

Individualized Education Programs (IEPs)  
as Lived Experiences

by

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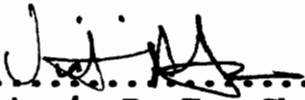
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INDIVIDUALIZED EDUCATION PROGRAMS (IEPs)

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Mary Cherian

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Family and Child Development

(ABSTRACT)

Policy analysis of individualized education program (IEP) regulations and their application was done by describing and interpreting IEPs as lived experiences of disabled people. An interpretivist paradigm was employed with research techniques informed by psychoanalytic theory. Five participants used their childhood life stories to critique the IEP policies and practices. The participants performed the roles of co-researchers as well. Through a focused synthesis of their analyses, the identified strengths and weaknesses of the IEP policies and practices were discussed in terms of the appropriateness of education received, the school environment, the cost of education and the empowering of disabled children. Recommendations were made for policymaking, service provision and further research.

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I felt privileged to work with "Brienne", "Caroline", "Olivia", "Pam" and "Tiger". They were exemplary co-researchers. They and friends who helped with the participant search shared my excitement. Two in particular, Dr. Doris Martin and Dr. Loretta Buffer, also gave me invaluable feedback.

I drew my inspiration from my family. My husband, parents, two brothers and in-laws were, once again, there for me. My six-month old daughter, Alisha, probably thinks the computer keyboard sounds are as much a part of the Appalachia as the howling winds are.

I extend my deepest gratitude to all these people. Finally, I dedicate this dissertation to my late godmother, Bibi Williams, who was my guru in the art of thinking with feeling.

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## Chapter I

### Introduction

#### Overview and Purpose of Study

The purpose of this study was to conduct policy analysis of individualized education program (IEP) regulations by describing and interpreting IEPs as lived experiences. An IEP is a program planned and implemented for a child with the intent of providing a free, appropriate education in the least restrictive environment possible. By federal law, IEPs must be provided for all children with disabilities (P.L. 94-142, 1975).

Despite nearly two decades of research, the value of the IEP remains uncertain. An overwhelming majority of school personnel surveyed applauded the IEP in philosophy but were frustrated by its implementation process (Weiner, 1985). Of those interviewed, observed and written about, conspicuously absent were the children themselves. Therefore, this study put them into the picture and, only then, asked whether the IEP actually enhances their learning.

My unit of analysis was the IEP. Traditionally, research has focused on the IEP as a written plan and

the process of constructing and implementing that plan. This study shifts the focus to the IEP as a program experienced in vivo by children. The lived experiences of IEPs were treated as the privileged aspect: It was the lived experiences that were centrally important to reflect upon. Lived experiences are broadly defined as experiences one has lived through (Manen, 1990). An individual's lived experience of IEPs may or may not include the IEP document and planning process. The individual's lived experience of IEPs does include all of school life which that individual perceives as being part of his or her individualized education.

Questions that guided this research were: How are IEP policies and practices experienced in the lives of individuals with disabilities? What are some tacit, often hidden, aspects of school life that these children experience? What are their views about IEP policies and practices in relation to their own educational experiences? These questions served to identify the perspectives of individuals who had IEPs when they were children.

The participants were adults who shared versions of a common predicament--that of being considered



handicapped students when in school. In relation to IEP policies, they were the "practiced upon". An uncommon feature of this research design was the role played by the participants. Brianne, Caroline, Olivia, Pam and Tiger (pseudonyms of their choice) were co-researchers in their own right. By conducting policy analysis through this reconceptualization of the IEP, strengths and weaknesses of the IEP regulations were illuminated from an alternative standpoint--that of the practiced upon.

#### **Background Information**

IEPs were first mandated by P.L. 94-142, the Education for All Handicapped Children Act of 1975. By then, there was a complex set of federal regulations already in place for the educational rights of disabled children. The twin pillars of existing special education laws are that a disabled child must receive a free appropriate education (FAPE) and it must be in the least restrictive environment possible (LRE). P.L. 94-142 defines "a free public education" as an education which is provided at public expense, under public supervision and direction, and at no cost to the student or family. "An appropriate education" is

defined as an education that is tailored to meet the needs of the child through the IEP. The "least restrictive environment" is interpreted as being educated alongside nondisabled peers as far as possible but only when this is in the best interests of the child.

