe that the use of “educators” as a generic term is appropriate in the context of this study of early intervention. This might not hold true for the “school age” (i.e., 5 to 21 year olds) educational context where the classroom teacher is primarily identified as the educator, the supervisors are seen as administrators and clinicians are viewed as support or itinerant personnel.

Data Collection

Interviews

I spoke with and observed parents and educators in their early attempts to work out their differences. Depending on the parent, the educators, and the nature of the difference that they were trying to work through I interviewed some people once and others I spoke with multiple times. I conducted 20 interviews with parents and 27 interviews with educators to gain an in-depth understanding of how parents and educators have differences, become involved in disputes and in some cases resolve their disputes. These interviews were the central form of data collection in attempting to address the study questions. Depending on the
number of educators involved with a child and the nature of the dispute, I interviewed one or more educators. In all, I completed eight paired interviews, i.e., a “pair” is one parent and one educator who are involved in a dispute over a child's educational diagnosis, placement, program, progress, frequency or level of service and the like. In several cases I interviewed more than one educator in regard to a particular parent and a difference that they (and the team) and had with the parent. The interviews were intended to gain an understanding of the perceptions and actions of parents and educators when they have differences and therefore interview questions were specific to the matter(s) in dispute. For both parents and educators, the interview questions centered on the nature of the parent's concern and the efforts by both parties to communicate, address or resolve their differences.

I interviewed parents and educators as they sort through the process of understanding the nature of a difference and how it might be resolved. As I came to understand their varying perspectives, I was able to see what happens at the local level, person to person, when parents and educators go about trying to resolve their differences. At times, the educational team members initiate a dialogue with a parent about concerns that they are having and this may evolve into a difference between the parent and the educator. This occurred once in the course of my research. More often, the process begins with the parent's voicing of a concern about the child's services, e.g., the child is not getting what they should, the agreed upon services are not being delivered or the child is not making progress, etc. The parents share this concern with the teacher, therapist
or designated parent liaison. Depending upon the particulars of the situation and
the style of the participants, there are a series of conversations between the
parents and educators. Often parents and educators speak with one another
individually, either in person or on the phone. The early intervention staff are
expected to notify their supervisor of any concerns that a parent voices. The
supervisor may give advice and counsel to the educator or may begin interacting
directly with the parent.

The course of events of who spoke with whom and when they spoke with
one another varied according to the people involved and the nature of the
dispute. The sequence of whom I interviewed was determined by how events
unfolded and the availability of the parents and the educators.

Observation

In this study, I had the opportunity to observe six meetings between
parents and educators. Four out of six of the meetings were called to specifically
discuss a difference among the parents and the educator. In two instances, an
IEP meeting was scheduled and held and the differences between the parent
and the educators were apparent during the IEP meeting. In one instance the
meeting turned into an IEP meeting as the educators realized that the child’s
annual IEP was due. In another instance, an IEP review was completed based
on a timeline that was specified in the IEP as part of a special intervention to
which the team had agreed.

Generally, the people who attended the meetings were the parents and
educators that worked directly with the child. For some of the meetings, the
program director or service coordinator also attended the meeting. In these cases, the director or service coordinator was aware of the concerns of the parent or the difference between the parent and the members of the team in advance of the meeting, and came to the meeting prepared to address the issue that was a source of difference between the parent and the educators.

Although the possibility of requesting a pre-hearing conference or mediation or a due process hearing was discussed and researched by a few of the parents and the educators, none of the parents or the educators in this study pursued these options. Of the eight parents, one parent actively researched whether a due process hearing would serve her child’s interest and received legal counsel from the Education Law Center that suggested that she not proceed.

In the course of my interviews with parents and educators I asked them about their approach or position prior to meetings where they expected to discuss their differences. I was also able to talk with parents and educators after these meetings to gain a sense of their understanding of what was or was not discussed or resolved.

Documents

I reviewed relevant state, local and program policy and procedures, meeting minutes, and training documents. With the parents’ permission I reviewed written products that directly reflected the dispute in question (e.g., IEPs, Evaluation Reports).
Data Analysis

I listened to and observed parents and educators as they tried to resolve their differences about the education of a young child. I asked clarifying questions so that I might understand their reasoning, their questions and their purpose. My method in the research and the analysis is what Lawrence-Lightfoot (2003) calls "the essential paradox of narrative work: to get close to the nuance and detail of a person’s experience so that we can see and understand the collective story" (Lawrence-Lightfoot, 2003, p. xxviii). My analysis of the events and the perspectives of the individuals offers specifics of each case and helps to explicate the underlying and common issues that many parents and educators face when they are in the process of trying to resolve a difference (Strauss & Corbin, 1998). This approach is particularly helpful since the complexity of the pertinent educational regulation and systems, and the strategies utilized by the parents and educators are not always evident to the participants themselves. In my analysis of the case studies, I elucidate the points at which conflicts dissipate or escalate and the issues or actions that stand in the way of resolution.

This research looks at the nexus where policy and procedure and overall parental satisfaction meet up with how parents and educators work to resolve differences at the local level. The challenges to productive communication, to flexibility and responsiveness, and to meaningful resolution are substantial (Lawrence-Lightfoot, 2003). My intent here is to develop a deeper understanding of the obstacles that parents and educators face as they try to work out their differences and meet the educational needs of the young child.
RESULTS
Where Conflicts Emerge

Parents' entry into the early intervention system can come at varying points in their child's development. Infants who receive a diagnosis at birth, or shortly thereafter, and have a condition that has a high probability of developmental delay, are often referred for service directly upon their release from the hospital. For children who present with delays in development over time, parents often bring up their concerns with their pediatrician, who may in turn recommend a referral for early intervention. Sometimes the suggestion to contact early intervention comes from other family members, friends, day care providers or pre-school teachers. The Keeping Children Safe Act of 2003 requires that children under the age of three who are involved in a substantiated case of abuse or neglect must also be referred for early intervention services.

When an infant or toddler enters the early intervention system, their parents are immersed in a system that has policies, procedures and practices in place to promote the parents' participation in decision-making and service provision. Parents are expected to dialogue with educators about goals, outcomes, services, supports and therapies for the eligible young child. Part C of the IDEA (2004) focuses on children birth to three, and seeks to minimize the alienation and intrusiveness of the system by mandating that policy, procedure and practice be family centered.

A family centered approach to services is a major component of Part C.
Family-centered practices are those in which families are involved in all aspects of the decision-making, families' culture and values are respected, and families are provided with accurate and sufficient information to be able to make informed decisions. A family-centered approach keeps the focus on the developmental needs of the child, while including family concerns and needs in the decision-making process. Family-centered practices include establishing trust and rapport with families, and helping families develop skills to best meet their child's needs (Dunst, Trivette & Deal, 1988; Office of Special Education Programs [OSEP], 2002).

In 1986, the federal legislation known as the Education for All Handicapped Children Act (EAHCA) was reauthorized and included a specific focus on the needs of the family to enhance the development of children with disabilities. In enacting Part H of the EAHCA, Congress acknowledged the need to support families and enhance their capacity to meet the needs of their infants and toddlers with disabilities. On the cutting edge of education legislation, Part H (now known as Part C of the IDEA) challenged systems of care to focus on the family as the unit of services, rather than the child (OSEP, 2002).

As required by Part C, parents are members of the multidisciplinary team that assesses a child's eligibility and needs. Parents are also part of the team that develops and implements the Individualized Family Service Plan (IFSP) where the outcomes, objectives for a child and family and the services and supports needed to address the outcomes and objectives are determined. The
participation and role of parents in planning for the transition between services and funders when their child turns three is also specified in the legislation.

The mandate for family centered services has influenced the provision of services in both positive and negative ways. Parent choice has at times undermined a team approach to services (OSEP, 2002). There is a balance that professionals struggle with when they accede to family desires and demands that are at times contrary to their judgment. A lead administrator responsible for early intervention service in Philadelphia for children birth to three years old, sees a tendency on the part of the professionals to acquiesce to parents’ demands: “For the most part the team leans toward whatever it is the family says they want or need because of this whole fear that they’re going to take us to due process [i.e. to a hearing].”

On the positive side, bureaucracies have implemented system changes with an eye towards creating opportunities for greater family participation and choice. In a proposed referral system for early intervention for children birth to three in Philadelphia, families are able to choose among providers rather than have a provider of service assigned to them based on system efficiencies.

For children who are three to the “age of beginner” i.e., a designation in Pennsylvania of the minimum age that a child can attend first grade in his or her own school district, Part B of the IDEA (2004) also outlines a model of parent involvement. Part B requires that parents have an opportunity to participate in meetings that concern the identification, evaluation, and educational placement of their child. Parents are also members of the team that develops the child’s
IEP. In Philadelphia, the majority of children between the ages of three to five receive services in pre-school settings, self-contained or inclusive, and intervention is school based with varying degrees of communication and contact with families. Here is an example of typical method of communication between educators and parents is described in a provider’s parent manual:

Expect a progress note following each session. These notes are either left with your child’s teacher or placed in your child’s cubby. Please review and pay special attention to the ideas for follow up at home. This note will indicate what occurred during the session and indicate the progress.

Parents’ Varying Levels of Satisfaction with the Early Intervention System

Our understanding of the level of parents’ satisfaction depends on the lens we use and the type of data we collect. In large-scale surveys, we find that the majority of parents are satisfied with their involvement and with what the system offers their child. The preliminary data from the first National Early Intervention Longitudinal Study (NEILS) for children birth to three, reports the results of a survey of over 3300 families (Bailey, Scarborough & Kebbeler, 2003). Half of these families had their child’s IFSP within 6 weeks at the time of their interview and thus were very early in their early intervention experience. In this survey, families were generally pleased with the decision making process and were very satisfied with the services they were receiving. The vast majority of families (93%) indicated that both their therapy services and other early intervention services were excellent or good. Families also reported a high degree of satisfaction with early intervention professionals. They found the communication among the professionals who worked with their family to be good and nearly all

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
had good feelings about early intervention professionals. In large part, families also agreed that early intervention professionals respected the family's values and cultural background. Families thought their opinions were being listened to and that professionals helped them feel hopeful about their child's future.

Some areas of dissatisfaction were also revealed in this national survey. Parents reported less collaboration with other team members in determining the kinds of services the child receives. Only 64% of parents reported that parents and professional determined the kinds of services together. Even fewer parents reported that they felt a part of the decision regarding the amount of services provided. Forty-three percent of parents reported that families and professionals made these decisions together. Families were generally pleased with the amount and quality of the therapy services (e.g., speech therapy, occupational therapy, physical therapy) as well as other early intervention services that the child received. Seventy-six percent of families thought their child was receiving the right amount of therapy. However, one in five (20%) parents reported that their child was getting less therapy than needed. One in seven (14%) families also thought their child needed a service that he or she was not getting. Interestingly, families of older infants, i.e., 12 to 24 months, were less likely to see decision making about the amount of services as made jointly by families and professionals. As parents gain more knowledge, perspective and experience and as their children progress or do not progress we might expect a change in their level of satisfaction. It may be that family's satisfaction with early intervention changes after more experience with the system.
The survey also found consistent differences in satisfaction based on race/ethnicity, caregiver education level and household income. Minority families, those with less education, and lower income were:

- more likely to report that it took a lot of effort to find early intervention services and to get services started
- less aware of the IFSP
- less satisfied with their degree of involvement in decision making about types and amounts of services
- less likely to have good feelings about professionals
- more likely to feel that professionals did not respect their values and cultural background and ignored their opinions
- less likely to believe that professionals made them feel hopeful about their child's future (Bailey, Scarborough & Kebbeler, 2003).

Family satisfaction surveys are becoming a routine measure of assessment of early intervention systems (Pennsylvania Department of Public Welfare, 1999, 2002). In the most recent Self Assessment Family Survey in Philadelphia (Pennsylvania Department of Public Welfare, 2002), the sample included families new to early intervention as well as families who had received early intervention over time. The majority of families reported high rates of satisfaction with their early intervention services. A large number (87%) of families felt encouraged by early intervention personnel to be present for their child’s assessments and evaluations and to participate in the process to whatever extent they chose. Many families (84%) reported that early intervention
personnel treated them as equal partners in the early intervention process. A substantial number of families (84%) also agreed with the statement: "As a result of participation in the early intervention service system, I feel more capable of securing the supports, resources and services to achieve the outcomes that I want for my child and our family."

Some areas of concern that were highlighted by the survey were that only 57% of families reported that informal and community supports such as nursery school, neighborhood play groups, community recreation were identified in their child's IFSP. When rating their child's current IFSP, only 44% of families said the emphasis on their child's communication and language skills "was about right." And only 51% of families said the emphasis on their child's self help skills "was about right." These findings suggest that families want more services and supports for their child in these areas.

As these national and regional surveys demonstrate, parents are generally satisfied with the early intervention system. However, some parents also experience a degree of dissatisfaction with aspects of the services that their child receives. Two leading advocates familiar with special education disputes regarding children, ages three to twenty one, list the common concerns as follows:

- Eligibility: The child has educational problems that suggest a disability.

  The school has not found the child eligible for special education.
• Failure to provide an appropriate education: The child’s IEP is supposed to be individualized to meet the child’s unique needs. Many districts offer “one size fits all” programs that do not meet the child’s needs.

• Failure to implement the child IEP: The school is not providing the services and supports specified by the IEP.

• Inappropriate Discipline: Although the child’s behavior is a result of the disability, the school suspends or expels the child (Wright & Wright, 2004).

In Philadelphia, the supervisor of the county department that administers early intervention services for nearly 2000 children from birth to three years, experiences parents’ issues and concerns as follows:

Sometimes families are not satisfied with their service providers. Sometimes families are not satisfied with the services. Either they want more, they rarely want less, or they want different duration or frequency at the beginning. In addition to wanting more, they sometimes want different – not services that are normally offered by service providers that we normally do business with. Every now and then they might be uncomfortable with their service coordinator but we don’t really hear that too much....The other area that I might just mention is that we may owe them make-up (services). There might be a question of delay in the start of service.
When a Child is not Making Progress

Lance and Lawrence Johnson are twin boys that were referred to early intervention at the age of two, due to concerns about their development. An evaluation by an early intervention team showed that each of the boys evidenced delays of 25% or more in cognitive and language development and that Lance was also delayed in his fine motor development. Lance has a diagnosis of developmental delay. The children originally received home-based early intervention services. When they were three years old, the Mother enrolled the children in a Montessori pre-school. This did not turn out to be an appropriate placement for them as the pre-school was unable to address their needs. The Mother then enrolled the children in an early intervention center-based program and was pleased with the progress the boys made. When the boys were four years old, the family moved and enrolled the children in a Head Start Program. Since early intervention agencies in Philadelphia that serve children between the ages of three and the age of beginner are assigned to regions of the city, the boys' enrollment in this Head Start Program required a change in the agency that provides early intervention services. From the current early intervention provider the boys receive “itinerant” services from a community based teacher, a speech therapist, and an occupational therapist. There is a case manager assigned to the team. The team became aware of Ms. Johnson’s dissatisfaction shortly after the initial IEP meeting, when she contacted the case manager and shared her disagreement with the special instruction goals for the boys. All of the team
members, especially the case manager, are aware of Ms. Johnson's expressed and continued dissatisfaction.

In my interview with Ms. Johnson she describes a high level of frustration with the current early intervention program and with the early intervention system as a whole.

Ms. Johnson: They're [this early intervention Program] coming in at the end. I'm disgusted at this point....Early intervention should have certain criteria. They should have some kind of standardized ways to educate the children.

Case Manager: Yeah, she told me, her statement was I am dissatisfied with the entire system - not necessarily with [the current early intervention program], just the system, early intervention. She is just glad her kids are moving on from this.

The Mother’s Concern

In my interview with Ms. Johnson she articulated her concerns:

Ms. Johnson: When we make goals, if he [Lance] doesn’t get his goals [then what]? Why is he not meeting his goals? The professionals couldn't give me an answer. Why couldn’t we work creatively? I’m concerned about my children going into [the next grade]. [Why can't the early intervention staff] pinpoint different methods?....I have a son [with whom] I’ll be working hard this summer. I don’t understand why he’s not grasping it but if you hold up an A [he doesn't know what it is]. I feel like somebody [should know why]. I, as the parent, don’t have the answer...I can’t tell you how disappointed [I am]. No one has been able to give me answers. Should I get him more testing, should I sit on my hands and wait and see? He's four and all he’s learned are color and shapes. I put in time and so do my husband.....My son is not processing material....there is something with his processing and nobody can give me an answer. Do we just keep waiting every year to see? At this point we'll have the same goals. We’ll do
the fifth or sixth CER [Comprehensive Evaluation Report] but I will go back to the drawing board.

As she made clear, Ms. Johnson was concerned about Lance’s failure to recognize letters and numbers and what this meant for his expected entry into kindergarten in the fall. The educators on the team appeared to have some understanding of her concern.

Community Based Teacher: I think they [the boys] have both progressed....I don’t think that Lance is as low as his Mom feels he is...and another concern of Mom’s - like her concerns are more like, rightly so, that their kindergarten readiness skills, like he can write his name. That they can count to this number, or that they can recognize numbers and things like that, which maybe they are not exactly at yet....I think her biggest concern right now is where they are going to be in kindergarten, and what the best placement is for them after this year.

Case Manager: I have asked her that question, what is it that is so dissatisfying to you about [inaudible]? And she said, “I really can’t say, I just don’t think my kids are benefiting. I can’t say one particular thing, but I don’t think my kids are benefiting. I think they did better when they were in [the previous early intervention program]...I saw more progress.” And I said, “if there is anything we can do, please tell us.”

Speech Therapist: I think a lot of the things she talks about is what is to become of them for kindergarten, that is a big concern that she has.

Though they were aware of Ms. Johnson’s concerns, they did not describe a discussion with her that includes the reasons that Lance may not be recognizing letters and numbers to the degree that she expected and what this means for him in kindergarten. While the educators appeared to recognize that this was a central issue for Ms. Johnson, they did not address this directly with her. Instead, they referred to the progress the boys have made and they express their willingness to help. Though these were helpful and necessary elements to a
discussion about Lance’s progress, they were not sufficient in that they did not speak directly to Ms. Johnson’s concern about Lance’s processing and his success in kindergarten. The absence of a direct discussion about Lance’s cognitive abilities, the instructional approaches that were used and others that could be tried, and his placement and success in kindergarten contributed to the mother’s underlying anxiety about her son.

*Frustrated and Strategizing*

Ms. Johnson’s dissatisfaction with the boys’ progress and their early intervention services became apparent shortly after the initial IEP meeting. Out of her frustration with the inability of the early intervention team to address her concern she adopted several strategies. First, she took over the writing of the children’s cognitive goals. After the first IEP meeting with the team, Ms. Johnson contacted the team and took the initiative to add more special instruction (i.e., cognitive) goals. The team agreed to these goals, with some minor modifications, and felt that the new goals were appropriate and on target.

Community Based Teacher: Well, initially she was having concerns about the goals that were written. Like I said, she wanted them to be more geared to kindergarten readiness things, so we re-wrote the goals and basically she had a lot of good ideas in her goals, so we took her ideas and put them into goals and changed them. Like I said, the letters of the alphabet are goals for them, but we kind of downsized it to work on the letters of their names, and then build from there.

This response to Mrs. Johnson’s interest to change and improve the goals was evidence of the team’s interest in working collaboratively with the mother.

However, this accommodation did not get at Ms. Johnson’s underlying concern about the need for the boys’ to make further progress. Though she was pleased
with the team's cooperation at letting her rework the goals, their willingness and openness to her involvement did not get at her need for the boys to make more progress. Though the team was responsive to her initiative to rework the children's special instruction goals she did not perceive that she was heard in a way that made a difference to her.

Ms. Johnson: When [the Special Instructor] gave me three goals we increased it to five goals, they are flexible. Nobody really has the answers – let's see what happens....It doesn't seem like there is teamwork, if they can't work with me....They hear you but when you turn your back they forget about it. It's precious time I can't get back.

Ms. Johnson's second strategy was to count the amount of time that her sons received early intervention services. She became vigilant about any scheduled time that the educators missed. After a number of the educators each missed a few visits, she advised the case manager of the missed visits. The case manager verified the missed visits and ensured that compensatory visits were given to the boys. After this communication from Ms. Johnson, each team member was very aware that they not miss visits with the boys to avoid the mother's close accounting.

Speech Therapist: Well, one of the main things is making sure that they are being seen for the amount of time they should be seen on a regular basis.. We know for example, with this mother that she keeps really good track of when you come, and how long you see the kids, and she asks the teachers and she has this book that we write in. So other parents, like if you are sick, it is not a big deal for the therapist, but with her, it is. So, just knowing that is very important, I make sure that I don't miss it.

OT: So I walked in expecting a mother...who was very much an advocate for what her children have based on the IEP. What that meant was, that if there was a session that was missed, for whatever reason, you better make it up or she will cause trouble.
The educators focused a lot of their energy on trying to avoid any missed visits. They were aware that their commitment to provide the agreed upon service was a legal obligation and once questioned by the mother they tried to reduce their vulnerability to any obvious failures to comply with the IEP. They struggled with this degree of scrutiny.

OT: What I have done is I have tried to make-up as many sessions as I can...I will see her kids as opposed to other kids. If there is a day off, or if school is closed, I will make that conscience effort - mainly because I don't want to have any grief. I don't think they need it more than anyone else, so I am struggling with that, as a professional...is that fair. You know in a certain week when school is closed, or there is a snowy day, somebody won't get seen, and I am still struggling with do I see the one who really needs it or the squeaky wheel.

**The Mother’s Critical Stance**

There were two areas that Ms. Johnson was critical of that challenged the educators. First was the testing of the children. Early intervention providers are required to test the children on an annual basis and may request permission to test a child on a more frequent basis as needed. Ms. Johnson expressed exasperation with the frequency of testing and the lack of useful information that she derives from the evaluations.