Many of the laws emerged in the 1960's and early 1970's, following on the heels of other human rights movements (Driedger, 1989; Percy, 1989). The laws were passed in quick succession to amend and improve earlier ones. At first the focus was on improving the quality of existing programs and providing more opportunities for handicapped children in state-operated elementary and secondary schools (P.L. 89-10, 1965; P.L. 89-313, 1965). Local schools were included next and efforts became more concerted as national coordinating bodies and resource centers were set up (P.L. 89-750, 1966; P.L. 90-247, 1968; P.L. 91-230, 1970). Procedural safeguards were introduced; the emphasis was on integration into regular classes wherever possible; and there was a push for nondiscriminatory evaluation (P.L. 93-380, 1974).

From this ongoing legislative evolution

crystallized a tangible instrument, the IEP. Regulations outline the content of these IEPs and dictate how often, when and by whom they should be developed (see Appendix A). Historically, public education had been considered a state and local responsibility but Congress extended its influence in this instance in response to advocates (parent groups, in particular) who had worked hard to be a felt presence. Many of them had had extensive experience in dealing with school systems that had denied their children special education services (Gliedman & Roth, 1980; Greenberg, 1986; Newman, 1991; Percy, 1989). Therefore, the IEP was intended to be a policing instrument--a document filed as proof of compliance--used to monitor and enforce P.L. 94-142. It was also hoped that the IEP would foster greater collaboration between parents and schools (Gerry, 1987; Simpson, 1982).

P.L. 94-142 has had several amendments since its passage in 1975. Incentives for preschool special education, early intervention and transition programs were introduced (P.L. 98-199, 1983). Individualized programming was mandated for children from birth with

Individualized Family Service Plans (IFSPs) for 0 to 3 year olds and IEPs for the rest (P.L. 99-457, 1986). Finally, a significant conceptual shift in the perception of handicap replaced "handicapped children" with "individuals with disabilities" in the wording of the legislation itself (P.L. 101-457, 1990). If anything, these developments have added to the significance of the IEP as the cornerstone of federal legislation for educating children with disabilities.

#### Researcher's Stance

My interest in IEPs stems from years of developing and implementing programs for children, disabled and nondisabled, in therapy and in the classroom. I believe effective programs have to be developmentally appropriate for each child. In effect, a program can be developmentally appropriate for every child only with individualized programming. If it sheds its special education cloak and, instead, functions for all children, then I am convinced that the IEP is the key to providing developmentally appropriate programs. To this end, the intricate machinery of the IEP has to be better understood.

I opted to work with disabled people because, of

all the IEP policy stakeholders, disabled people's voices have been the least heard. My own earliest memory of not being heard was in kindergarten. We were to color a diagram of three overlapping circles. Where the blue circle overlapped the red, we were to color purple. Where the red overlapped the yellow, we were to color orange and where the yellow overlapped the blue, green. I saw an alternative: The diagram could be seven independent parts sharing boundaries. I used colors that had nothing to do with neighboring colors. The teacher tried her best to make me correct my work but I refused. If I could see it her way, why could she not see it my way? In that world of worksheets produced by the mainstream adult culture, I learned my first lesson about the social minority experience: Members within the mainstream sometimes have difficulty taking the perspectives of those at the periphery. I am committed to seeking out such perspectives for the insights they have to offer. In doing so, they are credited with the ability to reason (Schon, 1991).

"People with disabilities" is the latest politically correct term to use. I use "disabled people" more often because my co-researchers and my

friends in Disabled People's International preferred to be called "disabled people". We all have disabilities or limitations in what we can do. In contrast, disabled people are disabled by more than their personal limitations. The disabled person is disabled by society's social and physical barriers as well. Therefore, the verb "disabled" has more powerful connotations for advocacy than its noun form "disability".

I operate through an interpretivist paradigm. The main tenets of interpretivism are: facts cannot be separated from values; reality is socially created; and a subjective/objective dualism is an illusion (Ferguson, Ferguson & Taylor, 1992). More about interpretivism is presented in the review of literature (chapter 2). Interpretivism fits comfortably with my definition of myself as a researcher and a person. The paradigm closely resembles the Indian philosophy of life, a celebrated part of my heritage. Both, in turn, lend themselves well to the form of policy analysis used in this study.

Within the interpretivist paradigm, my research strategy was strongly informed by psychoanalytic

theory. This is explained in greater detail in the chapter on methodology (chapter 3). The rationale is that evoking memories of past experiences lifts the person to a higher plane of consciousness from which he or she then operates. It is an approach I have used as a psychotherapist and have experimented with as a researcher. Within this approach, life stories are a powerful medium to work with.

The goals of research are perfectly compatible with the discovery of good stories...We tell our stories to interpret our lives for other people. Upon hearing them, other people interpret our interpretations (Ferguson, Ferguson & Taylor, 1992, p.1-3).

Many, many times I have used close-ended questionnaires with strict instructions for conducting the interviews, collected all the data I had set out to collect and after the session was technically over, found myself listening to lively, vivid stories. Those stories could have been valuable data had the design allowed for it. In my experience, people who volunteer to be respondents are motivated to communicate. To many of them, the invitation to share life stories is irresistible.

I chose to use adults instead of children. Because their school experiences are in the past, I

anticipated that adults would be able to distance themselves sufficiently from their experiences in order to reflect upon them with me.

The science (the theory) and craft (the methodology) of this study could be reported in conventional style. The art--the pace, style and manner of working (Rossi, Wright & Wright, 1978)--was more elusive. In the hope that some of that art may be captured within these pages, I use a prominent narrative voice throughout. Yet, it only hints at the thrill of shared revelations, the pain of reliving carefully tucked away memories, and the deep silences heavy with thought. The rest, I leave to you, the reader, as you interpret "Individualized Education Programs as Lived Experiences", the story I tell with Brianne, Caroline, Olivia, Pam and Tiger.



## Chapter II

### Review of Literature

The literature reviewed was drawn from the fields of special education, disability studies, child development, qualitative inquiry and public policy analysis. It is presented here in two main sections: research on IEPs and the disability experience.

#### Research on IEPs

The majority of early studies reviewed treated the IEP as a document and only later studies included the planning and implementation processes. The first and second sections of this chapter review that literature. The third section views the IEP as law and examines literature that sheds some light on the findings of the previous two sections. The fourth section makes a case for perceiving the IEP as being much more than a written statement or the process of producing it and, instead, researching the IEP as a program that is experienced in vivo by children.

#### The IEP as a Document

Studies on the IEP as a document have concentrated mainly on procedural compliance and the substantive content. One of the earliest was a large survey and

two substudies (Pyecha, Cox, Conaway, DeWitt, Drummond, Hocutt, Jaffe, Kalt, Lane, Pelosi & Weigerink, 1980). Pyecha and his team analyzed IEPs of 2,657 children in public schools, and 550 at state special facilities in 42 states. IEPs were in place for most handicapped children, and most of the IEPs contained the majority of the required elements. The IEPs were, on the average, five pages long. Mandated areas least frequently included were (1) proposed evaluation criteria and (2) a statement of the extent of participation in regular education. Of the subjects in regular schools, the basic survey found that only 1% received all their special education in the regular classroom. The investigation was conducted in the period 1979-1980, the first year of PL 94-142's full implementation for many districts. State and local education agencies (SEAs and LEAs) had made these changes in a remarkably short period of time. Pyecha et al., (1980) concluded that the SEAs and LEAs had invested tremendous efforts towards providing each handicapped child with an IEP.