Ms. Johnson: They’re constantly testing.... Do we just keep waiting every year to see? At this point we'll have the same goals. We'll do the fifth or sixth CER but I will go back to the drawing board. I will go back to work with them [her boys].

Prior to Lance and Lawrence’s next CER (now known as the ER or Evaluation Report) and IEP meetings, Ms. Johnson notified the Case Manager that she wants to postpone the meeting so that she had time to read the evaluation reports. The law requires that the parent receive a copy of the CER...
ten days prior to the meeting in order to have sufficient time to review the report. Ms. Johnson’s use of this legal mechanism again put the team on notice that she was aware of her legal rights.

At the meeting, Ms. Johnson was prepared with her notes and challenged the educators about what they included in their reports.

*Notes from Lance’s CER meeting.*

Case Manager starts discussing the evaluations for Lance that were done by the Community Based Teacher, OT and Speech Therapist. Ms. Johnson has crossed things out on her copy of the evaluation.

Case Manager: Why have you crossed out things?

Ms. Johnson: Because it’s wordy. I just think some things are irrelevant – like how long it takes to test.

OT: I think it is relevant to say how long the test took...

Everyone in the room looks tense.

Mrs. Johnson: Every little detail doesn’t have to be written down. I don’t think you need to document every little detail.

Ms. Johnson is talking about the OT evaluation. She disputes the OT’s recounting of how he did not draw a cross, how long it took to test him, how long he sits, if he is interested. Mother wants reference to Lance’s independent toileting taken out since “most kids his age can.” Discussion about taking out items, the staff agree to take out the disputed items.

This interaction between Ms. Johnson and the educators was quite intense. The educators were aware of the mother’s legal right to dispute the
items in the report and went along with her request to have them removed. The
Mother’s exercise of her legal right to dispute the evaluation report challenged
the educators’ routine manner of doing evaluations and signaled Mrs. Johnson’s
tenacity about protecting the interests’ of her sons.

Case Manager: In the beginning I was feeling like she comes at us for
reasons...I guess she thinks we are against her or something - I feel like
we are always defending ourselves - she has us on edge sometimes. We
do it very thorough for her and then she says, “oh, it’s too long.” So it is
like we can’t please her sometimes, that is how I felt as it was starting out,
we are never going to make this woman happy and that’s it. So we follow
all the rules, stay with procedure and hope for the best. And, then she
started to calm down a little bit after we said we would take some things
out, but I was pretty adamant about keeping testing information in, I didn’t
want to be swayed by her, I wanted to stay with that. Some of the things,
like toileting, that’s a strength, and I thought it was kind of funny how she
wanted to take it out. I thought it was a strength, so why not...but her
reasons for doing things I just can’t figure out. I do think I heard her say
that it was irrelevant for a five year old to have a statement to support that.
So, what I am doing is omitting everything she said....

Ms. Johnson’s second critique also heightened the educators’ awareness
of their need to make sure they do all that was required of them. This critique
was manifest in her pervasive lack of confidence in the expertise of teachers in
early intervention. She expressed this lack of confidence in numerous ways. She
questioned the qualifications of teachers, she was critical of the teaching
methods used, and she lamented the paucity of information that she got from
teachers, who were most directly responsible for instruction in cognitive skills.

Her experience and critique of the lack of qualifications included teachers
of children birth to three (commonly called special instructors), Head Start
teachers and community-based teachers.

Ms. Johnson: But I listened to the professionals. The [School District
Representative doesn't come around [to the Head Start classrooms] and see what's going on. They [the educators] don't know what to do. It's like let's try this and experiment and let's see how it's going to come out. I want teachers to be licensed. [Note: Ms. Johnson may not be aware that though Head Start teachers and special instructors who work with children birth to three years are not required to be certified, teachers who work with children 3 to age of beginner are required to be certified in either early childhood or special education.]

Ms. Johnson questioned the teaching method of play-based instruction used by many early childhood teachers. This method involves encouraging young children to learn through play and is considered a best practice in early childhood education and early intervention.

Ms. Johnson: When they were home-based the special ed teachers wanted to do arts and crafts with them. I understand that they learn through play but the teachers should be creative with play. The lessons were not age appropriate...Every time I walked into the class my son was playing. I have a lot of toys at home, there is a lot of play.

Ms. Johnson's critique of play-based instruction was not reserved just for the teachers. Other disciplines including speech and occupational therapy used the method and also received negative feedback from the Mother.

Speech Therapist: One time, she kind of peered in while I was working with one of the children, and she said "oh, it looks like they are just playing to me." So it is just trying to address that kind of thing...I try not to get upset about that, and try to explain what I was doing - whether it was heard or not... So I wasn't happy about that comment...it bothered me, but I just tried to explain what I was doing and I think that was OK.

Lastly, Ms. Johnson did not see the teachers as a resource. The teachers were unable to give her answers about why Lance was not identifying letters and numbers and they did not identify alternative instructional approaches.

Ms. Johnson: [Why can't the early intervention staff] pinpoint different methods?...I don't understand why he's not grasping it but if you hold up an A [he doesn't know what it is]. I feel like somebody [should know why]. I, as
the parent, don't have the answer....No one has been able to give me answers....My son is not processing material...there is something with his processing and nobody can give me an answer.

Ms. Johnson's questioning of the expertise of the boys' Community Based Teacher was evident at the CER and IEP meetings. At Lance's CER meeting, the Community Based Teacher reported on the results of her evaluation of Lance (the Mother was present during these evaluations). The Community Based Teacher reported that Lance received a score of 43.5 months, which put him right at the cut off of eligibility for special instruction and said, "He is very close to not even needing me to see him." A bit later, during Lance's IEP meeting, Ms. Johnson was openly contemptuous of the Community Based Teacher on the team.

*Notes from Lance's IEP meeting.*

Community Based Teacher: We can keep a lot of the goals the same.

Ms. Johnson laughs, rolls her eyes and says, "go ahead."

In this same meeting, the Head Start Teacher questioned the Community Based Teacher's methods. The Head Start Teacher then unilaterally requested an increase in Lance's special instruction.

Community Based Teacher discusses goals of identifying numbers, shapes and letters in his name, telling a story in a sequence.

Head Start Teacher: Is he getting that one to one, in a small group? How do you work with extended services during the summer?

Discussion begins about summer.
Head Start Teacher: I think he should get more special instruction. I've been asking that question and nobody has gotten back to me. I can't tell from Ms. Johnson's nonverbal expression if she was previously made aware of this request. I don't think so because she begins to chastise the teacher for not letting her know that she had concerns.

Community Based Teacher: Yes, he can get more special instruction. Can I come during naptime? Two times a week I'm going to say. I've got 16 places to go to see 33 kids.

In Lawrence's CER and IEP meeting there was a similar pattern of questioning of instructional approaches and expressed lack of confidence in the same Community Based Teacher. This was voiced both by Ms. Johnson and by Lawrence's Head Start Teacher, who was different from Lance's Head Start Teacher.

*Notes from Lawrence's CER and IEP meeting.*

Community Based Teacher: He came out at 42 months. He came out closer to the cutoff.

Ms. Johnson: Which, of course, I question.

Head Start Teacher: What's your question?

Ms. Johnson: I've seen a lot of testing - although this is more detailed. Discussion about what this test (Battelle) is assessing. Head Start Teacher's main concern is social skills.

Head Start Teacher: He's gotten so much better. He can focus on what he needs to do.
Head Start Teacher brings up topic of kindergarten. She says that Lawrence will need a small kindergarten class to be successful. Ms. Johnson talks about a “learning support” class. Head Start Teacher speaks highly of Speech Therapist working with Lawrence in the classroom. Community Based Teacher tries to explain why she doesn’t work with him in the classroom. She says the goals on his IEP are pre-academic skills and since she usually comes during their free play time she feels it works better to take him out of the class. Head Start Teacher talks about why she thinks it should work (to be taught by the Community Based Teacher in the classroom).

Head Start Teacher: He needs to handle other things in the classroom. [The Speech Therapist] does it. It [special instruction] should be more integrated [into the classroom]. I think he is going to need support for kindergarten.

When the Speech Therapist starts to talk about speech goals and Ms. Johnson says, “Can we end this meeting? I know who knows their stuff. I trust you [directed at the Speech Therapist].”

Ms. Johnson talks about how tiring the meeting is. The meeting ends.

The Mother’s Approach to Conflict

At the boys’ CER and IEP meetings Ms. Johnson was forceful when she disagreed with the team. She was direct in saying what she wanted changed in the CERs and maintained her position until the educators agreed to omit the items she requested. However, in my interviews with the educators they reported...
that Ms. Johnson often expressed her dissatisfaction with something and then retreated from her statement.

Community Based Teacher: Yeah, she initially called and said we weren’t...she didn’t feel like we were making enough progress and that I felt she was saying that we weren’t meeting their goals. And then we talked about it and said that they have made a lot of progress, socially they have made enormous progress and they are making small steps in their cognitive goals. And the she said it is not [this agency] that is not meeting the goals, “I feel like in the classroom they are not getting their goals met,” so she just kind of changed that a little.

Case Manager: I have asked her that question, “what is it that is so dissatisfying to you about [early intervention]” and she said, “I really can’t say, I just don’t think my kids are benefiting, I can’t say one particular thing, but I don’t think my kids are benefiting, I think they did better when they were in [another agency]...I saw more progress.” And I said, “if there is anything we can do, please tell us.” She said, “OK, it really isn’t you, it isn’t [this agency], I like everybody, I like [the OT], I like [the community based teacher], you’re a big help.”

We try to please her, but we are not always successful...sometimes she makes us feel like one minute she is fine with what we say, and the next minute she’s not, so, we don’t really know what way she wants us to go half of the time.

Speech Therapist: Sometimes I think it is one issue and then the next second, it’s not that issue, it is something else...and I think we all know that we are up against that - it can range from getting paperwork signed, doing an evaluation. Often it seems to be procedural things.

This combination of confrontation and retreat confused the educators. Ms. Johnson’s effort to soften the message after she shares dissatisfaction was motivated by her intent to not make the disagreement personal.

Ms. Johnson: I’m vocal. I’m opinionated but I try and not hurt their [early intervention staff] feelings.

After Ms. Johnson retreated from her message of dissatisfaction, the educators believed that her issue was no longer directed at them and they did not interpret
it as her intended expression. This was a pattern of communication that contributed to the Ms. Johnson’s continued sense of dissatisfaction and wariness on the part of the educators.

My own experience with Ms. Johnson was in keeping with her pattern of expressing her dissatisfaction and then retreating. At the end of the boys CER and IEP meeting the Ms. Johnson looked over at me and said, “Am I done with you?” She said this with an impatient tone in her voice. I responded that I would like to call her to set up a time to talk about this meeting. I called her on four different occasions. On two occasions, I left a message on the answering machine asking her to return my call. On two other occasions, she instructed the person answering the phone to tell me that she was unavailable. I believe that once it became clear to the Ms. Johnson that I too, did not have answers to her questions and further, that I was not making an impact on the process, her interest in participating in the research ceased. Rather than tell me directly that she didn’t want to continue she retreated by refusing to speak with me. As a result, I was unable to speak with her further about her understanding of the differences she was having with the team of educators.

**What About Kindergarten?**

Prior to the start of the boys’ meetings one of the educators gave Ms. Johnson the paperwork she needed to enroll the boys in kindergarten in September. Other than this exchange and the brief interaction between the Head Start Teacher and Ms. Johnson (described above) during Lawrence’s CER and IEP meeting, there is essentially no discussion of the children’s placement in
kindergarten. Typically, the subject of kindergarten would be discussed at the IEP meeting prior to an early intervention student’s transition to a school age program. In their anticipation of the meeting the educators had planned for this discussion to be part of the agenda.

Community Based Teacher: Right, well I think she wants, I mean I'm not sure exactly what kind of kindergarten I just know that she has said that is a concern of hers – probably the class size or the type of classroom. Like I know that Lance was in a Montessori, well I guess they both were in a Montessori before and that wasn't a good model for them, so I guess she wants to make sure that it is a smaller classroom in probably a good class. One where the teacher is aware of their needs. I'm not sure if she is looking towards a private school or staying in the school district or....I guess we are going to talk about that at the meeting, to see exactly what she is looking for.

Despite the intention to talk about kindergarten and the kind of class that would be appropriate, this discussion did not take place in Lance’s meeting. The discussion regarding Lawrence's kindergarten placement was very brief and the educators from early intervention did not participate in the discussion. In my subsequent interviews with the educators from early intervention, no one noted that this discussion was absent from the meeting.

In the context of the boys’ CER and IEP meetings, it appears that the subject of kindergarten did not come up because the educators were distracted by the need to defend their position. Ms. Johnson and both of the Head Start Teachers expressed their disagreements and complaints and the educators needed to respond to these concerns. At the beginning, the educators’ attention was on responding to the Ms. Johnson’s disagreement with the information to be included on the CERs. They listened to Ms. Johnson’s rationale and then after
some discussion, agreed to make the changes she requests. Then, the Community Based Teacher explained and defended her method of instruction with the boys and responded to an unexpected request for an increase in service by the Head Start Teacher. These were all very significant issues that required the educators’ attention and energy to resolve in a positive manner. With all of this going on, the subject of kindergarten, central to the Ms. Johnson’s concern about her children, was forgotten by the educators.

In the larger scheme of the educators’ general interaction with Ms. Johnson, the subject of kindergarten was not discussed in a specific and meaningful way. However, it is my experience that how this issue was handled by the educators is not uncommon. Many educators in early intervention have only a rudimentary understanding of what educational programs are offered by the Philadelphia School District and the local private schools. Often, given the turnover of staff in early intervention, the educators are learning about what is available along with the parents. The Philadelphia School District will sometimes host general discussions and brief classroom visits but this is not a consistent practice. In addition, early intervention staff are directed by Philadelphia School District staff to not be critical of and “talk down” the special education programs and classes offered by the School District with “transitioning” families. The range of educational options and supports offered by the Philadelphia School District often seem restrictive to early intervention educators whose own best practice guidelines promote individual planning for students and inclusion with typically
developing peers. Given all of this, educators in EI are sometimes reticent to engage in a full discussion with families about kindergarten.

*Generalized Anxiety and Avoidance*

The educators made use of some strategies in their efforts to resolve the differences that the Ms. Johnson shares with them. When Ms. Johnson approached the team with new IEP goals for the boys, the team responded to the mother in a collaborative manner. The educator and Ms. Johnson sat down and worked through her suggested goals, made some modifications and then adopted them. There is also evidence that despite their differences with Ms. Johnson, they were empathic in understanding her motivation.

Community Based Teacher: ...I try to have that mentality when I am talking to her to realize that she is calling because she wants to have the best for her sons and to make sure they are getting what they need. So you can’t really get upset with her or feel like we are doing the best we can do. You have to realize that she is coming from that place of wanting to get the best for her sons and do what is right for them.

They used the technique of “active listening” to help them deal with the Ms. Johnson’s expressed dissatisfaction.

Case Manager: We are just trying to do what we are supposed to do, at the same time, be actively listening to her. She seems frustrated and trying to be more clinical, in that way just kind of listen to her, kind of vent a little bit. We are also taking that position too.

However, the mother’s history of disagreement and attentiveness to detail put the team into a mode of self-protection.

JN: Do you have a sense that this situation is OK, is it escalating, are you concerned about it?

Case Manager: I think it is OK, if those are my choices - I think it is OK, it
is just that we are on top of it, we are very aware, we are following all the rules, we are making sure that the kids are getting service, we are not relaxing in any way, with anything.

No one dealt with the Ms. Johnson’s underlying anxiety about her children, their development and their schooling. There was a general pattern of avoidance on the part of the educators that contributed to miscommunication and further dissatisfaction. Some examples of this strategy of avoidance on the part of the educators surfaced at the boys’ CER and IEP meetings.

*Notes from Lance’s IEP meeting.*

Speech Therapist: I didn’t write any goals down. I wanted to ask you...

Ms. Johnson: I just want better clarity. I’m the mother, I can’t always understand him.

Speech Therapist and Mother agree on goals - work on increasing vocabulary, make language more complex.

Ms. Johnson: I’m going to get him more speech at [refers to local children’s hospital].

Speech Therapist says, “OK” hesitantly. She doesn’t ask any more about this.

In the case of one of the boy’s disinterest and opposition to participating in therapy sessions, the educators were reluctant to have a substantive discussion with Ms. Johnson to avoid further conflict.

OT: I actually sometimes dread going there because I know as soon as I show up he says “NO,” he is going to run around, and I’m going to spend 15 minutes trying to get near this kid.....I’m curious to know what that’s all about, and I don’t feel that we really addressed at the meeting, we kind of pussyfooted around that. I’m a little disappointed that wasn’t addressed,
but maybe that is something I can talk to Mom about separately. But I am a little hesitant, because I feel if I talked to her about it separately, I really don’t think she is going to see it the way I do.

The educators tried to protect themselves from further criticism and to weaken an argument that they are not doing their job well. They were motivated to avoid further conflict. The Community Based teacher’s desire to avoid more conflict was in large part why she agreed with the Head Start Teacher’s request to double the special instruction time for one of the boys.

Case Manager: I think it is a lot of service for them, again, I think the team is feeling like we’ll do whatever she says. I guess the impression I got was, “I don’t know what to do with her, it’s only for a few more months, and I’ll do it.” I can’t say she shouldn’t do that because it’s her client. If I was there I probably would have said, “Do you really think this is necessary? Could you give me some reasons? I might have posed the question to [the Community Based Teacher]....“Do you think this is the right thing? Do you think this is taking up too much time?” Or, I would have presented it in some way, depending on how the meeting was going, just to get the question out there, and have it go back and forth, but I wouldn’t of left it just completely alone. I would have questioned it. I think the frustration for her is that she [the Community Based Teacher] is just doing everything she can and, again, she can’t please [the mother].

The key topic that was avoided was why the boys, especially Lance, were not progressing to the degree that Ms. Johnson expected. The issue of lack of progress and its meaning for children is a very delicate area in early intervention. Unless a child is progressing well, meeting his or her benchmarks and no longer in need of early intervention, educators avoid making any prescriptive statements regarding a child’s future functioning. The reason for this approach can be traced to negative feedback from parents who receive pessimistic prognoses from doctors and teachers (Weinhouse & Weinhouse, 1994). The rationale is that since we truly don’t know how a particular child’s development will proceed, and
rather than presenting parents with a painful and perhaps inaccurate picture of their child's future, it is more appropriate to focus on the child's current abilities. As a rule, educators will steadfastly avoid the topic of future functioning with parents of young children in the belief that these conversations are the purview of developmental pediatricians, neuro-developmental specialists or licensed psychologists.

There is also a general practice in special education that educators emphasize the positive, the child's abilities and strengths rather than deficits. So, no matter how delayed a child may be the educators are instructed to speak with families and to develop educational plans that highlight what the child is able to do. Although intended to be supportive of families, this focus on the positive can be confusing for families who expect continued progress and instead experience a plateau in their child's development.

In this context, we can see that the full discussion of why the children, especially Lance, were not progressing at rates that would improve their success in kindergarten and what this will mean for them, was avoided. Given this general pattern of avoidance, it is not surprising that there was some degree of confusion on the Mother’s part regarding the children’s delays of which the educators were not fully aware.

Ms. Johnson: I was told Lance is developmentally delayed, I can't tell you what [that means]....My children are not slow. I know where my children lack.

Case Manager: A teacher told me once that she thinks she [the mother]
is expecting the kids to do too much, that she drills them, drills the kids, she will come in the classroom and drill them on their ABC's, and that the kids aren't really interested in that when she does it in class.

Community Based Teacher: I think she has a pretty good understanding of the fact that they have a delay, the skills that they do have, but seeing what is expected in kindergarten, I think is more difficult for her, like she would have liked to see them closer to the goals.

It may be that Ms. Johnson's intense scrutiny of the children's cognitive goals led the educators to think that she was further along in her understanding and acceptance of the boys' developmental difficulties. Certainly, their reluctance to enter into any discussion that may highlight a difference with the mother, also contributed to this misunderstanding.

The Johnson case is not atypical of how differences that arise among parents and educators about children with special needs are handled. In their desire to reduce the risk of further disagreement the educators avoid dialogue with parents about issues where they would like parental input. At some point in the course of conflict, educators sometimes acquiesce to requests for more service rather than have meaningful conversations about the needs of the child.

Pressures on Parents: Time, Acceptance and Perception

There are a variety of pressures that parents are under when they have a young child with special needs (Weinhouse & Weinhouse, 1994; Featherstone, 1981). Some of these pressures impact upon the parent's dealings and interactions with the educators who work with them and their child. These pressures include a sense of urgency to address the child's needs during a critical time for learning, a systemic demand that uses a diagnosis or level of
delay to determine eligibility for early intervention and the need for parents to actively maintain positive relations with educators who work with their child.

**Optimal Time for Learning**

In their efforts to advocate for their young child, some parents are acutely aware of the passage of time and are concerned with maximizing the child's opportunities for learning. As we saw above, this was a prime motivating factor for Ms. Johnson.

Ms. Johnson: Why is he [her son Lance] not meeting his goals? The professionals couldn't give me an answer. Why couldn't we work creatively? I'm concerned about my children going into [kindergarten]....They [the professionals] hear you but when you turn your back they forget about it. It's precious time I can't get back.

Joseph Hudson is a parent of a five-year old boy, Tyler, who recently received an evaluation that showed delays in areas of social and emotional development, language, cognition, and adaptive behavior. Mr. Hudson used the short time between his son's recent determination of eligibility for early intervention services and his impending entry into kindergarten in six months as leverage to get his child more service.