However, there were many wrinkles to be ironed out over the next few years. In 1981, the U.S. Comptroller

General reported to congress that a review of 456 IEPs from 10 states revealed a lack of compliance with IEP requirements: 78% did not meet PL 94-142's IEP content requirements; a large number lacked evidence that all required participants attended conferences; and deadlines were often missed. SEAs and LEAs reported difficulties attributed to insufficient guidance and vague directives from the Office of Special Education (Comptroller General of the U.S., 1981).

Several other studies resulted in similar findings. Schenck and Levy (1979) analyzed 300 IEPs and corresponding psychoeducational assessments of children with educable mental retardation, emotional disturbances, learning disabilities and so on. They found that a significant number of the IEPs did not meet content requirements of PL 94-142. More important, there was poor linkage between assessed needs and development of objectives. The efficacy of IEP content was, therefore, considered suspect.

Studies that examined the IEP document continued to be popular over the next decade. Smith (1990a) conducted a statistical comparison of 120 IEPs (1) between fourth, fifth and sixth grade male students

with behavioral disorders and those with learning disabilities and of these, (2) between those in resource programs and those in self-contained ones. In addition to examining procedural compliance and substantive content, he also assessed the congruence between students' performance levels and annual goals. He found no clear link between identified student need and program availability. The study also revealed procedural faults in a large number of the IEPs, thereby questioning the role of the IEP as a management tool of special education.

Lynch and Beare (1990) analyzed IEPs of 48 students with mild mental retardation and behavior disorders who were integrated into elementary and secondary schools. The students were observed in their general and special education classrooms. This study, too, found little relationship between written IEPs and actual classroom instruction.

These studies substantiate past research which questioned the validity, reliability and accuracy of the IEP document. Such identified weaknesses in the IEP as a document should be addressed (Lynch & Beare, 1990). Smith (1990a) recommended further investigation

with samples representing students with a wider range of disabilities, and students from different geographical regions. He also identified the need for studies using qualitative research methods because IEP findings resulting from a different methodological paradigm would provide varied and valuable information regarding the IEP document and process.

### The IEP as a Process

Instead of perceiving the IEP purely as a document, studies that focused on the process placed some emphasis on experience, and the meaning of that experience.

Such studies examined, for instance, the dynamics of IEP planning. In a frequently cited study, Goldstein, Strickland, Turnbull and Curry (1980) observed 14 IEP conferences for mainstreamed children with mild learning problems. Typically, all the conferees directed comments to the parents to the exclusion of the others present. The resource teacher, invariably the most dominant speaker, usually reviewed an already developed IEP with parents. Only a third of the conferences were legally constituted (see Appendix A). None had both parents present, the mother was

usually the parent attending. None included the child. The classroom teacher--ultimately responsible for implementing educational strategies--was present at fewer than half of the conferences.

Curiously enough, a follow-up questionnaire to all participants drew an overwhelmingly positive reaction to the conferences regardless of what had happened. Goldstein et al., (1980) identified the need for systematically training parents to fulfill their roles and responsibilities associated with IEP involvement and for training professionals to involve parents as full partners in this significant educational task.

Goldstein and Turnbull (1982) proceeded to investigate the effectiveness of two intervention strategies. Their sample consisted of 45 parents of children with learning disabilities. The parents were randomly assigned to three groups: (1) parents were sent questions with follow-up telephone calls prior to IEP conferences; (2) a school counselor was present as a parent advocate at the conference; and (3) a control group. Once again, IEP conferences were observed. After the conference, parents were also sent a questionnaire to which they responded over the phone a

week later. Only the group with the parent advocate demonstrated a statistically significant difference from the control group. However, the treatment group had a significantly larger number of fathers attending than the control group. Goldstein and Turnbull (1982) concluded that such strategies have the potential to improve parent involvement. They also described the processes observed including what the parent advocate did and the nature of parent involvement. Once again, regardless of the outcomes, all parents reported being satisfied with the conferences.