Mr. Hudson: So the goal was, if possible, to get him into kindergarten this coming academic year....At the IEP, they [the educators] said “okay he needs OT and he needs speech and language therapy and he needs special instruction.” I think the IEP team would have been satisfied to have that three days a week.... I said that given the magnitude of his deficits, some as many as two years and how broad the deficits were, five out of six areas, it was unrealistic I thought, to expect that he would be able to make all the deficits up in such a way that he would be ready for kindergarten in six months. I pushed for (and got) something more than the three days [Note: really three half day sessions a week.]
Mr. Hudson researched the relevant regulations governing the IEP process on the internet and spoke with a co-worker, a parent who was experienced with IEPs. It is because of Mr. Hudson’s vigilance and quickly acquired expertise that his son gets additional service. Mr. Hudson requested and reviewed the evaluation report in advance of the meeting. He anticipated the differences between his own position and that of the educators and prepared to make his request for more service.

JN: Do you feel that you have differences with the team?

Mr. Hudson: I felt that they were in accord up to a point. My main difference, I believe, was that they didn’t seem to have the sense of urgency about it that I did even though they documented the level of his deficit. I was alarmed when I read the report. I knew, for example, I was present for the evaluation, which was about two hours. It was interdisciplinary, three different professionals were there. I felt that the report was accurate; a 20 page report. The narrative was very accurate. In an hour and a half, two hours, they nailed him. They nailed his personality and what his problems were so I thought it was accurate, a good basis upon which to make recommendations. I read the report and I was alarmed and I knew the kid. He’s my kid! I’m, reading the report and [saying], “yes, this is him, this is him.” These were serious problems. They didn’t seem as concerned at the disparity between the goals we were setting for ourselves and the baseline where we were in terms of his abilities. And so, I needed to put a very fine point on that. It is unrealistic to expect him to make these deficits up if we’re only talking about preschool, two and half hours, three days a week and during that time really maybe just an hour of OT, an hour of speech therapy and hour of special instruction. We’re talking about less than nine hours a week for the next how many months. They were open to that. Once I brought it up, they were open to and open to talking about some of the possibilities. So we talked about some of the possibilities.

Mr. Hudson was also open to “a compromise” between himself, his wife and the educators. His goal was to have his son “get services every day of the week.” At the IEP meeting, the parents and educators agreed to have Tyler
attend an inclusive pre-school class three mornings a week, where therapy services would be provided, and attend a self-contained pre-school class two mornings a week. By agreeing to this arrangement, Mr. Hudson took what the early intervention system offered to accomplish his goal, rather than demanding changes that were problematic for the system (e.g., service time in one day for more than the typical half day session or services from one provider for five half days per week.) Mr. Hudson successfully used the pressure of time to increase the contact hours that his son was seen by educators and began to look for signs of progress in Tyler.

The passage of optimal learning time is one that parents are attuned to, but one that educators in early intervention do not often factor into their interventions. Educators in early intervention do not, as a rule, adjust the frequency, intensity or type of intervention based on the degree of discrepancy between the child’s current level and the level of performance expected in order to reach an agreed upon outcome, e.g., a regular kindergarten class placement. The decisions educators make about levels of service are within a context of limited resources and justification of service as appropriate, as well as within certain pedagogical prescriptions such as family centered service. I discuss how this context impacts the decisions educators make about services in the following chapter.

Acceptance

The parent’s acceptance of a diagnosis of their child is a process that can be filled with uncertainty and confusion for both the parents and the educators.
involved with the child. Parents differ in how they come to accept the diagnosis and how they interact with educators, based on where they are in this process of acceptance. Educators handle this uncertainty and confusion with varying degrees of understanding and skill.

Jason Richards is a four-year old boy who has a diagnosis of Pervasive Developmental Disorder (PDD). His mother, Lisa Richards, struggled with getting the diagnosis and what the diagnosis means for Jason.

JN: Why don’t you tell me a little about Jason?

Ms. Richards: He’s good. He’s quiet. He’s laid back. He’s sweet, not talking yet. We just thought he was going to a late talker. Till ChildLink [the service coordination agency for children birth to three years in Philadelphia] told me I could probably get Social Security for him. So we had him evaluated, finally. I backed out when I was supposed to take him [for a developmental evaluation]. Anyway, I was scared. I didn’t want him labeled and all that. So I got woozy and I backed out. Well Social Security sent me to a psychologist and she diagnosed him with PDD, which kind of got me off my ass getting him what he needs. He’s not just a late talker. Right!

JN: When did all this happen? When did you go through all this?

Mrs. Richards: I’d say about two months ago that we got him diagnosed....He was almost three when we started with ChildLink but my pediatrician kept saying, “he’s a late taker, don’t worry about it, don’t worry about it.” Well, I started worrying. They [the pediatrician’s office] finally gave me the number. They [ChildLink] evaluated him. They said he had delays. Then he went into [an early intervention] program.

Ms. Richard’s dissatisfaction with the first center-based program that Jason attended caused her to withdraw him from that program.

Ms. Richard’s: He was always in there with just an aide. The teacher was never...in there. They had him with really handicapped kids. Nobody talked. It was just kids that laid around, stuff like that....He’d always be off by himself, standing around. They didn’t get him to participate in stuff. But the big thing was, he wasn’t getting a teacher for nine hours.
As part of their process of sorting out what was best for Jason, the Richards then enrolled him in day care with typically developing children and requested that all early intervention services, except speech therapy, be stopped.

Ms. Richards: We tried the regular day care, you know, just get him around some regular kids.

JN: How did that work?

Ms. Richards: He made out in it. He didn’t progress with nothing, but it was just something for us to try, figuring regular kids - maybe they’ll break him out talking.

The Richards then enrolled Jason in a second center based early intervention program that they were happier with. But after talking with other parents of children with a diagnosis of PDD, Ms. Richards questioned why Jason was only receiving three half-day sessions per week of this program and not more. Ms. Richards recognized that her actions seem contradictory, i.e., first she withdrew Jason from a self-contained class, then enrolled Jason in a typical day care, then enrolled him in a different self-contained class and then questioned why he wasn’t able to attend the class five mornings a week instead of just three.

Ms. Richards: I feel like I’m flip-flopping right now just trying to find the best thing for him. I don’t know. I’m learning.

Ms. Richard’s concern for her son and her ambivalence about the diagnosis gave rise to the sequence of actions regarding Jason’s recent history of early intervention services that were noted in Jason’s file.
Notes in Jason’s file.

• Parent withdrew child from self-contained [i.e., center-based] class in summer.

• Enrolled child in day care. September 20, 2002 Mother only wants child to receive speech therapy services in [a typical] day care. Discontinue other services [special instruction and occupational therapy]. Father attended IEP meeting, not mother.

• December 24, 2002 Parents want center-based program.

• February 2, 2003 Service Coordinator contacted Education Director. Mother wants more service.

• February 24, 2003 Mother wants more service. Need IEP update.

The educators at Jason’s current center-based early intervention program are challenged by Ms. Richard’s recent request for Jason to receive more services.

Education Supervisor: It’s opposite of what she wanted initially. We’re all entitled to change our minds, but if she really wants a more intensive program, one of the options might be for her if he [the child] has that diagnosis [PDD], is to seek a different type of program altogether.

The educators saw Ms. Richard’s as someone who was demanding and generally dissatisfied and did not see her seemingly contradictory actions as a manifestation of her process of acceptance and learning about the needs of her son.

JN: Tell me how you kind of picked this up, you kind of flagged this [as a parent who had a pattern of difference with the educators]. As I recall correctly, she [Ms. Richards] had previous issues [with another early intervention program]. So, that was the flag for you?

Education Supervisor: That was my flag. That was my flag.
JN: Was it the particular kind of issues she had from the previous...knowing her history?

Education Supervisor: Just in general. I already know that program. I would equate it as a very good program so the fact that she claimed to be so dissatisfied said to me there has to a reason for this. The fact that I was also told that she came in with very specific instructions for his community based service and when they gave her what she asked for, then, she was dissatisfied with that. Okay, well that says to me “what’s going on here?” I think there has to be some reason between all these factors.

JN: So, you just started to string this together? This pattern?

Education Supervisor: You know, now here we are, she’s been with us for two months and she wants more and she wants it different and she wants more and she wants it different. You know. So, that says something to me. I think it would say that to anybody.

JN: So, is this something that you’ve seen before, so when you recognize...

Education Supervisor: We always have families that have this type of pattern. Here was another family indicating that same kind of pattern. When you’ve been in early intervention for a period of time, special education, you get to see certain patterns evolve and clearly this is one of those patterns.

Even when educators do recognize that a parent is “in denial,” they often do not know how to do deal with the processes of parent denial and acceptance and do not know how to support parents during this period.

In the case of Alex Martin and his mother, Sharon Martin, the educators were clearer about the process of denial and intentionally used an approach that helped them in their work with Ms. Martin. Alex is a three-year old boy who was born with a rare physical anomaly that required him to undergo a number of surgeries. Alex was closely monitored by his parents and at school and would likely need additional surgeries to address the anomaly. When Alex
was two years old, his mother had him evaluated for early intervention because
"he wasn't very cuddly....something struck me as not quite right." At age two, Ms.
Martin also had Alex evaluated by a developmental pediatrician who "mentioned
a possible diagnosis of PDD." However, Ms. Martin did not share this diagnosis
with the educators who work with Alex until a year later. The educators saw her
withholding of this information as part of her struggle to accept the diagnosis of
PDD.

Speech Therapist: She [Ms. Martin] has a lot of denial. He [Alex] had
a diagnosis for over a year before we were told about it. She knew, and he
was here and [didn't tell us] he had already been to a developmental
pediatrician.

Alex exhibits increased stereotypy (self-stimulatory behavior) and a
continued lack of interest in other children. The educators associate Ms. Martin's
lack of experience with PDD children with her lack of understanding of what
these behaviors signify.

OT: I think she observes some of the things that we observe, but I don't
think she has the same frame of reference that we do. So I don't think it
has the same red flag to her as it does to us. Even if we point out
something that is not a typical behavior, she may find a positive thing in
that.....Alex was repeating the same sentence over and over....there was
one day that he kept saying the same thing, and it was something from
TV, a commercial. And he kept repeating the same tag line from this
commercial, and when that was told to Mom [by the speech therapist], she
said, "Oh, but he said a full sentence." So, it was kind of like, "yeah, but,
we don't want him to be just repeating the same sentence over and over.
It doesn't have any meaning, there was nothing contextual that made that
come up." So, I think she may observe some of the same things we
observe, but I don't think she associates the same things that we do with
it.

The educators saw Alex's increased social withdrawal and stereotypic
behavior and determined that he needed a more structured educational approach
in order to prevent regression. They planned to bring this issue up with Ms. Martin at the six month review of Alex’s IEP.

Physical Therapist (PT): He has a medical diagnosis, but that’s not really at issue. It’s the diagnosis of PDD that he has, his behaviors and such. He’s becoming more kind of autistic like, it appears that there is an increase in the behaviors that withdraw from activities within the classroom. He doesn’t really interact with the other children, he really only interacts with adults that he comes in contact with, and that is with our strong effort to kind of force some kind of interaction. This issue came up in thinking about his transition for next year. Right now he’s in a small classroom, where he does get individual attention and that seems to be doing okay for him. But we’ve really not seen improvement in his behavior, in fact, a little bit of back sliding, I guess, of his behavior --more withdrawal, more repetitive vocalizations and movements. So that next year, the choices for where he is going to go are two very big, large open classrooms, and it is felt that neither one of those is going to best meet his needs. Alternatively, keeping him in the classroom where he is now would not work, because the group of children is going to be a lot younger then him. So, the recommendation that we are coming to, and the reason for the meeting on Thursday, is to recommend to the Mother that he be placed [somewhere] other than in our center, because we can’t best meet his needs. And what [we] are thinking, is....to have [the program] structured and closer to one on one supervision in order for him to thrive. Instead of just kind of going off into his own little world, which I think is...[what would happen] in the large classroom, that he could just go off in a corner and do his behaviors and he’d be very happy, but that is not benefiting him.

Not only did Ms. Martin not share Alex’s initial diagnosis of PDD at two years old, she also rejected the possibility of his enrollment at a specialized school for children with autism after she had him evaluated at the special school when he was two years old. Given this history, the educators believe that Ms. Martin was struggling with the meaning and implications of the PDD diagnosis and therefore, they were concerned that she would be unwilling to accept their recommendation that Alex receive specialized services for children with PDD offered in a special school or class for children with autism.
Speech Therapist: Yeah, I doubt Mom would want to send him to the [special school for children with autism]. I think she might agree to a wrap around [an aide that provides one-on-one support in the classroom]. I don’t know if she’d want him to stay here, or go somewhere else.

JN: So, do you see that you have a difference with Mom about this?

Speech Therapist: Oh, yeah.

JN: What do you see that difference as?

Speech Therapist: I would recommend the [special school for children with autism], most likely. But I doubt that is going to be Mom’s choice, and he is her kid, and she needs to make the decision that’s right for her.

JN: So, you think that educationally that would be the best program for him?

Speech Therapist: Yeah.

JN: But, you anticipate that Mom is not going to make that choice.

Speech Therapist: Yeah.

The educators prepared for the meeting with Ms. Martin and were anxious about the possibility for conflict.

PT: Ultimately, our feeling is...ultimately, it is the mother’s choice where she wants him to be....so we are going in with our strong opinion. But it’s not heavy handed..."this is what has to be done, kind of thing"...because that definitely wouldn’t work with Mom. She’s a strong woman, very intelligent, thinks things out and is a take charge kind of lady. So we are going in knowing who we are meeting with. So dropping directives in her lap is not going to be something that is going to work for her.

JN: Do you anticipate that there will be conflict at this meeting?

OT: I’m definitely preparing myself for that. Because, I don’t know exactly what’s going to come of it [the meeting].
In my interview with Ms. Martin she shared her perspective of Alex’s PDD diagnosis and her understanding of the upcoming meeting.

Ms. Martin: ....Now somewhere in there, I guess it has been a year ago, we had him evaluated at [a special school for children with autism]. He also has a developmental pediatrician...and she initially was hesitant to diagnose PDD, but also clear in mentioning that that was a possible diagnosis. Having said that, she [the pediatrician] always gives out excellent reading material, research information, and that kind of ‘a time will tell’ attitude. And again, as time has gone on, she feels from the evaluation at [the special school for children with autism] there was a mild diagnosis of PDD....So, and I am agreeing, I’m not at odds with that, I am definitely agreeing with that. That is, again, having never seen that before, but from what they are saying of what that diagnosis is and what Alex does, it looks like that is what it is...to me. So, now the question is whether or not the [early intervention program] can provide the services necessary....But, I think the question is whether or not they have the right services that Alex needs. So, that is kind of where we are right now.

JN: You have a meeting next week, correct? What is your understanding of why that meeting is happening?

Ms. Martin: I was instructed it was two fold, one that there has to be...well, there was one in the fall, but I think there is one every six months. But also, that they want, they being the therapists and the team, they want to make sure they are providing the services that he needs....The way early intervention is structured, it’s supposed to be a group agreement by the team....So, the meetings, and they are called a number of things, the IFSP, IEP, CER - all the terminology, yuh, it drives me batty....but the meeting should come to some conclusion as to....what next step that is needed. So, my sense is...that [the meeting] will be the opportunity for those sort of questions to come up. I mean, the way I read the guidelines if at any time I feel that something is needed, I can call a meeting. But I would also hope that, particularly since there are therapists who are seeing him from a different perspective than I am, if they see something that needs to be addressed, they can also call a meeting, which is happening from the way I see it in this case. So, I am open to that....[The program director] also mentioned that this was kind of the concern and she caught me one day as I was walking to come and pick him up, and that is fine with me...if there is something that I am missing, I mean that is one of the whole points of having early intervention services, that there is something that’s not quite right that a parent is not in a position to see, so
if they see that there is something that needs to be addressed, by all means.

Mrs. Martin explained her previous rejection of her son’s placement at a special school for children with autism as a concern for his safety. She was evolving in her understanding of the diagnosis and what it may mean for her son.

JN: So, at this point you're not seeing that you have any particular issues that are different from what the rest of the team is [seeing]?

Ms. Martin: Well, yes and no....I said I feel comfortable if they are suggesting that something, that there is a need for a meeting, and maybe there is something they are seeing....but, as I mentioned earlier, I had him, Alex, evaluated at [special school for children with autism]...and my thinking at the time, was that he was just too little and too young. I don't know if you know where it is located, [she gives directions]....which meant either I was driving there to drop him off or the transportation van was picking him up and you know it was a major highway.....He was two, but barely two. And then in the classroom that they were talking about putting him in, which the ratio was fabulous, it was almost something like one or two students to one teacher or therapist and...they had a very focused approach to children in all stages of autism.....The downside was that they didn’t have the medical, like the nurse, which kind of in a way, I was a little bit surprised. And, the other... downside was that while the classes were....the kids in the classes were put there at some developmental level, but there were also like six year olds in a class with developmentally two year old kids. And, Alex was two, and he was acting two, and I was really not trying to see a six year old kid have some kind of problems that day and endanger my little two year old. Selfish, maybe. Mom, definitely. So, at that stage, I was just not comfortable with that possibility of an arrangement....I mean, maybe that is an option that can be revisited. But, at two, I wasn't really ready for that. So, I'm not sure if that is what they are saying at [the early intervention program]. I don't know if that has become a discussion, I don't know.

JN: So, what I understand from you is that you feel like you have a pretty good sense of communication as to what is happening and you are open to talking about your son’s development?
Ms. Martin: Yeah, I mean I'm fairly open. I am open to the possibilities....I also want to make sure that, first and foremost, I want to make sure Alex gets what he needs...if he needs [the special school for children with autism], then that is what he needs.

_Notes from Alex's IEP meeting._

During the meeting, Ms. Martin and the educators “compared notes” about the behaviors they saw Alex doing at home or at school. At the mother’s request, the educators described what a more structured, intensive educational program would look like. The Program Director facilitated the meeting, asked various people to give examples and then clarified points as needed. The Program Director then explained the primary concern of the educators and the mother responded.

Program Director: We feel like he [Alex] is slipping backwards.

Ms. Martin: Are there other approaches? Are there some thoughts about what you can do?

Alex’s teacher shared why she believed that the special school for children with autism was what Alex needed. The Program Director talked about their struggle to meet the needs of children with PDD and how at some point the staff’s skills were not sufficient. The mother shared her uncertainty and ambivalence and the Program Director recommended a next step.

Ms. Martin: I don’t think I’ve been naïve. I’ve seen some changes but didn’t know the extent....How much of this is him saying “I’m going to control some part of me” [relative to his medical condition and the medical procedures he must endure]. I don’t know how much of it is a function of the PDD...So now what?

Program Director: The team would like you to explore [the special school
for children with autism] and we would encourage you to take someone for another set of eyes.

The Social Worker volunteered to accompany the mother and assist in arranging the visit to the school. The mother recounted her concerns with the school when Alex was previously evaluated. Ms. Martin then shared a more recent evaluation of Alex that confirmed the diagnosis of PDD, dated three weeks before the meeting. The Program Director responded with an easygoing retort.

Ms. Martin: I didn’t think it [the special school for children with autism] was appropriate. I didn’t want to get a call that he [Alex] got kicked in the mouth by a nine year old. I’m not rigid enough to think that it may never be appropriate....Not that I’ve been holding out but I’ve been holding onto this evaluation from his developmental pediatrician. He does have PDD.

Program Director: And we didn’t even have the report!

Ms. Martin: Truthfully, I forgot that [the evaluation report] was in there [referring to her handbag].

The educators and Ms. Martin went on to talk about the merits of the special school for children with autism versus a Therapeutic Support Services (TSS) worker (i.e., an aide that provides one-on-one instruction in the classroom). After a bit, the mother let out a heavy sigh. A few of the team members sympathized and said, "it’s a lot to take in." The mother asked how long she had to make these arrangements and confirmed that the educators would keep trying to work with Alex while she explored the special school for children with autism. The meeting ended with Ms. Martin and the Social Worker discussing arrangements to visit the school.
A purposeful approach: understanding and patience.

In her interactions with Ms. Martin, the Program Director saw the mother as strongly identifying with Alex's medical diagnosis and all that was entailed in his medical care. The Program Director had knowledge of the family pressure that Ms. Martin was under and how this may have affected the mother's perception of the child. She was able to see how Ms. Martin was coming to terms with the services that Alex may need, while struggling to accept her son's PDD diagnosis.

JN: Do you think that Mom sees that she has a difference with the team?

Program Director: I think that Mom is still struggling with the PDD autistic diagnosis that Alex has and because of that can't think about a program or environment that maybe is better suited for his needs.... In my perspective, the autism diagnosis as compared to the [medical diagnosis] per se has...in my mind, more implications for his interactive abilities and his schooling, the environment that he's in. Everyone can learn the skill of taking care of where his urine is excreted from [referring to his medical condition], but the challenge of the environment and how to direct his actions and how to help him not become so involved in himself to me is the big challenge. And she has further shared...that her immediate family and support system, both mother and mother-in-law, mother who is a teacher and mother in law who is another kind of professional in the human services field have said to her, "you know, he's just fine." In essence, "you really don't have to believe in that diagnosis, we don't believe it to be correct." So I think she's getting that message from extended family [and that is] yet another challenge here.

I think it goes back to that root of not sharing the doctor's report. I don't think it's a deliberate thing that she says to herself "well, let me test these people and see what they're going to come up with." I don't think she holds that diagnosis as real so the doctor gives her this report and like, we didn't know she had a report....It's not real [to her], it's not a part of who she sees as Alex....I don't think she disagrees with the team's picture of him. She doesn't disagree with the skills that we see or the concerns that we have because she sees similar things or the exact problems at home. It's taking that information and how you apply it to the plan and the environment that you may need as a result of that. I think
we're moving in that direction and I think she's accepting of that, but not
the diagnosis.

I asked the Program Director about her approach to helping Ms.
Martin and the educators who work with Alex as they sorted through this process.

JN: You played a key role in the meeting. Is that what you usually do?

Program Director: I will do that if the team presents or the parent identifies,
that there may be a conflict that will occur at the meeting in terms of the
team's recommendations or parent's request. Either I, the parent or the
team may suggest that I sit in on the meeting and the Martin meeting had
that potential for that conflict to occur.

JN: Can you talk about...your approach?

Program Director: Well, my approach in that role is that to make sure
ahead of time that people are aware of what the potential conflict might be
so that when we go to the meeting people aren't hit with a surprise on
about what a recommendation might be. That everyone, all of the
participants at the meeting, have time to think about: "this is going to be
our recommendation" or "this is the direction we would like to recommend"
but we know another member of the team or the parent, specifically, might
not be agreeing because she's given us information ahead of time that
says "don't even go down that road." So, I view my role as making sure
that all the members of the team know what the agenda are [sic] and have
been given that information ahead of time and are able to discuss that
issue pro and con from their particular point of view. My role is just to
facilitate and, quite frankly, be the mediator in that to make sure that if the
parent has shared a piece of information with me to remind her "that you
know we talked about that one particular aspect important to you," "you've
shared this piece of information with me" and vice versa from staff.
Sometimes staff may be reluctant to share a piece of information and once
again I might say then "in my observations of the child I've seen what the
staff have said" and have presented an issue on more than one occasion
where the parent doesn't seem to be responding to that. Sometimes I'll
assume that role. "Yes, I have seen Alex flapping his hands" and my
observation is a kind of a backup to the staff as well.

JN: It sounds like...it's an approach that you have used [before] and been
successful [with]?

Program Director: You know, we have been in situations where the
outcome has [been a parent who] pursued due process or a higher authority being called to the table for an issue, and sometimes that is necessary to happen if a call needs to be made at a different level whatever the issue is. But a piece of my goal is to not destroy a relationship that we have with the family. I want families to know that we will present opposing points of view if clinically and professionally staff think that’s the right road to go down, but we’re going to tell you that up front and up close and personal that we are acknowledging that this is an opposing opinion to yours, but want to be able to discuss it and not leave the meeting feeling like people are now angry with each other, but leave the meeting recognizing that people have different points of view about how to pursue this.

This approach reflects an understanding of how to address and manage differences and conflict. It is informed by a social work and counseling perspective and the input of people in the administration of the organization to assist and support the educators in the differences and conflicts that they encounter with parents. The Program Director also recognized and used the status of her leadership role at the agency to help parents and educators hear one another and to highlight the salient elements of information that needed to be shared.

JN: Where did you get this skill sense? Did you acquire it over time, in your administrative capacity?

Program Director: Yes, acquired over time both as part of my administrative capacity but probably more so in raising these kinds of issues with our administrative team and calling on the social worker of the day or the year who was employed with us to help guide us in these discussions. “So from your social work perspective, how would you have addressed this, what are you looking for, how would you direct the conversation and what should we be [saying].” Because I want staff to be this skilled not just that I have that skill and, again, simply it’s that I have the title of Director I think makes the difference not necessarily because I am exhibiting a particular skill. I think that many in my staff have the same skill, but they are not the Director. So, the Director says it and it sometimes comes across differently. But I think it’s a combination, sitting
in the [Director’s] seat as well as using our administrative team to kind of problem solve these sorts of issue and talk about them as a group so that we can begin to learn more about how to deal with conflict.

JN: So you have these social workers and you consult with them in terms of how to present these difficult issues?

Program Director: We might in other circumstances have done a team meeting with the social worker ahead of time, say, “this is what the issue is. Have you any suggestions about how we would approach this with this particular family?” So, it’s having done that on numerous times and occasions.

JN: Is that is that your background? Social work?

Program Director: No, education. Teaching.

The Program Director has a clear approach on how to deal with differences that parents have with a diagnosis or educational recommendation and used this approach with Ms. Martin.

Program Director: I think when I first met this family and our staff and other agencies were seeing them at home, clearly people were flagging, “these are our concerns for this child and maybe he needs a more restrictive setting.” I don’t know if it would have been a better move to have pushed that point with her [Mrs. Martin]. We always do try to bow to the parent. If a parent feels strongly that a child needs services in one environment versus what the team might recommend in the beginning, we’ll bow to that. Because, again, our first look a child is a glance, it’s a moment in time. And so, we look at a child, evaluate a child…we’re working with a child for a short period of time and say, “maybe this is a better environment” and the parent says “absolutely not, I object to that for the following reasons,” we’ll back off from that. I wouldn’t even go down that road to attempt to have this kind of conversation. I will bow to what the parent says. “I want an inclusive environment” but if we bow to the inclusive environment…and we see the child not being successful in that environment, or we need to give him additional level of support, or the child’s backsiding into something that we feel is not good at all, then [we] call for a meeting and in good conscience say, “we can’t continue with this because this is what we see.” I think to go through that process also adds to our credibility as clinicians, also helps to maintain that relationship with the family that says “we understand that this is your first choice and we...
tried it for this amount of time and this is what we've done to support that. But we're still seeing this, we're seeing this aspect of him going backwards and everybody else is going three steps forward.”

Same team, different outcome.

In the case of a five year old girl named Darla and her mother, Mariette Wilson, this same team saw another parent who, they believed, was in denial. However, in this case the team required the mother to revisit the possibility of a mental health diagnosis despite the mother’s use of clinical opinion, obtained outside of early intervention, that asserted that the daughter’s early experiences contributed to her difficulty modulating sensory input and therefore, her aggression, and that this was a developmental issue. Darla spent her infancy in an orphanage in China and was subjected to harsh treatment at the orphanage, the details of which Ms. Wilson wishes to keep private out of respect for Darla. Based on “outside” clinical information, Ms. Wilson had successfully advocated for the educators’ use and support of an alternative, sensory-based approach for Darla. However, after the services had been in place for a while, the team made a concerted effort to get the Mother to see her daughter’s aggressive behavior as symptomatic of an underlying mental health issue. At a meeting to review Darla’s progress, the educators asked the mother to consider mental health services for her daughter. This was a very difficult and emotional meeting for the mother and staff. Ms. Wilson, with the support and agreement of some of the educators on the team, successfully argued that Darla was making progress with the sensory-based approach. Ms. Wilson repeated her position that her daughter’s behavioral difficulties stemmed from a developmental and sensory-based delay and
therefore, her daughter was entitled to receive early intervention services. Ms.
Wilson refused to consider a shift to mental health services. The Program
Director shared her rationale for the team's determination to address the mental
health issue with the mother.

JN: How do you think it (the meeting) went?

Program Director: I think it went reasonably well. The qualifier is because I
think that the team still deep in their heart feels that there is a component
of a mental health issue here and clearly presented that to Mariette. But
[the team] also recognizes how very strongly she feels about pursuing that
service as an option or as an adjunct service to her daughter's intervention
services. So, I think they certainly recognize the progress that Darla has
made and will agree, "why mess with the program when it appears to be
working?" However, that [the mental health issue] will be a component that
will be explored the next time we meet and will continue to be a service
that is encouraged.

JN: Are the questions of early intervention funding [the one-on-one staff
for Darla] and the mental health concern intertwined?

Program Director: Well, I don't necessarily see the funding as intertwined
because I think the funding is pretty straight and clear. I think it is
ascertaining the root of this problem, and, therefore, assigning it to an
appropriate service, and, therefore, funding source. I think in Darla's case
it is complex and it is not so clearly defined, but...I would venture to guess
somewhere down the road it's [the mental health issue] going to play itself
out one way or another.

During the meeting, Ms. Wilson was very emotional as she articulated her
rationale and defended her position. Some of educators also became emotional
and provided data to support Ms. Wilson's position. Since Darla was making
progress and exhibited an overall decrease in her aggressive behavior, the team
agreed to continue the services (i.e., one-on-one aide at a community based pre-
school, occupational therapy and speech therapy). However, some of the
educators, including the Program Director, continued to press the issue of whether mental health services should be considered for Darla. As the facilitator of the meeting, I asked the Program Director about the need to press this issue with the mother.

JN: So you think it [the question of the need for mental health services] is important [for it to] surface now?

Program Director: Yes, because I think for this parent now who has from day one in our initial meetings with her and our discussions about what services are warranted under early intervention or mental health. She has such very strong feelings about accessing mental health, I think the team's approach is appropriate to say, "this is something that is available. We see this as an aspect of it." Could we as a group say, "Absolutely! It's one or the other. No!" And, respecting her opinion in all of this, to bow to early intervention [services]....But I also think, as the picture gets clearer the team will need to call a spade a spade and say "this is what we believe this is." You know to the point where the program stops working, because there is a piece of the approach that's not in place that mental health might address.

The meeting was an extremely tense and intense meeting. At one point, Ms. Wilson threatened legal action if the educators attempted to withdraw the one-on-one services that Darla received. Despite this, the Program Director did not think that the meeting was adversarial.

JN: Do you think it was an adversarial meeting?

Program Director: I do not. I think that we have all been and me, especially, having had the initial contact with Mom, and attempting to be the problem-solver when she was having difficulty keeping the one on one aide and the daycare center, etc...I think we've been up front with Mariette about our thoughts about Darla and getting services for any potential services she might anticipate. So, adversarial, no, because Mariette knew what the agenda was, what our concerns were, and this was probably going to be presented...and discussed. So, I don't think it was adversarial. I think she knew what the agenda was and we were going to raise it as an
issue, not because we were trying to save money or skirt our responsibilities, but because it is our responsibility to look at that.

The Program Director saw her role as supporting families and educators in their efforts to address and dialogue about difficult issues. She saw herself as a problem solver and willing to present difficult issues even in the anticipation of opposition.

JN: Your approach, what would you characterize it as?

Program Director: I characterize it as the problem-solver. You know the person who, when the staff are attempting to facilitate services to meet the needs of children, if they hit a roadblock, a stumbling block. For whatever reason they can’t access or the service isn’t available, “whom do I turn to?” Or, in the case of Darla, were it not mental health, my role is to come solve this problem, or at least help facilitate the discussion that leads the team to a reasonable conclusion.

JN: So you feel that’s where your skills are? That you’re in there to problem-solve with folks when they come to an impasse or work them through to a solution?

Program Director: Or when the team anticipates that there will be an impasse. If the team has, and in this situation, the psychologist has a conversation with Mom, “you know, this is what I’m thinking, let’s see this mental health piece” and Mom’s reaction to that is clearly of concern. She gets red in the face, or the tone of her voice increases, and her body language says this is offensive to me. The team member at that point may back off and say, “okay, I understand you have strong feelings about this.” But from that team member’s perspective, [if] she feels that is an important consideration to raise, then, again, they bring me in as the mediator, [to help] problem-solve the issue with the person.

Since Darla was making progress and exhibited a decrease in her aggressive behavior, the team agreed to continue the services that were in place (i.e., one on one aide at a community based pre-school, occupational therapy and speech therapy). Perhaps it was the manner or degree to which Ms. Wilson
opposed the team’s recommendation to consider mental health services for
daughter, but I found myself questioning why the educators continued to press
the mother on this issue. In her role as facilitator of the meeting, I tried to
understand the Program Director’s position and her experience of the meeting.

JN: Do you think that it was a difficult meeting?

Program Director: I think it was difficult because I think staff recognize the
love, the care and the attention, and the thoughtfulness that Mariette has
given to Darla. And the challenges that she has faced as a single parent,
as an adoptive parent and getting booted out of two or three nursery
schools already, continuing to have these problems and feeling very
strongly about the approach that needs to be taken for Darla. There is a
degree of sensitivity there by the staff that recognize that. Again, I also
feel that as a professional you got to raise this as an issue….I appreciate
the fact that they are able to present the opposing view, if you will, the
other side of the coin. I think Mariette recognizes that and appreciates
that.

JN: Do you think that it could have or should have been handled differently
at any point?

Program Director: Again, it’s a question of time. I think the team
recognized Mariette’s concern about using the mental health system. It is
important to lay that option on the table. Mom says, “no, I don’t want to do
it.” But there, again, it’s a process. It will come up again and could
potentially be more strongly advocated, and if not the [public] mental
health system then choose the mental health provider of your choice
through your insurance company if that’s what you choose for that piece—
the counseling piece of mental health intervention….It’s okay to put it on
the back burner for now, but it’s on the back burner it’s not, as is so often,
put in the back of the refrigerator.

Some of the team members felt professionally obligated to continue to
present the possibility a of mental health diagnosis for Darla despite the child’s
progress with a sensory based approach. It was not clear that this helpful to the
mother. Ms. Wilson gathered data to suggest that some of the educators did not
have the expertise to assess her daughter's needs. At a later meeting, Ms. Wilson agreed to a decrease in the amount of time that the one-on-one aide would spend with Darla based on Darla's continued progress. Yet, Ms. Wilson also continued to articulately and passionately present her rationale, supported by clinicians outside of early intervention as well as some within early intervention, that Darla's issues were developmental in nature and required the support of early intervention services.

Perception

As they engage in a difference with educators, parents are often sensitive to how they are perceived and express an interest in not being seen in a negative light.

Ms. Wilson: It's difficult when I'm in a meeting. I'm anxious. I try to be a reasonable person. I really try to see it from their side. I try to unite people rather than keep them separate...It's unpleasant to have to fight for things – to have to be assertive or rigid. It doesn't work for people at a personal level. I don't want to do that. It's unpleasant.

Ms. Johnson, mother of Lance and Lawrence, saw herself as balancing her advocacy for her children with consideration for the educators with whom she had differences.

Ms. Johnson: I'm vocal. I'm opinionated but I try and not hurt their [early intervention staff] feelings.

Parents, despite their successful articulation and advocacy of their position, worry and take care to avoid making their disagreement with the team personal.

Repeated disputes, however, tend to erode this commitment to not personalize the conflict. A leading advocate in the Philadelphia area suggests
that when the parents have experienced more than one, perhaps many, differences with educators, it may be that they bring to a current difference not only accumulated knowledge and experience but a determination to ensure that they achieve a particular outcome rather than a mutually agree upon resolution (R. Landsman, personal communication, October 12, 1999). An example of the debilitating effect of repeated disputes was evident in the case of Ms. Wilson and her daughter, Darla. Historically, Ms. Wilson had been very accommodating to the early intervention provider in an effort to be cooperative and to ensure that her daughter was not excluded from her pre-school (e.g., she was willing to accompany her daughter to pre-school when the one-on-one aide was on vacation or ill). After learning of the decision by the Pennsylvania Department of Education’s refusal to fund early intervention services while Darla attends a private kindergarten, Ms. Wilson expressed her rage at what she calls the “bureaucratic response” that “kindergarten is kindergarten and they won’t give her early intervention services.”

Ms. Wilson: I hate them all. I hate them all. I hate them all....They are so caught up with their bureaucracy. They forget what they are there for....They’re so caught up in their penny-pinching....I’ve tried to be a very positive person and I try to be fair, but I’m disgusted....I will go after them any legal way I can. I will make them pay. And I’m not this way at all.

As a last resort, Ms. Wilson prepared to argue for compensatory time, paid by early intervention, to provide the supports she believed her daughter needed to succeed in kindergarten.
An EI agency that serves 200 children, who each receive on average 1.5 services, could provide approximately 300 services on a weekly basis. These services primarily consist of special instruction, speech therapy, physical therapy and occupational therapy. Agencies and schools can and do lose track of the services that they commit to children and families. This "loss" of service happens with varying degrees of frequency depending on the school’s ability to track services and to monitor gaps, and the degree and management of staff turnover. Often it is the parent, not the early intervention provider or school, who notices that the child is not getting the agreed upon service. Cindy Chisholm is the parent of Charlie, a lively three and a half year old boy who had speech and motor delays resulting from a stroke at birth. Ms. Chisholm noticed that she was no longer getting progress notes from Charlie’s OT.

Ms. Chisholm: Charlie was signed up for OT and it dawned on me several weeks later I wasn’t getting the yellow forms and then realized he was not getting his service....They didn’t restart...after the summer. It was probably around November that I realized that he hadn’t been getting them from the beginning of the [school] year.

Ms. Chisholm alerted the educators and they immediately scheduled Charlie for regular OT sessions as well as compensatory sessions to make up the time that he did not receive the services due to their oversight. Ms. Chisholm acknowledged their responsiveness and did not appear disgruntled by the oversight or the gap in services.

Ms. Chisholm: [The Education Supervisor] was quite shocked and she got right on it....It was quickly resolved. I was upset that it [the interruption in services] had gone on that long and I was very pleased with how quickly it
was resolved.

In my experience as an administrator of an early intervention program, parents are disturbed by the failure of schools to monitor and keep track of the services that are committed for a child. A failure to provide service is often seen by parents as a demonstration of poor management or incompetence and an encroachment on the child's optimal time for learning.

Educators, meanwhile, often see the parent's vigilance of the services that their child receives as a challenge. When describing Ms. Richards, the educator shared her perception of the mother's tracking of Jason's services.

Education Supervisor: She is formidable. She needs to know where her [son's] services are. She asks me questions.

JN: When you say she's formidable, tell me more about that.

Education Supervisor: For example, she will say to me, the speech therapist originally assigned to him was ill but she didn't know it, "why hasn't he got his therapy?" I explain to her that we assigned somebody and he (Jason) actually got some makeup service on Friday when he was here last. There is a new therapist who is going to be picking him up directly. In that respect she's a good advocate for her child.

Parents who keep track of services put educators on notice that they are aware and able to advocate on behalf of their child. Ms. Chisholm, Charlie's mother, believed that a rapid response by the educators to her concerns was important and that the responsibility for monitoring her son's services is hers.

Ms. Chisholm: It's the parent's responsibility to keep on things and once I bring it to their attention they have the thing in place and go right ahead [and fix it].
Parents who inquire about missed service at times encounter educators who hesitate or question them about the missed service. Ms. Johnson, the mother of Lance and Lawrence, gets a measured response to her questioning of therapy time that she believes the boys did not receive.

Case Manager: When I spoke with Ms. Johnson about [her concern], she said, “I just want to make sure my kids get their service.” And I said, “we are going to make sure” and I said, “I just need to check in with the team before I tell you they are going to make up time and find out what the situation is, I just can’t make a decision just talking to you without talking to anybody else first”....At first, she was like, “fine, you don’t believe me.” She said that with an attitude. And I said, “it’s not that I don’t believe you, I just want to talk to the team and see if they were absent or if the kids were absent. If they [the teacher and therapists] were there and the kids weren’t there.” And sure enough, one time the kids weren’t there so that was why. But then I called her [Ms. Johnson] back and she was okay with it.

Although educators verbalize their appreciation of parents who advocate for their child, this level of monitoring by parents is not typical of all parents of children who receive early intervention and can put educators on the defensive.

Case Manager: Ms. Johnson understands the system and she know what the rules are, the policies, so she is very active in making sure she is given all her rights. I advocate for that...she is empowered, I guess, because she knows the rules. That is the only reason this seems different. A lot of parents that we work with really don’t know the system and they kind of go along with what we say, and they say, “yes, yes, yes.” And she not [like that], she’s like, “yes, but I’m going to exercise my rights...”

JN: This is different because other parents don’t do that?

Case Manager: No, they don’t really challenge or question...they just nod and say, “yes” most of the time because they are happy that they are getting the service. They are just happy that their children are being seen, that they are getting extra help. But for Ms. Johnson, that is just not enough, she doesn’t feel completely satisfied with just that, where other parents are.
In all three of these cases, (i.e., Richards, Chisholm, and Johnson), the issue of missed service was one of a number of differences that each of these parents had with the educators that worked with their children. For educators, a parent’s close monitoring of services is indicative of a parent who is aware of her rights and puts the educators on notice that the s/he may also question other aspects of service. Although a parent’s questioning about services may be a signal to educators that the parent is more likely to be dissatisfied with early intervention or more likely to express other concerns about services, the reaction that educators have to a parent’s questioning about their child’s service may make a difference to parents. In the case of Ms. Chisholm, the educators’ courtesy and responsiveness to her inquiry contributed to her positive view of the early intervention system.

*Educators Make Unprofessional or Insensitive Remarks to Parents*

Despite their professional credentials and training, educators sometimes make remarks to parents that are unprofessional or insensitive to children and parents. Ms. Chisholm, the mother of three and a half year old Charlie, has just such an experience. As with Ms. Chisholm’s questioning of missed service, in this instance of a callous remark by a speech therapist working with Charlie, the Education Supervisor promptly responded and remedied the situation, and gained the parent’s appreciation instead of incurring more anger.

Ms. Chisholm: Charlie’s speech therapist has been seeing him since December and is well aware of his IEP and all the things that make him tick and just the fact that he had a stroke at birth and has struggled to get to this point since then. He spoke no words at all in early December and then he had surgery in December and the next day he started talking. So,
it's been a very dramatic change and she [the speech therapist] saw him after the surgery so she really didn't know him before. From December to now she's been working with him and I went to pick him up one day. I said, "Why don't you tell her what we did last night?" He very unintelligibly said, "we went to the baseball game." She said, "what?" I had him repeat it and he did. I then said, "yeah, we went to the baseball game." She looked at me and said, "I was supposed to get that?" I took him by the hand, got him out of there and went to [the Education Supervisor]. Immediately, she said [the speech therapist] will no longer be seeing him. That happened about eight, nine days ago.

JN: It's that fresh?

Ms. Chisholm: Very fresh. Do you hear the tension in my voice? The following Thursday, he had already gotten a new speech therapist. So again, they were right on things.

JN: So within a week or two weeks...?

Ms. Chisholm: Within one week. Within five days I knew he was going to start with someone else. I was very pleased and the thing that most impressed me, they worked with me for two years with different issues and not once did they question my word on what happened....The fact that they didn't say "are you sure you heard right?" Or anything like that. They just took the complaint, took care of it, got me somebody else, apologized profusely and went on with things.

The willingness and consideration with which the Education Supervisor apologized to Ms. Chisholm made a positive difference. This apology, combined with prompt corrective action, sent a very powerful message that helped to heal the parent and right the wrong that she and her son endured. Levi (1997) has pointed out that the timing and manner of an apology influences the likelihood that the apology will be accepted. In this study, the immediate acknowledgement and regret expressed by the educator, as a supervisor and representative of the agency, directly influenced the effectiveness of the apology.
Parents as Experts

When children are complicated in their needs or have issues that are low incidence the parent may develop a substantial degree of expertise about the child's needs. The parent may advocate for the inclusion of approaches or types or levels services that either are not familiar to the educator or the educator resists for other reasons. These parents may also embark on a path of advocacy.

Parents may find themselves at odds with educators over the nature of the child's needs and what approaches to use to address these needs. Ms. Chisholm is the mother of Charlie who had a severe delay in speech, until a recent surgery successfully increased his overall level of oxygen. Following the surgery, Charlie began talking. Prior to this wonderful development however, Charlie's parents were caught up in a dispute with the early intervention system about the need for Charlie to be taught sign language. The Birth to Three system agreed to support Charlie's enrollment at a school for the deaf so that he and his family could learn sign language. In anticipation of Charlie's third birthday, and a transition to the regulations and funding for services for children three to age of beginner, Ms. Chisholm prepares for a conflict with Gladstone, the agency who administers early intervention services for children who are three to age of beginner in Philadelphia.

Ms. Chisholm: Charlie has been in [early intervention] services since he was two months old. He has had three open-heart surgeries. He had the stroke [at birth] and we've always known there probably would be issues during his life....Early on the speech therapist diagnosed him with apraxia. So, knowing that there was a possibility that he may never talk, I went full force wanting him to learn sign language and really wanted him to get the best of both worlds [sign language and verbal language development].

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
But I found that [for] the early intervention system, [we, the parents] wanting to teach him sign language and that he didn’t have a hearing loss, that [it] would be difficult [to get the support of Gladstone]. So, that’s when I tried nosing around myself to see what was out there and available. I contacted [a school for the deaf] and presented our situation and the uniqueness of it and said, “that I would really like him and the family taught sign language.” They [the school for the deaf] were all for it. They thought it was great. Then I went back to the early intervention system [for birth to three] and they thought it was great but also knew [that there would be] difficulties [getting support from Gladstone]. In Birth to Three it ended up not being a problem….I was able to get him enrolled in the [school for the deaf] with all of us not knowing if it was the right place for him but thinking that he needed to learn sign language. So, he went through a year of services and…I was starting to get wind that once he got into the [Gladstone system] that there was no way, without a fight, that I was going to get him to stay in the [school for the deaf] because you have the “least restrictive environment.”

So that’s when I started my little campaign to keep him in there and how important that was. It just began a long process of putting on paper that everyone thought keeping him there [was important] and the plan we laid out for him. We wanted him a couple of days down at the [school for the deaf], a couple of days…in a regular pre-school environment. They all thought that on paper it sounded great, but again, we were coming up with “the insufficient funding issue” and as a mom I was getting the silent outrage going.

Ms. Chisholm talked with experts and gathered information from them to figure out a recommended course of action. Given the uniqueness of Charlie’s needs, Ms. Chisholm struggled with what approach to language development would best serve her son.

Ms. Chisholm: I had really gotten a lot of support through the early intervention Birth to Three system on who to contact, who would be my best allies….I had the woman who is the head of all of speech therapy [for the Philadelphia School District]; she was talking to me. I had the people from the [school for the deaf], they were telling me …how to get things going in the right direction. I also didn’t know the right place to put him…but I didn’t want him [only] in a quiet environment. I wanted him to have the same opportunities as everyone else to be able to express [himself]. As a parent I didn’t know where to go.
Charlie's health was deteriorating as the date of Charlie's scheduled IEP meeting to transition him to the Gladstone system.

Ms. Chisholm: At the same time, his health started to [worsen], actually at that point he was going to go on full time oxygen or have a trach [tracheotomy] so it was a very intense time....

At the IEP meeting, Gladstone refused the Chisholms' request to have Charlie receive services in both an inclusive class and in a special class for children who are deaf.

Ms. Chisholm: The downside of being so vocal is they [Gladstone] knew exactly how to have things [planned] for the IEP meeting. They knew that I was going to come in with two guns flaring saying that I wanted him to stay [at the school for the deaf]. So they [Gladstone] had everything prepared to say that this [placement at the school for the deaf] is not good for certain reasons. They were just as prepared, if not more, than we were.

A dual placement such as the Chisholm’s wanted for Charlie, would have not only been costly but would also set a precedent for Gladstone to authorize the funding of both a private school setting and an inclusive preschool placement. As an alternative to the school for the deaf, Gladstone offered to give Charlie additional speech therapy in the inclusive setting. The parents are given the message that this was “more than what most kids get.” Gladstone refused the parents' request for part time placement in a class for children who are deaf so that Charlie can learn to sign.

Ms. Chisholm: We did come to the conclusion that he certainly needed intensive speech therapy and they agreed on that and he ended up getting more time than most kids get. He ended up getting forty-five minutes in class and he gets forty-five minutes outside of class, which is like the
maximum in age three to five. When it came down to the [school for the deaf] they just right out said, “that you will have to go to due process to get [a ruling] that [the inclusive placement with speech therapy] is not a good placement for him.”

The Chisholms debated the merits of fighting this decision, decided to accept Gladstone’s plan for Charlie’s placement and services and did not pursue the private school placement that would have immersed him in sign language.

Ms. Chisholm: I probably shocked everybody. My husband, through the whole meeting, was really, really upset the whole time that Gladstone was saying that the school for the deaf was not an appropriate place or that we didn’t really know what the best placement for him was and he said, “we are going to fight this. We’re absolutely going to due process.” I looked at him and [asked for a] five minute break and everybody [else] left. We talked to each other and I just said to him “we really have to think of what we’re fighting for here. If this really is the best, we got a great amount of speech therapy.” I really didn’t want to put up a fight. Charlie was about to head off to surgery in two days too, so we had those emotions going. He went to surgery and [before the surgery] he was receiving seventy-five percent oxygen to his body....After the surgery he was receiving one hundred percent. The very next day he started talking...So what we fought so hard for, ended up not really being the best thing to be fighting for...

As a result of the surgery Charlie began to talk. The Chisholm’s decision turned out for the best. Charlie was no longer a candidate for sign language and received speech therapy to help him with his verbal speech.

I will explore further the messages that the Chisholm’s received regarding the “usual amount of therapy” and “insufficient funding” in the chapter that follows. For our purposes here, we see a parent who, with the help of experts, designed and advocated for a set of services that would meet the unique needs of her child. Parents in these situations are often at a disadvantage going up against educators who use “one size fits all” programming, who can justify their proposal as an appropriate placement and can effectively cut off any possibility of
demonstrating that an alternative approach is appropriate or more effective. In the case of Charlie, fortunately, his medical intervention made the difference in his ability to communicate.

Educators may not recognize the relative differences of a child with a low incidence need and consequently may attempt to map on the usual approach to services or may disagree with the parent about the use of a different approach. The parent may be the most knowledgeable member of the team regarding a child's needs and the approaches that need to be used with the child. Educators can find it very challenging to work with parents and children who may need special or unique approaches to services. At times, parents are in the role of educating the educators about the particular needs of their child. This can be a challenge to educators who may have different opinions or little knowledge about a particular disorder or new instructional approach.

It can also be difficult for those educators who support and agree with an alternative approach and must maintain a professional role on their team. In the case of Darla Wilson adopted at fourteen months of age, her mother consulted with psychologists and occupational therapists outside of the early intervention system. According to these clinicians, Darla had difficulty with regulation and sensory integration and this was, in their opinion, a developmental issue. Based on this information Ms. Wilson refuted the suggestion that Darla's aggression indicated that she was "disturbed" or should receive a psychiatric diagnosis. As a result of this stance, Ms. Wilson was at odds with many of the educators on the team. However, the Occupational Therapist on the team supported Ms. Wilson's
position while trying to maintain a cautious balance at the same time. In my interview with the Occupational Therapist, we discussed a very intense and emotional meeting for both the mother and the educators, where the issue of an underlying mental health concern was discussed and the Occupational Therapist provided evidence to support the continued use of a sensory-based approach with Darla.

JN: So when you went into the meeting...was it planned on your part to take the position that you took?

Occupational Therapist: No. I knew we were going to discuss Darla's progress. I knew we were going to discuss her need for a one to one. I felt like she was doing well....I didn't know that the [issue of a mental health diagnosis] was necessarily going to come up again at this meeting. I didn’t know that the [Program Director] was going to throw it out on the table. I think it was good that it was put out there because in the future, depending on how Darla continues to progress, it is something that is going to have to be revisited. I think as Darla becomes school age it’s going to be something that, okay she’s learned strategies, yes, she has some sensory processing problems, she knows strategies....And I think as a school-ager if [Darla does] not [improve in her behavior] then we’re going to need to look elsewhere. But, I think for where she is now considering her history, considering the progress she’s made and her incorporation of those strategies, I think that where we are now is appropriate.

To counter the other educators' efforts to argue that Darla was in need of mental health services, the Occupational Therapist took a public stance in the meeting that supported Ms. Wilson’s view that Darla’s concerns were sensory based and represented a developmental lag based on her early deprivation.

Occupational Therapist: It was kind of all unfolding in front of me that I’m seeing Mom get really upset right now and feel like maybe the piece that she feels so strongly about isn’t being validated right now. So I kind of felt like I had to say something about it.
JN: And you’re okay with that?

Occupational Therapist: Yeah.

JN: You don’t feel uncomfortable?

Occupational Therapist: It was fine....I even saw [the Program Director] afterwards and I said “I hope that was appropriate for me.” I kind of felt like I was going out on a limb a little bit even thought I felt comfortable with what I was saying. I didn’t want to be objecting to what my director was sort of throwing out there. She said, “absolutely not. That was fine. You presented your viewpoint very well.”

In this case, the Program Director supported the staff person that publicly diverged from the team’s opinion. Based on her continued progress, Darla continued to receive her one-on-one support through early intervention funding.

The supervisor of the county department that administers early intervention services for nearly 2000 children from birth to three years of age in Philadelphia suggests an approach to the “parent as expert” dynamic that will support the team charged with making the decisions about the child’s services:

One of the things that is very difficult about this is that we’re almost saying to the team and to service coordinators that you have to be an expert in every area. They’re not, nor can we expect that of them, really. To me with the research and the body of information that any of the parties bring to a meeting is for the purpose of educating the team to the level that you’ve been educated....We’re hoping to have the knowledge and the information that is brought into the meeting...not used to fight each other or as a battle ground of “this says this but this says that,” but enrich the knowledge base of everybody on the team so they can make a better plan and recommendation for the child that encompasses all of the information at the end.

When a parent develops expertise about a child, in a best-case scenario, the team incorporates this information and designs a program that meets the needs of the child. However, parents, sometimes seek out alternative
approaches that are experimental or otherwise do not have data or evidence to support their use in an educational plan. Educators are accustomed to parents who pursue vitamin therapy, high frequency noise therapy, and any number of idiosyncratic and questionable approaches to treat a child with special needs. The challenge is for educators to keep an open mind about their own approaches to working with children so that appropriate alternatives that meet the unique needs of a child are considered.

Friction Points That Are Endemic to Early Intervention

Year after year, the same essential issues and concerns develop into conflicts between parents and educators. In this study, the points of friction were when the child did not make progress, there were pressures on parents, the child did not get the service on his IEP, educators made unprofessional or insensitive remarks to parents and parents became expert at their child’s disability and needs.

In addition, the national data of parents’ satisfaction with early intervention point to a substantial minority of parents who do not believe that their child is receiving an appropriate level of service (Bailey, Scarborough & Kebbeler, 2003). This issue also occurred in this study, and we will take up these data in the “Context of Limitations” chapter that follows.

I have been involved in the field of early intervention for fourteen years, five of which I served as a Director of an early intervention program that provided services to over 250 children. These friction points are entirely consistent with my direct experience. These points of contention are endemic to the system and as
such, repeat themselves independent of the individual parents and educators involved.

The articulation of these friction points is important for a number of reasons. First, this information, along with recommended strategies to reduce their occurrence and planned approaches to appropriately and effectively manage these differences, might help to decrease the level of agitation and distress that families experience. Some of the families in this study used terms such as "disgusted," "hate," "distrust," and "uncomfortable" when describing how they felt about the educators with whom they had some level of difference and about the early intervention system in general. Second, as I discussed in relation to parent's concerns with how they are perceived by educators, the level of animus can escalate for parents who find themselves in multiple struggles with educators over time. Third, educators also experience their own stress around conflicts with parents. A considered and planned approach to preparing staff on how to go about addressing these differences with parents would greatly assist educators in their efforts to work effectively with parents.

Despite the fact that educators regularly encounter these issues with families, educators are not trained and often not prepared to effectively deal with and support parents during these times of disagreement. Beyond the occasional conflict resolution workshop and an educator's individual capacity to be empathic or negotiate a resolution, the educational system more often reacts to each difference with parents in terms of the individual circumstances and persons involved. Though a respect for individual needs and specifics is vital, it may be
that increasing the overall expertise of educators as well as a coherent approach to addressing differences with families would benefit everyone involved. Based on the data obtained in this study, in the concluding chapter I discuss the implications for how educators can improve their capacity to manage differences between parents and themselves. The data in this study strongly suggests the need for educators to be trained beyond the traditional approaches to conflict resolution in order to address the circumstances that are specific to early intervention and special education. A major finding of this study is that when differences between parents and educators first start to occur, educators often have opportunities to resolve conflict provided that they are prepared and trained.

The context within which educators operate is a complex one. There are substantial demands on educators to make decisions about service according to certain pedagogy, to legal requirements and within a limited financial expenditure. These pressures are what guide the decisions of educators about services. In the next chapter, I examine how these pressures manifest themselves as conflict between parents and educators.
A Context of Limitations

Nearly three decades ago, researchers documented educators' attempts to ration special education services. In a study entitled "Street-Level Bureaucrats and Institutional Innovation," Weatherly and Lipsky (1977) examined "how new demands are accommodated into the work structure of people who consistently must find ways to conserve resources and assert priorities to meet the demands of their jobs" (p. 30). Three main reasons were identified to explain why educators rationed services to students with special needs. The first of these reasons, "workload pressures" was seen as the primary difficulty for educators. The educators were expected to be responsive to newly enacted legislation (i.e., Chapter 766) that required an individualized approach to educating children with special needs. This law demanded of the educators a comprehensiveness in detail and responsibilities that made full implementation of the requirements a daunting ideal. A second reason for the educators' rationing of services was attributed to poor planning and implementation of the law by the Massachusetts Department of Education. A lack of clear direction by the administrating agency caused confusion on the part of the educators, and delays in services for children. The third reason, a lack of adequate funding for the special education mandate, amounted to the imposition of a new set of rigorous requirements without the fiscal resources necessary to fully meet the requirements within the specified timelines. In response to the pressures and demands placed on them, the educators used the following rationing techniques:
a) Teachers were deterred from referring problems by the need to complete forms and give justification to the principal and specialist.

b) The principal would dissuade parents from requesting an evaluation by assuring that the child was doing fine or that services were already being provided.

c) Principals and specialists would not process referrals and simply fail to follow through.

d) Administrators would issue instructions to cut back on referrals (Weatherly and Lipsky, 1977, p. 45).

The educators also developed a pattern of balancing the multiple demands and limited resources. As part of this pattern, they rationed the number of assessments they performed, they rationed services by reducing the amount of time each child was seen by specialist, they diluted individual treatment in favor of group treatment and they promoted instruction by students in training rather than experienced personnel (Weatherly & Lipsky, 1977, p. 69). The rationing of special education services by educators continues today. A recent article in The New York Times details numerous failures to follow through on requested assessments and services (Winerip, 2004). In this news report on special education services in New York City, the failure to process referrals for assessments, as well as an across-the-board reduction in services without a direct evaluation of individual children entering kindergarten, are attributed to a shortage of special education personnel.
Here in Philadelphia, educators also find ways to ration services. An educator reports, "if parents request a meeting for an addendum [to the IEP], they are put off for months." As we will see in the data collected for this study, the practice of meting out services pervades the early intervention system. This is true not only for children ages three to age of beginner who fall within an under-funded legislative mandate, but also for children birth to three years of age whose services are part of an entitlement funded program. The justifications for rationing of services, disseminated in the form of policy, are increasingly sophisticated and impenetrable. Unfortunately, this creates a context where inflexibility and a truncated understanding of the principles that guide special education, dominate the practice of educators.

At this point in the evolution of the special education and early intervention systems, educators are accustomed to resisting and refusing parent requests for anything beyond what they typically offer to other similar children with special needs. The resistance that parents experience when they question educators or attempt to resolve differences may be reasoned and based in educational research or legal precedent, or may be spurious and based on a rigid interpretation of educational guidelines. Unfortunately, parents are not likely to know the difference and the educators themselves may not understand the degree to which their services are in alignment, or not, with educational standards of best practice. The following cases illustrate how educators go about the work of limiting services.
When a Child Needs More Service and Early Intervention is Unwilling to Provide

Jason Richards is a four-year old boy who has a diagnosis of PDD. Jason had delays in all areas of development (i.e., cognition, language, social-emotional, gross motor and adaptive behavior). Jason verbally imitated less than 10 words and did not use spontaneous language to express himself. He received special instruction (i.e., special education), speech and occupational therapy in a self-contained pre-school classroom three mornings per week. After some research, his mother, Lisa Richards, began to question why Jason was not receiving more service.

JN: So you're trying to get him in a program that has more hours?

Ms. Richards: Cause he's doing well in school. I mean he's starting for the "more" and "eat" and all this. Why can't he have it five days a week? Why can't he have it four hours a day or five hours a day?... I know there are five day a week programs....But everybody [parents] I talked to even says "why shouldn't he have more time?" That's why I think it hurts.

JN: So you're looking for five days a week and five hours a day?

Ms. Richards: Whatever they can give...

In my interviews with Ms. Richards she shared her reticence to talk with the educators who worked with Jason about his needs and about her frustration.

JN: Who do you communicate with at [the specialized pre-school that Jason attends]? Who's your contact? Is it [the Education Supervisor]?

Ms. Richards: Who do I talk to?

JN: Yes, about all this stuff?

Ms. Richards: No!

JN: You don't talk to anybody about this stuff?
Ms. Richards: About what stuff?

JN: Well, that you want more days and you want to visit another school?

You don’t tell them that?

Ms. Richards: The more days [the Education Supervisor] knew about from the get-go….I must have asked her I don’t know how many times “you don’t have four days?” She knew I wanted more time. To discuss anything with her? I don’t know. To talk to her about things changing in the school? Wouldn’t bother until the IEP meeting.

Not Knowing Who or How to Ask

Ms. Richards believed that the educators saw her son as one of many students and therefore, were not motivated to address his needs. She was also uncertain of how to go about asking for more services for Jason.

JN: It wouldn’t bother her whether he goes to another school? Is that what you think?

Ms. Richards: Why would it? There’s always another kid who could come in. I know that sounds terrible, but there’s always another kid to come into his spot. I know [they’d] have no problem replacing him. You mean do I feel comfortable enough to just sit down and explain how I’m feeling? No!

JN: So, you don’t feel like the staff at [the specialized pre-school] are a resource for you to try to get this figured out?

Ms. Richards: They will be. Like I said he’s only been there two months. Like I said not until the IEP anyway. I ask “how he’s doing?” They tell me he’s doing good….But to ask them if they think he needs a five day program? I don’t know what they’ll say. I wouldn’t even know who to ask. You only have the aides and the one teacher, and that poor woman is busy as hell.

In Ms. Richards’ response to a family satisfaction survey conducted by Gladstone, the organization that oversees the early intervention services for all children three to age of beginner in Philadelphia, she shared her concern and her...
interest in more service for her son. As a result of this feedback, a service coordinator followed up with Ms. Richards and the Education Supervisor responsible for Jason' pre-school class. When Ms. Richards communicated her dissatisfaction to Gladstone, she effectively went over the head of the Education Supervisor and the Director of the specialized preschool and went directly to Gladstone. This was problematic for the specialized preschool and the Education Supervisor because it potentially signaled to Gladstone that the Education Supervisor and the staff had been so unresponsive to the parent that the parent's only recourse was to notify Gladstone or that the Education Supervisor and staff were unaware that the parent was dissatisfied and there was some sort of breakdown in communication between the parent and provider. In either case, this level of attention from Gladstone put the Education Supervisor and the specialized preschool under scrutiny.

In my conversation with the Education Supervisor, she shared her view of the events to date, and also repeatedly underscored that Ms. Richards had not directly asked her for more service for Jason. The Education Supervisor used the lack of a direct request by the parent to justify her inaction to date.

Education Supervisor: The reason, I understand, we're having this meeting is that Quality Assurance from Gladstone called her and she, in turn, responded to their survey. That's why we're having this meeting.

JN: Okay, so there's a parent satisfaction survey out of Quality Assurance at Gladstone and Ms. Richards expressed some concerns.

Education Supervisor: Right. She wanted more services and so [her
service coordinator] said “you need...to have this meeting.”

JN: How are you feeling about all this?

Education Supervisor: Ms. Richards has not said any of this to me, other than I called her and said “I understand you have some concerns and I heard from [the service coordinator] that you would like to have an update.” She has not said to me “I want more services.” I got that from Gladstone, from [her service coordinator]. I set this [meeting] up for her but she had not communicated that to me.

The educators were aware of Ms. Richards' history of expressed dissatisfaction with a previous EI program that Jason attended and that she withdrew him from that program. They were also aware that she subsequently enrolled Jason in a day care and requested to stop all of Jason’s EI services except speech therapy. Because of this history and their own interactions with Ms. Richards over a two month period while Jason has attended the specialized preschool, the educators perceived Ms. Richards as demanding and “formidable”. As a consequence, the educators misjudged Ms. Richards' ability to understand and negotiate with the EI system on behalf of her son and were defensive about their own practice.

JN: Do you have any concerns about tomorrow’s meeting?

Center-Based Teacher: I always get that way only because, like I said, she didn’t come to me and say, “this is what I'm doing” or whatever. Maybe she felt she didn’t need to do that because she’s been through this in another instance. Apparently she knows her rights and she knows how to get what she needs in services for her kid. I have to commend her as a parent that she knows how to do that. Apparently the teacher is just not somebody she has to talk to as far as that’s concerned. I mean certainly if she would have approached me, I would have told her that she would need to speak with [the Education Supervisor]...I don’t think she spoke with [the Education Supervisor] either. I don’t really know. I guess she went right to or I don’t know who she went to. A caseworker or... I just
heard that she expressed that she was upset.

JN: Do you think that she’s using this as a strategy; that she did not contact you or that she didn’t talk with [the Education Supervisor] about this? Do you think that it’s going to have a different outcome than if she would have spoken with you or [the Education Supervisor]?

Center-Based Teacher: I don’t think the outcome will be any different. I personally think that she just knows how to get action fast and she just grabs a hold of the problem. That’s my own personal feeling. She’s an efficient person who just has her life organized that she needs to do the essentials and the little things don’t matter to her. Politeness? Well, I would call it politeness, but she feels “this is my right as a parent and this is the way I went about it before and this is what I need to do.” She may just be looking at it as, “I know what to do. I know who to talk to and that’s that.” Since I don’t really know exactly what she’s expressed other than what [the Education Supervisor’s] told me. I mean I don’t know what she’s said about…or if she’s said anything, or what her whole, I don’t want to say complaint, but what her complaint is. I guess that’s the part that makes me apprehensive. I don’t really know other than what [the Education Supervisor] told me and sometimes supervisors try not to get you upset so they don’t want to give you like the whole blown picture. I don’t really think in my capacity that I’ve done anything wrong or that I should be worried about it in that sense. But I’ve never…yeah, I had one other parent that did this. When it came down to it, again, they were just looking for more services for their child. It worked out that that was what they achieved.

Educators Resist Requests for Additional Services

As the educators prepared for the meeting with Ms. Richards they shared their approach to what they anticipated would be Ms. Richards’ request for additional service or instructional time for Jason. They gathered data about Jason’s performance and asserted that he was making progress.

JN: So what does that present to you in terms of this meeting?

Education Supervisor: What my intention for this meeting is for us to review his IEP, to see what services he’s getting. To give some explanation, to have the staff explain where he’s functioning and how we’re meeting his needs. And then we have to determine is this the least restrictive environment for him as services stand? Does he need more
services? More is not always better. Does she need to look at her other options? These things need to be discussed....He is making progress. Mother wants more service. I'm not sure that is appropriate for him. I think the team has to meet and have that discussion. She is looking for a five day a week program, it’s my understanding. A five day a week program is considered in early intervention a rather restrictive [program].

The educators anticipated the possible arguments that Ms. Richards might use. They developed a fall back plan to compromise and offer an additional day of special instructional time (i.e., 3 more hours for a total of 12 hours).

Center-Based Teacher: If worst comes to worst, so we’ll have to give him another day. Worst case scenario, so that kind of relieved me. I said to [the Education Supervisor] “what’s the worst case scenario that could happen?” and she said to me “we’ll have to give him extra time.” That was her [the Education Supervisor’s] problem. Maybe in her eyes it is because she has other children she has to fit in the program.

The educators did not make an effort to talk with Ms. Richards and understand her fundamental concerns. Instead, they readied their position and prepared to use their decision making process to counter her request.

_The Maze: Appropriate, Least Restrictive Environment and Progress_

Unbeknownst to Ms. Richards, the burden was on her to demonstrate that her son needed additional services and to effectively counter or incorporate the criteria of appropriateness and least restrictive environment, as the educators presented it. When Ms. Richards began to ask about what was available for Jason, the educators required Ms. Richards to follow their hierarchical process of decision making.

_Notes from Jason's IEP Meeting._

Service Coordinator: Is there any new information about Jason?

Ms. Richards: He has been diagnosed with Pervasive Developmental
Disorder [PDD]. I was curious about – are there programs just for children with PDD?

Service Coordinator: We look at what is appropriate. What are the goals we want him to work on. First we look at the goals, then services, then placement. We need to go back to the goals….Autistic support programs are very restrictive. The goal is least restrictive environments like pre-schools and day care.

The educators asserted that Jason was making “significant progress.” However, Ms. Richards was unaware that she could and must argue otherwise for Jason to receive more service. When she attempted, again, to ask questions about Jason’s needs, the educators put her off by telling her their method of determining services. When Ms. Richards tried to directly enlist the Service Coordinator to give her opinion on Jason’s need for service, the Service Coordinator refused.

The speech therapist begins her report. She has seen Jason four times so far. There were some missed sessions [which Ms. Richards had previously inquired about].

Speech Therapist: Jason is starting to imitate words. We’re not seeing spontaneous speech. He is using signs.

Ms. Richards: Will talking come next after the signs?

Speech Therapist: We pair words with signs, hopefully.

Service Coordinator: [Asking the parents] Are there other goals?

Ms. Richards: Do you think his program should be longer?

Education Supervisor: [We have to decide] what’s the best program for him before we determine that.
Service Coordinator: When there is progress, then it doesn’t indicate that more is better.

Ms. Richards: This is all new. We are just trying to ask because we don’t know....He now has a diagnosis of PDD.

Service Coordinator: EI doesn’t look at diagnosis. It doesn’t determine what we do. We look at the MDE [multidisciplinary evaluation].

Ms. Richards: He’s had a lot of transitions – home, specialized settings. Does he need a program for PDD?

Service Coordinator: I don’t know Jason. I can’t make that judgment. Hearing the team he’s made progress in the last ten weeks. You can continue to explore the option.

Ms. Richards: I didn’t know if he needs a more specialized program.

Mr. Richards says that they’ve been told that Jason is borderline [Pervasive Developmental Disorder]? He says Jason is lovable and sleeps through the night. No discussion about parent training, i.e., specific goals and strategies to help Jason learn more. [Note to self: Whole system is conspiring to limit services.] The Service Coordinator tries to open up conversation about his need for more speech services.

Service Coordinator: How significant are his communication needs? Does he have a system to communicate?

Discussion about Jason’s current level of communication.
Service Coordinator: If they [his communication needs] are severe, that is a special consideration.

Ms. Richards: That is still a big consideration.

Education Supervisor: Language means absolutely nothing to him. [She describes a scenario to illustrate the severity of his communication].

Speech Therapist reviews Jason's speech goals. The first goal refers to improving his receptive communication. The speech therapist reports that Jason is starting to follow some basic directions in the classroom. The second goal is "Jason will express two or three word phrases." The speech therapist says he is not making progress on this. The third speech goal refers to sorting and they are just beginning to work with Jason on this.

Ms. Richards: Do you think he will speak?

Speech Therapist: I think he has potential. He is picking up signs.

Ms. Richards: Is there anything else you have?

Speech Therapist: He is starting to use some words. I hope so. I don't have a crystal ball.

Ms. Richards [to Service Coordinator]: Are they missing anything?

Service Coordinator: I am not a speech therapist. I'm not going to say anything.

Education Supervisor shifts the discussion to transition goals for Jason in anticipation of his move to kindergarten in September.

Speech Therapist: I recommend that he continue to get individual speech
therapy 45 minutes per week.

Service Coordinator is looking intently at the Speech Therapist but doesn’t verbalize disagreement or suggest an alternative. Speech Therapist looks at the Service Coordinator.

Speech Therapist: In my view it’s appropriate for him. He is in a language-enriched classroom.

Education Supervisor: I think every piece of evidence is he’s okay with it. If we go back to “more isn’t always better…”

The parents agree to the level of speech service recommended. The speech therapist leaves, saying to the parent “if you guys ever need anything, I’m here. Call me anytime.”

Service Coordinator tries to explore Jason’s sensory needs with parents. She suggests that “they might want some guidance.” Ms. Richards refuses, saying “I know about the brushing.”

Discussion about what Jason does at home.

Service Coordinator: It sounds like he is pretty high functioning.

Education Supervisor: If we continue the OT, speech [speech therapy], and classroom at the present levels, then we are saying he will continue to make progress.

Ms. Richards: I know other parents with kids with PDD get more time.

Education Supervisor: Three days seems to be about the average. You are talking more restriction: less time for interaction with typical children.

Ms. Richards: That is what I’m asking.
Education Supervisor: Your child is demonstrating gains. I can say that there are other children that we are not meeting their needs and they are in need of a more restrictive environment. I can’t say that for your child. He is making significant gains.

Ms. Richards: I am trying to do what is best for him.

Education Supervisor: There are more specialized, five day a week approved private schools. They would take more time away from [interacting with] typically developing children….One of the things you might want to look into is story time [at the public library]….In a program for strictly PDD children you are going to get kids that don’t speak.

Ms. Richards: Well, that’s what I’m trying to find out. You don’t know until you ask.

Education Supervisor: What you are doing at home is important.….Discussion about Jason’s opportunities to interact with typically developing children. This is presented as something that the parents have the responsibility to do, are doing and that these episodic casual encounters will benefit Jason and they will help him learn to interact socially.

Education Supervisor also shares anecdotal information about Jason when he is with typically developing peers who attend an inclusive class at the specialized preschool, for episodic group music programs. [Note to self: Contrary to research that says children with PDD need frequent and direct instruction to learn to interact with peers.]

Education Supervisor: [We’re suggesting] that service be maintained at three days a week. Are you agreeable with that?

Ms. Richards: Yes.

Mr. Richards: I’m happy with the school.
I found this meeting to be extremely disheartening for two reasons. First, the educators believed that this was an appropriate level of service for Jason despite data and reports that indicated he may be "high functioning" and yet had only acquired two signs to express his needs in 10 weeks time. Second, it was apparent to me as an educator that my fellow educators were effectively colluding to resist the parent's request for, what they saw as, "additional" services. The educators served the system's need to conserve resources and, sadly, their own abilities and expertise to meet Jason's needs were effectively blunted.

A week later, while waiting for the start of another meeting in my role as consultant with the program, a senior staff person at Gladstone spoke with the Director of the specialized preschool and reminded her that the "standard of practice" that Gladstone endorsed was that children with autism and PDD receive 20 hours of service (i.e., as opposed to nine hours of service). I believe that this was communicated as a follow-up to the Richards meeting, based on the service coordinator's report back to her supervisor at Gladstone subsequent to the meeting. I do not know if the Program Director understood the background of this comment nor if she followed up with the Education Supervisor. I am not aware that Jason's program changed in any way as a result of this conversation.

Subsequent to Jason's IEP meeting, Ms. Richards arranged for Jason to receive an additional weekly speech therapy sessions which she paid for through her health insurance. She also enrolled him, for the two remaining mornings of the week, in an inclusive preschool where the teacher was experienced with
children who have special needs. As a result, Jason began to receive instruction five mornings per week and individual speech therapy two times per week. Ms. Richards believes that there was “nothing wrong with this [early intervention] program but it is not enough.” Her efforts to get additional services for her son from early intervention were resisted and she concluded, “that it is not worth the hassle.” She does not blame the educators and believes “they only give what they can” and that “they are doing as much as they can, as much as they are allowed.” Ms. Richards accepted the bureaucracy and designed her own plan to get her son the services that he needed.

Limiting Service is an Entrenched Educational Practice

The message and expectation to limit services is so much a part of the current practice of educators, even exceptions modeled or endorsed by Gladstone, the agency responsible for oversight of all early intervention services for children three years to age of beginner in Philadelphia, have little or no impact. This occurred in the Richards case when a senior Gladstone staff reminded the Director of the specialized preschool of the need to provide more service to children with PDD and yet no changes were made to this child’s (or any other child with PDD) program. Another example of a lead educator holding fast to the belief in limited service despite a compelling rationale provided by a parent and an alternative model of service delivery developed by the Gladstone, the overseeing agency, occurred in the case of Tyler Hudson.
Tyler is a five-year old boy who received an evaluation that showed delays in the areas of social and emotional development, language, cognition, physical development and adaptive behavior.

JN: "Do you feel that you have differences with the team?"

Mr. Hudson: I felt that they were in accord up to a point. My main difference, I believe, was that they didn't seem to have the sense of urgency about it that I did even though they documented the level of his deficit. I was alarmed when I read the report. I knew, for example, I was present for the evaluation, which was about two hours. It was interdisciplinary, three different professionals were there. I felt that the report was accurate; a 20 page report. The narrative was very accurate. In an hour and a half, two hours, they nailed him. They nailed his personality and what his problems were so I thought it was accurate, a good basis upon which to make recommendations. I read the report and I was alarmed and I knew the kid. He's my kid! I'm, reading the report and [saying] "yes, this is him, this is him." These were serious problems.

Mr. Hudson was purposeful in the execution of his role as an advocate of his son. To prepare for Tyler's IEP meeting, Mr. Hudson conducted a great deal of research on IDEA, researched relevant case law, attended conferences and consulted with another parent of a child with PDD experienced with IEP meetings. According to the Education Supervisor, Mr. Hudson called her and the Gladstone Service Coordinator and Supervisor of Service Coordination on numerous occasions to ask many, many questions about Tyler's evaluation, the upcoming IEP meeting and the process.

Mr. Hudson: I knew that I had to study for the IEP, for example, because how that goes, from what I had read, has a lot to do with a parent's input and pushing for things to happen...

JN: So you've gone to conferences and you've been on the Web?
Mr. Hudson: Been on the Web and read. Got a couple books out on the subject. Spoken to his evaluators and his teachers. The whole big full evaluation report, the evaluation prior to the IEP. The basis of the IEP, I guess you’d say.

JN: Yes.

Mr. Hudson: Got a hold of that report. A lot of the terms in that report I was able to assimilate those terms and use those as a springboard for finding out more about the problems that he has.

JN: You knew that you wanted [Tyler to receive services for] more than three days and it sounds like you’ve done a lot of work on your own, research on your own to get up to speed on all this stuff and how the process works. I’m guessing that not that it was not just done for your own comfort level but to prepare...

Mr. Hudson: The reason was really a very practical one. To make sure that I could go into a meeting that was going to determine his educational future and make a convincing case for what I felt was necessary for him.

Mr. Hudson used the information that he had acquired to ready himself to request that Tyler be given adequate services to meet his goals. He was prepared and strategic in his approach at the IEP meeting.

Mr. Hudson: Tyler showed deficits in five out of six areas and some of the deficits were as much as two years. The goal was to get him into kindergarten by this coming fall because he was born in October...but he would still be eligible for kindergarten this September. So the goal was, if possible, to get him into kindergarten this coming academic year. During the IEP I pushed for more than three days a week because that was all he was getting without any special services.... He wasn’t getting speech and language therapy at that point and they said “let’s wait for the IEP so we can determine exactly what he needs.” At the IEP they said, “okay he needs OT and he needs speech and language therapy, and he needs special instruction.” I think the IEP team would have been satisfied to have that three days a week, so I played dumb during that meeting. I said, “given the magnitude of his deficits, some as many as two years and how broad the deficits were, five out of six areas, it was unrealistic, I thought, to expect that he would be able to make all the deficits up in such a way that...
he would be ready for kindergarten in six months." I pushed for something more than the three days [Note: really three half day sessions] a week.... They [the educators] didn't seem as concerned at the disparity between the goals we were setting for ourselves and the baseline where we were in terms of his abilities. And so, I needed to put a very fine point on that. It is unrealistic to expect him to make these deficits up if we're only talking about preschool, two and half hours, three days a week and during that time really maybe just an hour of OT and an hour of speech therapy. We’re talking about less than nine hours a week for the next how many months. They were open to that. Once I brought it up, they were open to talking about some of the possibilities. So we talked about some of the possibilities.

Mr. Hudson's goal is to have his son “get services every day of the week.” He anticipated the differences between his own position and that of the educators and was prepared to make his request for more service. He used the short time between his son’s recent determination of eligibility for early intervention services and his impending entry into kindergarten in six months as leverage to get his child more service. His argument for more services than what the team originally offered was cogent and effective. In response, the team agreed to have Tyler attend an inclusive preschool class three mornings per week, and a specialized, i.e., self-contained, class two mornings per week.

In my subsequent interview with the Education Supervisor of the provider agency who had administrative responsibility for Tyler and his IEP, she shared her concern about the agreed upon arrangement for Tyler. She noted that it was “the Gladstone staff who ran the meeting,” as opposed to her, and twice stated “it is a lot of service.” She saw the Hudson case as one where a smart and insistent parent advocated for his son and was given more service. What was salient for her was the parent’s level of engagement and questioning and that this was what
caused the educators from Gladstone to be mindful and willing to offer additional service. She was not convinced that Tyler needs the service and does not see the applicability of the service model developed for Tyler as potentially relevant to other children. To see it otherwise, that Tyler needed a higher level of intensity of service both in terms of hours of service and therapies, would upset the balance that the Education Supervisor achieves everyday in her decisions to dole out limited resources to numerous children. She believes that limited services are all that children need. Despite the fact that it was Gladstone, the overseeing early intervention agency, that put the service package together, that an alternative approach to service delivery was offered and modeled and that this was an example of when to deviate from the practice of limiting services, the Education Supervisor of the provider agency, (i.e., the educator responsible for recommending service levels for over one hundred children annually) did not see this case and the issues presented as applicable to her own work. In the case of Tyler, the rationale to intensify his service for a short period in order to enable him to reach the goal of enrollment in regular kindergarten was not seen as necessary by the Education Supervisor. The practice of limiting services becomes so entrenched in the minds of educators that they are unable to recognize when it is appropriate to deviate from this set pattern of doling out services or see it as an exception to the practice rather than an alternative.
Early Intervention Splits Hairs: Service is On the IEP but Early Intervention Doesn’t Want to Pay

According to IDEA, the team, made up of the parent and educators, is the mechanism that is supposed to design and individualize services. However, educators do not operate in a political vacuum and the constraints put on teams are very real. In reference to a service that was cut from a child’s IEP even though the child had a delay of more than two years in this area, an educator laments: “the problem was that it wasn’t a team decision. It was made by the Education Supervisor….There are decisions being made that aren’t team decisions.”

Parents may be unaware of the pressures that educators are under by their supervisors and funders to ration services, yet awareness doesn’t necessarily improve the parents’ disposition. In this environment of limiting services in order to conserve resources, the ability of parents to advocate well on behalf of their child is not a guarantee of an improved outcome. The system has become accustomed to resisting and refusing parent requests and though this may be detrimental to the relationship that the educators have with a parent, the larger purpose of conserving resources is served. The case of Carlo DeFrancis is one where the parent meets with frustration and manipulation by the educators despite a history of positive relations and successful advocacy for her son.

When I first met with Ms. DeFrancis, it was a reunion of sorts. Her oldest son Gabriel was enrolled in the early intervention program I directed years ago. She happily told me that Gabriel had since gone on to do well in school and was
enrolled in honors classes at his high school. Her youngest son, Carlo had delays in the areas of cognition, language, gross motor and adaptive behavior. He was diagnosed with apraxia (i.e., a disorder of the nervous system that affects the ability to sequence and say sounds, syllables, and words).

Ms. DeFrancis was "admired" by the educators who worked with her for her ability to advocate for her Carlo's needs and to obtain needed services. Ms. DeFrancis had "learned the ins and outs of the system," attended conferences, regularly logged onto web-based support groups, and used her contacts with parent and legal advocates when necessary. In my initial conversation, Ms. DeFrancis perceived her experience with early intervention in a positive light saying, "I've never had a problem" and "they've been good to me." She had worked cooperatively with the educators to get the information they needed in order to substantiate her son's needs for services. This approach, to become knowledgeable about who, what and how to ask for services and to develop a positive working relationship with educators at the local level, is a recommended method of advocacy (Wright and Wright, 2003). Unfortunately, educators working on behalf of the bureaucracy have become more and more emboldened to refuse parent requests for services despite agreements negotiated in good faith and documented on the IEP.

According to the Director of the specialized preschool, Ms. DeFrancis contacted her to arrange for Carlo's speech therapist to accompany Ms. DeFrancis to an intensive six hour training for an augmentative communication device for Carlo. Ms. DeFrancis and the speech therapist had been actively
exploring various devices for Carlo and had decided that this particular device had great potential for Carlo's to express his needs. Ms. DeFrancis had been careful to make sure that training on for an assistive technology device was written on Carlo's IEP as a support service and then followed through by requesting this agreed upon service.

The Director hesitated to comply with Ms. DeFrancis' request out of concern that she would need to pay the contracted speech therapist at her hourly rate of $60. Her concern stemmed from two reasons. First, she needed to exercise budgetary control over an expected deficit budget for the program. Second, she was reluctant to make an exception to the standard and sanctioned practice in early intervention to not pay for training for contracted therapists. Faced with this resistance, Ms. DeFrancis told the Director that she would immediately contact a leading advocate in the city and "I am writing down everything you say." As a result, the Director in turn felt compelled to contact the funder, Gladstone, to get direction about how to proceed. The Director was told by the lead administrator to offer Ms. DeFrancis a version of the training that totaled three hours that the Director had researched as an alternative. The Director reported that Ms. DeFrancis expressed her dissatisfaction with this alternative saying, "six hours isn't three hours." When the Director attempted to further negotiate with Ms. DeFrancis asking "can one hour of the three hour training count for the one hour that Carlo is seen [for
individual speech therapy] for one week?" the Director acknowledged “this proposal seemed to upset Ms.DeFrancis.”

Ms. DeFrancis: I have a lot of problems over at the school. I would have had an easier time getting security clearance from Donald Rumsfeld or Condaleeza Rice. The last two weeks. Such a power struggle. In my [son’s] IEP I had put there that Carlo is to have training along with support for his device. It is in Carlo’s IEP for staff to have training. I had asked his speech therapist. They didn’t want to pay her because she is a contractor. I said to her, “you are playing a power struggle.” It is called assistive technology! She [the Director] went back and forth for days. Finally, the head of training, she agreed [to come on-site and do a training]. I need to learn how to work it [the communication device] and program it. This is horrible, I feel sorry for parents. The teacher don’t (sic) know how to work [the device]. I want to learn the program [how to program the device]. I’m really unhappy with the school. I’m an oldy moldy [a parent with years of experience with early intervention] and I’m shocked and appalled. You’d think it was coming out of [the Director’s] own pocket….Once I purchase [the device] they’ll teach me how to program it. How can I borrow it for the next few months [and not know how to program it]? I didn’t go [to the training]. I’m really unnerved. I’m going to write a letter as an addendum [to Carlo’s IEP]. [The Director] sent me a letter. The letter says, “you agreed to the three hour training.” I didn’t agree. She asked if this would count toward Carlo’s time on his IEP. I said, “no, this is training for the speech therapist and me, not Carlo.” I’m non-confrontational. I’ve got bigger issues. A big fight. So unnecessary, so draining of [the Director’s] time. I had it in his IEP.

As we can see in the DeFrancis case, the pressure to conserve resources has a direct impact on the decisions that educators make about the services for individual children. Further, when a parent signals their willingness to contact parent and legal advocates, educators feel compelled to take direction from and align with the educators in charge of overseeing and funding early intervention, who themselves are increasingly willing to refuse or limit parent requests.
Enactment of a Constraint Driven Ideology

It would be easy to explain the cases presented above as the missteps or limits of individual educators as they go about their work. Yet, this would miss the effective collusion that the system supports through its communication and training of educators to get them to use and believe certain justifications. The limiting of service for each child is, in effect, a manifestation of the system’s efforts to limit overall services and to guide the actions of educators. As one educator in an administrative capacity put it: “there is a limit to what I’m allowed to do or that I feel comfortable, in my position, to be allowed to do.”

The pressure to limit services is so consistent and unrelenting that it is incorporated into the educators’ thought process and actions to the exclusion of other aspects of sound educational practice (e.g., the use of effective treatments or approaches). As a result, as they go about their work of creating plans for service for each child, the educators serve the needs of the system and abdicate their responsibility to children and families.

Ms Richards: They’re [the educators] not giving no (sic) advice and that’s what they’re supposed to be there for. You guys [educators] are supposed to know so much. Let’s hear some advice. Not “oh, well!” especially from a [service] coordinator. What do you think is the best program?!

A sad consequence of educators’ enactment of the agenda to restrict resources is that educators not only adopt the view of the system but also personalize issues and are, at times, unable to maintain an empathic view of parents who try to advocate for their child.

Education Supervisor: I get the feeling that she [Ms. Richards] likes the fact that he’s in a program three morning a week and she has her freedom
three mornings a week. That’s a good part of it. Well, she would like it five mornings a week with freedom. Who wouldn’t like five mornings a week with freedom? I’d like five mornings a week with freedom. You would too! My feeling is that that’s part of it. So, you need to look at, but if she has this diagnosis and if she wants a full time five day a week program, we’re not the type of provider to give her that. She does need to look elsewhere....But we do have that documentation [that with] the three [mornings] a week program he is starting to make progress. We see it and some families think we’re an instant fix. We are not an instant fix. No EI program is an instant fix.

In all of my numerous communications with Ms. Richards, she never gave any indication that she was looking for additional services as a means of child care or as a way to gain some “freedom” from looking after her son. To the contrary, she consistently expressed an interest in advice about how she could best help her son. However, the notion that early intervention not be used as a substitute for child care is one that is often voiced by the people in positions of power and authority in early intervention in Philadelphia. Unfortunately, these broad political determinations can and do get interpreted and implemented at the local level in a personalized way.

The drive to limit services is so pervasive that educators’ ability to accurately assess and effectively design an instructional service or program to meet the needs of children is substantially impeded. In the Richards case, the educators presented their position that the services that Jason received were appropriate and that he was making “significant” progress so there was no need for him to have additional services. The educators tracked Ms. Richards through a decision making process that presented a more intense program for children with PDD as more restrictive and therefore, less desirable, without a discussion
of how the intensity of instruction may have benefited Jason. This is consistent with other efforts to use the "special" aspect of special education as a way to deter parents from asking for these, more costly, services. In a document authored by Gladstone and used to train early intervention professionals in the use of standard scores to determine a child's eligibility for early intervention, there is a section titled "how to explain eligibility to parents under new standard score criteria." In this section, they advise educators to "use the words 'special education' rather than early intervention. This emphasizes the delay aspect to parents and may also help them prepare for the transition to the school district."

Before and after this section, are illustrations of when it would not be appropriate to recommend a child as eligible for special education. These efforts suggest that Gladstone is training staff to increase their capacity to recommend children as ineligible and to feed into the parents' hesitancy to have a child categorized as needing special education at three or four years old, so that the parents might be more easily dissuaded from insisting on services for their child. This interpretation is consistent with a substantial decrease in the number of children who have been determined eligible for early intervention subsequent to the implementation of these guidelines.

*Family Centered Services*

The limiting of service for children three to age of beginner is an extension of the practices that occur in special education for students through 21 years of age. The practice of limiting service can be seen as the system's way of fending off demands to expend additional resources when a viable program (i.e.,
appropriate educational services) is available to the child. For services for children birth to three an entirely different philosophy of service determines how the team makes decisions about services. Interestingly, this philosophy of family centered service is also often used to limit early intervention services to families.

Family centered practice is an approach where educators work with a parent, usually the mother, to become the primary interventionist for her child (Dunst, 1997). The intent is for the parent to use and integrate teaching techniques and strategies throughout the child’s daily life to promote the child’s development. The goal is for the child’s learning to be maximized by the presentation of natural and frequent opportunities for learning by the child’s primary caregiver. An intended outcome of this approach to service as it has been implemented to date, is that if educators are successful in their efforts to help the parent become the child’s primary teacher, then educators themselves will provide less direct service to the child. A byproduct of this approach is that plans for service that involve multiple services (e.g., speech therapy and physical therapy and occupational therapy) are seen as “a lot of service.” In addition, service by a discipline that occurs more than once per week is also seen as “a lot of service.”

There are two common accusations of “too much service” leveled at early intervention providers both at the agency level and at individual educators, by researchers and administrators who work for state departments that fund early intervention. These are first, that the provider does not follow or believe in family centered practice and second, that the provider recommends that the child
receive more service than necessary to meet their own needs, (e.g., convenience of scheduling, financial incentive). In the former scenario, the provider is assumed to not follow the practice of family centered services if they are providing “a lot of service” and are believed instead to be working directly with the child rather than with the parent, contrary to the family centered philosophy. There is a common perception among administrators who work for state departments that fund early intervention and also researchers that the prescription of “too much service” is a rampant and pervasive problem in early intervention (Bruder, 2000).

Recently, I had the opportunity to do some data analysis for services to children birth to three in Philadelphia and found that the amount of service that each child receives is, on average, much less than is widely reported and that the assignment of “a lot” of service (i.e., three or four services) is actually the exception rather than the norm. In my role as Policy and Planning Specialist (i.e., a consulting position) with Mental Retardation Services (MRS), the agency that oversees all early intervention services for children birth to three years in Philadelphia County, I was asked to facilitate a workgroup of County early intervention staff and early intervention providers to develop a proposal for an alternative to the current system of referrals of children to early intervention providers. As part of this assignment we reviewed data reports about the number of children in the early intervention system, the services they receive and the early intervention system’s compliance with regulated timelines. Though the common wisdom was that each child received multiple services (e.g., three or
four services), a close examination of the data revealed that children receive an average of 1.5 services per child. This average level of service has been consistent for at least four years, the time for which the data is available. I also cross-referenced this data with other data collected as part of the information system maintained by Philadelphia County Early Intervention. These data also have been corroborated by other early intervention staff with access to data on IFSPs and confirmed that, in fact, a substantial number of children receive only one early intervention service and that very few children indeed receive more than two services.

One interpretation of these data is that if limited services are an indicator of the use of family centered practice, then services are in fact being recommended within the family centered model. Educators and service coordinators, along with parents, are responsible for making decisions about levels of service on IFSPs. Another possible interpretation of these data are that the educators and service coordinators are keenly aware of shortages in personnel in various specialty areas, such as speech, physical and occupational therapies. Despite frequent and consistent direction and admonition to develop a plan for service based on the child's needs and not the administrative concerns of the early intervention system, it is reasonable for educators to make recommendations for a child that have the best chance of being carried out and are motivated to not place additional stress on a system that struggles, at times, to meet the needs of children. Another interpretation is that children are in fact receiving the services they need to receive based on their presenting concerns.
To help understand which of these interpretations are accurate, we need comparative data on aggregate outcomes for children who receive early intervention as well as research on frequency and intensity of early intervention services as variables in children’s learning. These are areas for future research.

Educators are trained to present family centered service as the state of the art approach in early intervention and parents who resist this approach are often described as people who, mistakenly, want the professional to fix the child. Yet, the current model of service delivery offers little in the way of variation of service, (e.g., the majority of IFSPs offer service once per week) and increased intensity of service as a method of instruction is effectively discouraged. A flexible approach to services, which is, perhaps, a more logical extension of the family centered approach, e.g., more frequent and intense as the parent needs more guidance and less while the parent is successful at implementing recommended teaching strategies, is essentially nonexistent in early intervention. Without outcome data on effective educational approaches for children who need early intervention, controls and limits on services are based on policy and threshold criteria endorsed in legislation, (e.g., appropriate, family centered), as well as economic constraints. Currently, there is an active national discussion among educators about the design of outcomes that will accurately measure the impact of early intervention services on children and families. A handful of states have developed systems to measure outcomes for children and families who participate in early intervention (FPG Child Development Institute, 2005).
Inflexible Systems

Though there are challenges to developing a system to measure the success of supports for children and families, there is a great need for decisions about services to be based on results. In Philadelphia, sweeping changes have been made to the early intervention service delivery model as a response to changes in Part C of IDEA in 1997 that called for services for children and families to be in “natural environments” and to be family centered. When this legislation was enacted, the majority of toddlers in need of early intervention were assigned to “center-based” programs, for anywhere from three to five hours of their day. Few educators today would endorse a return to the center-based model of EI as a way to meet the needs of the majority of young children. In Philadelphia in 2003, 98% of EI services are being delivered in home settings with the parent, seen and worked with by the educator, as the primary interventionist. Though there may be some young children for whom the home based model is not sufficient or effective, the early intervention system is highly resistant and reluctant to support services for these toddlers outside of their homes. The lead administrator of the County department that oversees early intervention services for infants and toddlers in Philadelphia discovered that even fiscal “schedules” issued by the Commonwealth of Pennsylvania eliminate center-based services as an educational option.

With regard to this particular issue the pendulum has swung completely in the other direction. I think that it doesn’t take into account certain special populations [we had just finished discussing children who are deaf or hard of hearing] who might benefit more from being in a center-based program with children like themselves for a period of time or in conjunction with
other services that they get. The research supports it in terms of their ability to ultimately be mainstreamed and to overcome this challenge that they have. But our system being very black and white in its direction hasn’t moved completely away from [worrying about] center-based services. You have to look at the individual needs of families and children. I think that part of the hysteria on the part of the Commonwealth and the County about this moving away from center-based services, and it’s so funny because I’m realizing it now even under these schedules that we issue to providers. When it comes down to other than home services, it says “not applicable”....So, I go send an e-mail to Fiscal telling them to change the fee schedule. Note comes back “we took that off of there with state approval”.... They don’t want to issue us a fee schedule. [The leadership in the MRS office in Philadelphia County requested that the State remove the listing of center-based services on the fee schedule they issue to providers thereby eliminating the possibility that providers will be able to offer and bill for this service]....The idea of us trying to be creative figuring out alternatives and getting resources where we can [is effectively blocked by the lack of a mechanism to bill for these alternatives to home based services].

The fear is that early intervention providers, if given the opportunity, would return to center based services since this type of service is easier to operate than home based services. Home based services require recruiting, training and scheduling staff to work with families and children as well as planning and costs related to travel. That a center-based service or some variation might meet the educational and developmental needs of some children, is not an early intervention option in Philadelphia. The administrator continues:

Part of it, the hysteria, is that the County and the State realized that they wouldn’t be monitoring this. They had this whole thought that they would look up one day not having closely monitored it and all the children would be back under [center-based] services. I think some of that now can be relaxed because I have the Program Analysts doing annual monitoring. They are looking at the percentage of services in home and in center....We are meeting with the providers on a regular basis. They are very clear about what our expectations are. We’ve done all the training and requirements...I don’t think that unless we just fall asleep and go into a deep coma that we’re going to look up one day and be back at center-based services. I feel a degree of freedom and comfort to be able to look
at individual situations and allow it. I'm not sure that my superiors can move in that direction yet so I haven't done it. I'm going to be broaching that topic soon because I really think that we're doing a disservice by being totally anything.

For infants and toddlers and for preschool children the models that are developed for early intervention services, whether they stem from a theoretical or legal framework, become rigid in their application. Whether originally based in educational research or in the extension of the civil rights approach to children with special needs, the service delivery systems that are responsible for the implementation of early intervention become calcified. Pedagogy and legal criteria devolve into ideology that leaves little, if any, room for alternatives. Though it is the intent that a child's educational program be based on his or her individual needs, the frequency and intensity and, often, type of services that a child receives must fit within approved frameworks. Most educators become thoroughly indoctrinated into what the system expects and requires, and are corrected should they attempt to deviate from the sanctioned approach.

In the absence of data on effective educational approaches, educators are missing a critical source of information about whether a program or service, as it is designed, meets the needs of young children. With data on the results that children are able to attain, decisions about educational approaches and programs can play a more determinative role in the type, frequency and intensity of educational service that is recommended for a child. Without these data, educational decisions are based on ideologies that derive from legal criteria, economic constraints and pedagogical prescriptions.
As the data in this chapter show, the early intervention system has effectively trained educators in the use of decision-making processes and educational approaches to the exclusion of alternatives. The power and ability of educators to develop individual programs or service levels for children that are anything beyond the approved frameworks has been effectively eradicated. Though there are exceptions to these processes and frameworks, they are a slim minority. And there are limits to parent advocacy. No matter how skilled the parent becomes at advocating for their child, the early intervention system has become accustomed to resisting and refusing parent requests.

The message to limit services to children pervades early intervention. This message actually consists of a barrage of messages that derive from legal standards, pedagogical approaches and economic considerations. The ability to effectively change the current approach to educational service delivery lies in educators becoming more responsible and responsive to the children that they serve. To do this a fundamental part of educational practice, the ability to demonstrate that an educational approach is effective in meeting the needs of children, must be established. In the concluding chapter I outline what a remedy based on educational outcome data would mean for educators and for the children they serve.
DISCUSSION

Why Some Differences are Resolved

What enabled parents and educators to resolve differences? In this study, educators who used a therapeutic approach and were highly informative in their work with parents were successful in resolving differences with parents. This therapeutic approach was informed by a social work and counseling perspective that guided the educators to develop a substantive understanding of a parent’s concerns and to present issues that were difficult for parents in a manner that was helpful and supportive. Using this approach, the educators were able to recognize and acknowledge conflicts they were having with parents and developed specific strategies to address very difficult issues with parents. These educators also guided parents to become knowledgeable about relevant regulations, important decision points and the merits and disadvantages of various instructional approaches. Though multi-layered and sophisticated, this approach speaks to the complexity of issues that Lake and Billingsley (2000) identified as factors in the escalation and de-escalation of conflict between parents and educators. Educators that incorporate the use of counseling techniques and guidance through decision processes address the specific issues that are important to parents of children with special needs.

The approach of apology and prompt remedy by educators was also particularly effective in resolving differences when the child was not getting the services on his or her Individual Education Plan and when an educator made an unprofessional or insensitive remark to a parent. Even in circumstances that
involved a considerable oversight by educators, such as when the educators lost track and did not provide a child an agreed upon service for over two months or when the remarks made by educators were quite offensive and unfortunate, this approach was well received by the parents in this study. This means that educators can do very specific things to avoid the escalation of conflict well before the need to use the strategies that Kosmoski and Pollock (1999, 2001) recommend for educators to deal with hostile parents. Further, this finding is a demonstration of when, where and how apologies play a role in dispute resolution (Levi, 1997).

Why Some Differences are Not Resolved

There were a number of factors that contributed to unresolved differences and differences that were not resolved to the parents’ satisfaction. As parents began to learn about their child’s developmental delay, they often had questions for and sought advice from the educators. The parents presented concerns about their child’s development, educational needs and future. When educators failed to adequately address these concerns, a pattern of misunderstanding and conflict arose between themselves and parents. Educators who avoided engaging parents in any substantive dialogue in response to these concerns frustrated parents. Educators who were unable or reluctant to communicate information about alternative instructional approaches also faced continued conflict with parents. These breakdowns speak to Russell’s (2003) argument for educators to do a better job of understanding and clarifying parents’ expectations. This fundamental gap in what parents expect from educators and
what educators are willing and able to address is an obstacle to meaningful and successful communication.

More than half of the parents in this study used an advocacy approach to resolve their differences with educators. There were instances where the advocacy approach directly contributed to the resolution of a difference between a parent and educators. However, despite the parents’ considerable efforts to advocate for their child, the majority of parents in this study who used the advocacy approach were not able to achieve what they saw as a positive outcome. For some of these parents, their difficulty with resolving a difference was preceded by previous positive resolutions to disputes with the educators. For these parents, they reached a point where they were unable to make any headway against a context of limits on educational services that satisfied legal requirements, pedagogical prescriptions and the drive to conserve resources, but, arguably, did not meet the needs of the child.

Educators were also challenged when faced with a child who was unique in his or her needs. In these circumstances, educators failed to recognize or acknowledge their lack of information and expertise about the child’s needs. The educators resisted efforts to address the unique needs of the child and instead offered services within the scope of their existing program rather than develop an alternative approach to services for the child. This finding is consistent with the observations of mediators interviewed by Lake and Billingsley (2000) who expressed frustration at the lack of willingness of educators to reassess and advance their program options based on children’s needs. The inflexible
implementation of services and programs by educators is a barrier to successful partnership with parents and to effective programs for children.

When Parents Pursue Mediation or Due Process

In this study, only one parent actively pursued the possibility of due process to resolve a difference. This parent had a history of regularly accommodating the educators by substituting for the child’s one-on-one staff whenever the staff was absent. After repeated attempts by the educators to convince the parent to have the child evaluated for mental health concerns and to withdraw the one-on-one staffing for the child, this parent responded by bringing in outside experts to support her position that her child’s issues were of a developmental nature. The parent then requested that the child receive one-on-one staffing in kindergarten as compensation for the staffing absences that occurred during the previous preschool year. The parent was advised by legal counsel that based on pertinent education regulations that she would not be successful and chose not to request a due process hearing.

This very limited finding involves one parent who explored the possibility of pursuing due process and did not proceed based on information she received about the relevant education regulations. There may be other reasons parents do or do not pursue due process. These reasons may be similar to or distinct from the reasons that parents pursue mediation. Lake and Billingsley (2000) interviewed parents retrospectively about their reasons for pursuing mediation. The parents in Lake and Billingsley’s (2000) study reported reaching a “turning point” in their ability to trust the educators involved with their child’s schooling.
These parents viewed their relationship with educators as one of broken trust and saw the educators involved with their child as uncaring, unresponsive and even detrimental to their child's education. Although the parent in this study certainly reached a low level of trust and confidence in many of the educators, her reason for investigating the possibility of due process had more to do with trying to secure an extension of services for her child than with an unwillingness to place continued trust in the educators' ability to make supportive recommendations or decisions.

Resolving Differences: Implications for Educators

With preparation and training, educators can increase their capacity to effectively resolve the differences they have with parents about a child's early intervention program. A joint negotiation training that educates parents along with educators may help to resolve conflict.

Joint Negotiation Training

The level of intensity and, at times, distress that parents experience when they are in conflict with educators was apparent in this study. Conflicts with parents also negatively affect educators. The joint training of parents and educators would offer all parties the opportunity to learn together about pertinent education legislation and regulations and would foster an approach to resolution that addresses differences with mutual interests in mind. Joint training may be an effective approach to help parents and educators to develop a working knowledge about legal requirements and effective negotiation techniques. Instruction in conflict management offered to parents as they enter the early
intervention system might help both parents and educators prepare for future disputes that may arise.

The commitment to family centered practice and family involvement is part and parcel of early intervention today. However, the challenges that parents face in attending trainings and workshops are substantial. Many schools and providers struggle with parent attendance at meetings and workshops (Lawrence-Lightfoot, 2003). In early intervention, a fraction of families attend trainings and meetings despite sustained and creative attempts to increase involvement. While joint training of parents and educators must be included as part of a comprehensive approach to effectively resolve differences and to further actualize the commitment to parents as equal partners in decision-making, the capacity of educators to support and better understand parents from the initial contact onward must also be improved. In addition to joint training, the data in this study clearly suggest that educators can anticipate and prepare for conflicts and develop effective approaches to address parent concerns that regularly occur in early intervention.

**Anticipate and Prepare for Conflict**

This study illustrates the common differences or friction points that occur with regularity in early intervention and special education. Given the endemic nature of these friction points, educators can develop a cohesive plan to address these common differences so that they, individually and as a team, can work with parents to effectively resolve differences. Educators must go beyond the situational view of each conflict as a separate event and develop a more planned
approach to conflict that supports both parents and themselves to address their mutual interest to meet the needs of children (Ertel, 1999).

Though there will likely be circumstances specific to an individual child and parent, on the whole educators can expect that the issue of a child's lack of progress will come up regularly in their practice. To prepare for these occurrences, educators can develop a set of questions that they need to ask and answer when a child is not making progress. A thoughtful analysis of a child's progress can support a meaningful discussion between educators and parents and reduce the stress and strain that often accompany a conflict surrounding a child's lack of progress. An example of this approach would involve an educator's review of a child's performance on an educational task, a review of the child's targeted objective or outcome and an assessment of the intermediate steps that the child needs to learn to accomplish this outcome. In this example, an important next step would be for the parent and educator to then agree on a timeline to check in with one another to review and discuss the child's progress. Further, educators who develop a substantive understanding of a variety of instructional and therapeutic approaches may be in a position to offer alternatives for children who are not making progress with a particular approach and also serve as a resource to parents. An example here might involve an educator who is experienced with developmentally and behaviorally based approaches to teaching young children with autism spectrum disorders. A teacher working with a child who is not making progress with a "floor time" approach to instruction where the teacher is highly responsive to child initiations and minimizes adult
direction (Greenspan & Weider, 1998), might suggest and try out a more teacher
directed approach to instruction with the child and assess its effectiveness.

The pressures for parents in this study arose from concerns about the
child's optimal time for learning, the parent's process of acceptance of the child's
delays and learning needs and the concern that they not offend or be perceived
harshly by the educators. To help understand parents better, educators can learn
about what these pressures mean for parents and can improve their capacity to
meaningfully communicate with parents about these issues. Educators can
familiarize themselves with the research about children's optimal time for
learning. Based on this information, educators can adopt approaches that
address the need to optimize children's learning during critical periods of
development. To the degree that educators ensure that their own teaching and
practice is in line with recommended standards, educators can then speak more
directly to parents' concerns regarding their child's optimal time for learning.

Educators in early intervention have regular contact with parents who
have received news of a child's diagnosis or need for early intervention within
days or months of beginning services. An important lesson from this research is
that educators need to develop greater competence in working with parents who
are in the process of accepting a child's diagnosis and learning needs. The
research of Abrams and Goodman (1998) and the model offered by Ulrich and
Bauer (2003) begin to get at information that educators need to understand about
parents who are in a process of acceptance. Abrams and Goodman (1998)
analyzed the strategies that psychologists used as they met with parents to
disclose a diagnosis of mental disability. Rather than a fixed presentation of information that was candid and thorough, Abrams and Goodman found that the psychologists used euphemisms, such as developmental delay rather than retardation, and hedged and “negotiated” about the diagnosis in response to the parents’ reaction. These negotiations centered on the diagnostic label (e.g., severe retardation versus moderate retardation) and the degree of optimism or pessimism expressed by the parent upon hearing of their child’s diagnosis. The psychologists consistently shifted parents from “extreme” positions of optimism and pessimism to closer approximations of the child’s reality and prognosis. This research also looked at parents’ state of understanding and acceptance by the close of the diagnostic conference. When parents had a clear sense of the diagnosis, they addressed questions about prognosis to the psychologist. When parents had an ambiguous or vague sense of the meaning of the diagnosis they tried to clarify the diagnostic category and did not ask the psychologist questions about the child’s prognosis. Further research is needed to see if educators can accurately assess a parent’s understanding of their child’s diagnosis and whether this assessment might be helpful to educators as they work with parents in the weeks and months following the diagnostic conference. Ulrich and Bauer (2003) offer a model for how parents adapt to the identification of a child with a disability. In this model, parents are seen as progressing through four levels of awareness, i.e., uninformed, action-oriented efforts to “fix” the child, desire to see the child normalized and preparing for the reality of living with disability. Ulrich and Bauer suggest that parents experience “transformational moments” where they move to
another level of awareness and consequently, may contradict previous requests for services or other related beliefs. Their research looks at the degree of similarity between parents and educators in their levels of awareness, suggesting that mismatches contribute to miscommunication. Beyond an assessment of the level of match between parents and educators in their level of awareness about a child's disability, research is needed to further develop a framework that will guide educators in their work with parents during the process of acceptance.

Educators in early intervention encounter children with low incidence needs and rare disorders and parents who become expert on the child's diagnosis, condition and educational requirements. To improve educators' ability to recognize and address the unique and special needs of these children, educators need a systemic mechanism that enables them to get access to expertise about recommended approaches and educational services. An example of such a mechanism is under consideration in Philadelphia for the infant and toddler early intervention system. In this proposal, the team of educators and the parent that are responsible for the development of a child's Individual Family Service Plan, will have the opportunity to call in an expert who will advise the team about state of the art approaches to intervention as well as matters of implementation. To support educators in the successful development of programs and services for children with specialized or unique needs, educators need training to recognize the limits of their knowledge and capacity and they need ways to readily access expertise that will help them.
Improve Educators Capacity to Manage Differences

With the continued legislative support for inclusion more "regular" educators, in addition to special educators, will interact with parents about a child's educational program. Yet, there is a paucity of training for all educators about how to make their interactions with parents positive and effective. In a compliance review of school districts, OSEP found that seven of eight districts that they visited in Pennsylvania were unable to identify any training provided to educators about meeting the needs of parents and involving them in the special education decision-making process (OSEP, 2002). This lack of training was evident in the educators in this study who relied on their own individual capacity as well as the authorized interpretation of pertinent regulations to address the needs of parents.

Educators need training beyond the traditional approaches to conflict resolution to improve their understanding of conflict and how to work through conflict to better support parents and themselves. With this level of training educators can then develop guidelines and systemic support to address the common issues and concerns of parents. One example of such a guideline might be that when a parent is struggling with recognizing and accepting their young child's learning difficulties that the educators work with the parent individually and in a parent group to help the parent understand the child's challenges and what can be done educationally to help the child. Another example might involve the case where other family members are struggling to understand the child's learning needs and as a result, there is internal conflict within the family. In this
situation the guideline for educators would suggest inviting the extended family in
to discuss their views and concerns and to learn about the child's educational
needs. Gorman's (2004) set of guidelines for dealing with specific challenges that
educators encounter with parents of children with special needs address some of
the techniques that educators need to learn and integrate in their practice. An
area for further study is whether educators require coaching from a psychologist
or social worker to apply general guidelines for addressing conflicts in ways that
are relevant and important to successful partnerships with parents.

Along with training and guidelines, an important factor in the successful
implementation of an informed and planned approach to the resolution of
differences is the role of educators. In this study, the Director of an early
intervention program established relationships with parents, developed a skill set
informed by a counseling perspective, provided guidance to parents about
important decision points and recognized and used her status as director to
facilitate the resolution of differences. Both parents and educators saw this
strategic approach as highly supportive of their efforts to work together through
difficult issues.

*Need for Data Driven Decisions*

All of the methods I have described would amount to little real change for
children, parents and educators without recognition of the legal, political and
economic context in which educational decisions are currently made. Lake and
Billingsley (2000) identified constraints on resources as a critical factor in the
escalation of special education conflicts. The data in this study show us that the
context for limiting services is broader. The current state of decision making about educational programs and services rests on the legal standards of appropriateness, least restrictive environment and natural environments as set out in Parts B and C of the IDEA of 2004, the generic application of pedagogical approaches (e.g., family centered practice) and the pressure to reduce services and costs. Educators can fundamentally shift the current framework for determining services by creating, recommending and using educational programs and approaches that are scientifically based and that demonstrate effective instructional practice. With this approach to decision making, educators can develop and evaluate an instructional technique or program and make changes based on the resulting data. Hoffman and Kalnin (2003) describe how the use of individual and local program data and the alignment of these data with major research findings helped groups of educators improve their math and science curricula and teaching strategies. The impact of an evidence-based approach on decision making about special education services and programs and how this approach would affect the balance of legal, pedagogical and economic considerations that currently govern these decisions warrants further study.

The need to develop innovation in educational practice is vital to improved instruction and service and ultimately improved outcomes for children. Research that addresses the limits and potential of service delivery based on results for children may offer alternatives to the inflexible and constrained standards of practice that currently exist. Data driven decisions can drive and support the
creation and use of educational programs and services that can meet the needs of one child and all children.

An Educational Approach to Resolving Differences: Implications for Research

Research is needed to further identify and understand the strategies that educators use to effectively resolve differences with parents. This study identified two approaches, one that is informed by a counseling perspective and both advises and supports parents through key decisions and a second approach, specific to oversights and insensitive remarks by educators, of apology and prompt remedy. Additional study of how parents and educators go about resolving differences as they first arise may suggest other specific strategies that parents and educators find helpful.

The approach to resolving differences that draws on a social work and counseling perspective combined with specific efforts by educators to inform families about relevant regulations and important decision points needs to be studied further. There are a number of questions that need to be answered to determine the viability of this approach for educators. What are the elements of a counseling perspective that educators need in their efforts to resolve differences with parents? What method of professional development is most effective for educators to learn these techniques and develop the ability to apply them? What degree of competence do educators need to develop to effectively use these techniques and resolve differences with parents effectively? Is ongoing support and coaching of the educators from a capable psychologist or social worker needed or once trained can educators implement this approach consistently and
effectively? What are the relationships between competence and the role and status of educators as they use this approach and what impact do these factors have on parents’ level of satisfaction with resolutions?

The data from this study indicate that an approach to resolving differences that is informed by a counseling perspective, that offers specific guidance to parents through decision making processes, and that includes the use of data to support decisions about children’s program and services has promise. This approach is a sophisticated one that involves a substantial expansion of skills and processes for educators to integrate into their practice. The participants in this study were all parents of young children who received early intervention services. Future research can determine whether this approach would apply to the effective resolution of differences between educators and parents of children who are school age and who receive special education services.

For the educators and parents of young children, the early stages of understanding and acceptance of the child’s needs and diagnosis can be a difficult and emotional time. Research is needed on this early phase, immediately after diagnosis and in the first few years, of the process of parent’s acceptance and how educators can accurately assess parent’s understanding and needs during this time. Further research of this early phase could focus on what parents need to make fundamental decisions about the education of their child, the degree to which acceptance plays a role in decision making about education decisions, and how educators can successfully work with parents and reduce conflict during this time. The early years offer opportunity not only to young
children to learn and grow, but also to educators to further their understanding of all that is required to serve young children and their parents in a way that is both effective and supportive.
Appendix A: Glossary

Age of Beginners. The minimum age that a child can attend first grade in his or her own school district.


Early Intervention (EI). Services and supports that help eligible young children, from birth to age of beginners, to learn and develop.

ER Evaluation Report. A report about the evaluations done to assess a child’s development and progress.


IEP Individual Education Plan. A written plan developed by parents and educators for eligible children from their 3rd birthday to 21 years of age.

IFSP Individual Family Service Plan. A written plan developed jointly by parents and educators for eligible children from birth to their third birthday.

MDE Multidisciplinary Evaluation. A set of evaluations performed by a team comprised of the child’s parents and professionals from various disciplines to determine whether a child is eligible for early intervention and for re-evaluation of children who receive early intervention services and supports.

OT Occupational Therapist or Occupational Therapy. Services provided by a qualified occupational therapist, who helps children to develop fine motor and self-help skills, such as writing and holding small objects.

PDD Pervasive Developmental Disorder. Correct term is PDD-NOS, Pervasive Developmental Disorder not otherwise specified. A developmental disability that is usually evident by age three and affects a child’s ability to communicate, understand language, play and relate to others. Children are given this diagnosis when they display similar behaviors of autistic disorder but do not meet the criteria for autistic disorder.

PSYCH Psychologist or Psychological Services. Services provided by a qualified psychologist, who works with children who to develop their thinking, learning, and remembering skills.
PT  Physical Therapist or Physical Therapy. Services provided by a qualified physical therapist who helps children with gross motor skills such as standing, walking and climbing stairs.

SI  Sensory Integration. A theory that maintains that the processes of the brain that organize and interpret information about sensory experiences, including touch, movement, body awareness, sight, sound and the pull of gravity, are crucial for learning and behavior.

SI  Special Instructor or Special Instruction. A teacher in early intervention who helps young children learn and develop.

ST  Speech Therapist or Speech Therapy. Services provided by a qualified speech pathologist who helps children develop language and communication skills.

SW  Social Worker or Social Work Services. Services provided by a social worker to a child and family that may include the coordination of needed services, advocacy, counseling, information about and referral to resources, and intervention.

TSS  Therapeutic Support Service Worker. A trained and designated staff assigned to a child to address behaviors that may interfere with learning.
Appendix B: Consents

UNIVERSITY OF PENNSYLVANIA

Jeannette E. Newman, Ph.D. Candidate
Graduate School Of Education
Education Leadership Department
(610) 247 - 3668

CONSENT FORM - PARENT

*From the Beginning: What educators and parents of children with special needs do to resolve their differences.*

INVITATION TO PARTICIPATE: You are being asked to participate in this research study because you have a child who is receiving early intervention services and you have shared some concerns in regard to your child’s education.

PURPOSE: The purpose of the study is to learn more about how parents and professionals work out their differences successfully.

PROCEDURES: I would like to interview you about your child and the differences you have or have had with your child’s teachers and/or therapists. With your permission, I would like to observe any IEP and related meetings that concern your child. Also with your permission, I would like to review your child’s IEP document and related documents (i.e., ER).

BENEFITS: The results of this research may help parents to resolve differences with the professionals who work with their children. Beyond the longer term results of this study, there is no direct benefit to your participation in this study.

COMPENSATION: There is no financial compensation for your participation.

RISKS: There are no known risks to participating in this study.

COSTS AND FINANCIAL RISKS: There is no charge for you to participate in this research study.

ALTERNATIVES: If you do not participate in this research study the alternative is that your interactions and differences with the team would proceed without being interviewed or observed. There are no potential adverse effects from this alternative.

CONFIDENTIALITY: Every attempt will be made by me to maintain all
information collected in this study strictly confidential, except as may be required by court order or by law. Authorized representatives of the University of Pennsylvania Institutional Review board (IRB), a committee charged with protecting the rights and welfare of research subjects, may be provided to research records that identify you by name. If any publication or presentation results from this research, you will not be identified by name.

DISCLAIMER/WITHDRAWAL: You agree that your participation in this study is completely voluntary and that you may withdraw at any time.

YOUR RIGHTS: If you wish further information regarding your rights as a research participant, you may contact the Director of Regulatory Affairs at the University of Pennsylvania by telephoning (215) 898-2614.

You also understand that if you have any questions pertaining to your participation in this research study you may contact me by calling the telephone number listed at the top of page one.

You have been given the opportunity to ask questions and have had them answered to your satisfaction.

CONCLUSION:

You have read and understand the consent form. You agree to participate in this research study. Upon signing below, you will receive a copy of the consent form.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature of Participant</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of Person Obtaining Consent</th>
<th>Signature of Person Obtaining Consent</th>
<th>Date</th>
</tr>
</thead>
</table>

10/02
CONSENT FORM - PROFESSIONAL

From the Beginning: What educators and parents of children with special needs do to resolve their differences.

INVITATION TO PARTICIPATE: You are being asked to participate in this research study because you provide early intervention services and a parent of a child that you are working with has shared some concerns in regard to their child's education.

PURPOSE: The purpose of the study is to learn more about how parents and professionals work out their differences successfully.

PROCEDURES: I would like to interview you about this child and your understanding of the differences the parent has expressed about their child's education. With the parent's permission I will observe any IEP and related meetings that concern this child. Also with the parent's permission, I will review the child's IEP document and related documents (i.e., CER).

BENEFITS: The results of this research may help parents and professionals in their efforts to productively resolve differences in their work with children. Beyond the longer term results of this study, there is no direct benefit to your participation in this study.

COMPENSATION: There is no financial compensation for your participation.

RISKS: There are no known risks to participating in this study.

COSTS AND FINANCIAL RISKS: There is no charge for you to participate in this research study.

ALTERNATIVES: If you do not participate in this research study the alternative is that you would proceed with your work without being interviewed. There are no potential adverse effects from this alternative.

CONFIDENTIALITY: Every attempt will be made by me to maintain all information collected in this study strictly confidential, except as may be required...
by court order or by law. Authorized representatives of the University of Pennsylvania Institutional Review board (IRB), a committee charged with protecting the rights and welfare of research subjects, may be provided to research records that identify you by name. If any publication or presentation results from this research, you will not be identified by name.

DISCLAIMER/WITHDRAWAL: You agree that your participation in this study is completely voluntary and that you may withdraw at any time.

YOUR RIGHTS: If you wish further information regarding your rights as a research participant, you may contact the Director of Regulatory Affairs at the University of Pennsylvania by telephoning (215) 898-2614.

You also understand that if you have any questions pertaining to your participation in this research study you may contact me by calling the telephone number listed at the top of page one.

You have been given the opportunity to ask questions and have had them answered to your satisfaction.

CONCLUSION:

You have read and understand the consent form. You agree to participate in this research study. Upon signing below, you will receive a copy of the consent form.

Name of Participant  Signature of Participant  Date

Name of Person Obtaining Consent  Signature of Person Obtaining Consent  Date

10/02
UNIVERSITY OF PENNSYLVANIA
RESEARCH SUBJECT AUTHORIZATION
CONFIDENTIALITY & PRIVACY RIGHTS

Protocol Title: From the Beginning: What Educators and Parents of Children with Special Needs Do to Resolve Their Differences

Principal Investigator: Jeannette Newman, Ph.D. Candidate – Graduate School of Education
(610) 247-3668

You have agreed to participate in the study mentioned above and have signed a separate informed consent that explained the procedures of the study and the confidentiality of your personal health information. This authorization form gives more detailed information about how your health information will be protected and includes:

- What personal health information about you will be collected in this study
- Who will use your information within the institution and why
- Who may disclose your information and to whom
- Your rights to access research information about you
- Your right to withdraw your authorization (approval) for any future use of your personal health information

By signing this document you are permitting the principal investigator on behalf of the University of Pennsylvania to use your personal health information collected about you for research purposes within our institution.

What personal health information is collected and used in this study, and might also be shared?

The following personal health information will be collected:
- Parent and Child Name
- Address
- Telephone number
- Child’s Age
- Child’s Diagnosis
- Child’s Evaluation Report and Individual Education Plan

The following personal health information may be disclosed as part of your involvement with this research study:
- Child’s Age
- Child’s Diagnosis
- Child’s Evaluation Report
Child's Individual Education Plan

Your name and your child's name may be shared with my dissertation advisor as part of transcription of interviews and meetings. Your name and your child's name, address and telephone number will not be disclosed to anyone else or in any publication. Your identity and that of your child will be changed in my dissertation and in any resulting publications.

Why is your personal health information being used?

Your personal contact information is important for the principal investigator to contact you during the study. Your information regarding the child's diagnosis, evaluation report and individual education plan is being collected as part of this research study and for the advancement of early intervention practice.

Which of our personnel may use or disclose your personal health information?

The following individuals and organizations may use or disclose your personal health information for this research project:

- The Principal Investigator
- The University of Pennsylvania Institutional Review Boards (the committees charged with overseeing research on human subjects) and University of Pennsylvania Office of Regulatory Affairs
- The University of Pennsylvania Office of Human Research (the office which monitors research studies)

Who, outside of the University of Pennsylvania, might receive your personal health information?

- In all disclosures outside of the University of Pennsylvania, you will not be identified by name, address, telephone number, or any other direct personal identifier unless disclosure of the direct identifier is required by law.

How long will the Principal Investigator be able to use or disclose your personal health information?

Your authorization for use of your personal health information for this specific study does not expire. This information may be maintained in a research repository (database). However, the Principal Investigator may not re-use or re-disclose your personal health information collected in this study for another purpose other than the research described in this document unless you have given written permission for the Principal Investigator to do so. However, the University of Pennsylvania Institutional Review Board may grant permission to
the Principal Investigator or others to use your information for another purpose after ensuring that appropriate privacy safeguards are in place. The Institutional Review Board is a committee whose job it is to protect the safety and privacy of research subjects.

**Will you be able to access your records?**

You will be able to request access to your record (i.e., transcription of your interviews) when the study is completed. The investigator is not required to release to you research information that is not part of your record.

**Can you change your mind?**

You may withdraw your permission for the use and disclosure of any of your personal information for research, **but you must do so in writing** to the Principal Investigator at the address listed on the first page of this form. Even if you withdraw your permission, the Principal Investigator for the research study may still use your personal information that was collected prior to your written request if that information is necessary to the study. If you withdraw your permission to use your personal health information that means you will also be withdrawn from the research study.

By signing this document you are permitting the University of Pennsylvania to use and disclose personal health information collected about you for research purposes as described above.

<table>
<thead>
<tr>
<th>Parent or Professional's Name [print]</th>
<th>Parent or Professional's Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person obtaining authorization [print]</td>
<td>Person obtaining authorization Signature</td>
<td>Date</td>
</tr>
</tbody>
</table>
BIBLIOGRAPHY


McGrath, D. & Kuriloff, P. (1999). They’re going to tear the doors off this place: Upper-middle class parents’ school involvement and the educational opportunities of other people’s children. Educational Policy, 13(5), 603-629.