Related questions are how parents themselves perceive their involvement in IEP planning and what would they like it to be. Lusthaus, Lusthaus, and Gibbs (1981) asked parents this about 9 decision areas directly related to their children's education. Parents responded that the role they played most often was one of information giving and receiving. This was, in general, the role they wished to play, too. However, parents did want control over decisions regarding the kinds of information kept on their children, medical services for their children, and the transfer of their children to other schools.

Lusthaus et al., (1981) speculated about whether parents' desire for decisional control in these three areas may indicate the beginning of a change in the way parents see themselves and their roles. As they participated more in planning for their children and understood the education system better, their desired level of participation may shift to one of making and monitoring decisions in other areas as well.

It appears that, presently, parents and professionals tend to agree about who should be making which educational decisions. This common ground may be useful as a basis for cooperation in planning the IEP (Lusthaus et al., 1981). Others, too, stressed the importance of strengthening the parent-professional partnership (see e.g. Gress & Carroll, 1985; Lynch & Beare, 1990; Simpson, 1982; and Williams & Hartlage, 1988). Some proposed models for such collaboration (e.g. Maher, 1983).

The above studies showed that the IEP has the potential to be more than a lesson plan. It can also be a management tool designed to facilitate the delivery of instructional services (Comptroller General of the U.S., 1981). It provides a central focus that



allows service providers to establish a network for developing collaboration. To this end, Hartwick and Blattenberger (1986) proposed a five-stepped model for inter-agency collaboration involving professionals and parents.

The models detailed by Maher (1983) and Hartwick and Blattenberger (1986) are characteristic of much of the literature offering guidelines for effective practice. The child's involvement is not mentioned. If the IEP is, indeed, a tool that may be used to establish service networks, then, at some stage it should be placed in the hands of the individual for whom it was planned. As adulthood is approached, he or she should be encouraged to take responsibility for orchestrating these networks in order to foster the development of self management skills.

Also neglected in this process conceptualization of the IEP is a focus on development over time. Each child's IEP for a particular year belongs on a continuum that has a life course from its inception (the first IEP) to its termination (the last IEP). We should study the transitions more closely: not only from one IEP to the next but also with changes of

classes, teachers, family members and neighborhoods.

In fact, most of the studies reviewed were, in essence, cross-sectional. An exception was the investigation by Pyecha et al., (1980) described earlier. In one of their two substudies, they evaluated changes from one year to the next in significant aspects of the IEPs. They found an increase in the number of pages, inclusion of more short-term objectives and an improvement in the internal consistency of the IEPs from one year to the next. Their approach was still limited in that it was the document, not the processes, that was examined.

Another limitation of these studies has been the tendency to focus on individual factors. The resulting explanations or analyses will fail to unearth the complex and wide-ranging nature of issues involved (Barton, 1988; Madge & Fassam, 1982). Therefore, existing research should be complemented with studies that seek to give a more global portrayal of the problem.

### The IEP as Law

These gaps in the literature may be partly attributed to a preoccupation with the legislative

aspects of the IEP. This is not altogether surprising when we consider how precise the IEP policies are (see Appendix B). Schools have to comply with relevant regulations from several laws. At the federal level, elaborate sets of regulations exist for the education of children with disabilities (National Information Center for Children and Youth with Disabilities, 1991).

Studies on the planning and implementation of IEPs suggest that it was the regulations' mechanistic assumptions and bureaucracy that often constrained effective planning and implementation (Smith, 1990b; Weiner, 1985). Many teachers have found the IEP process too time consuming and cited insufficient support from school personnel to meet the regulations (Fiscus & Mandell, 1983; Greenberg, 1986; Hartwick & Blottenberger, 1986).

Since federal education funding for states is partly dependent on providing IEPs for all handicapped children, there is pressure to comply. When effort is concentrated on satisfying numerous regulations, an IEP will be considered adequate if it reflects minimal compliance. It may, however, be deficient in important qualitative aspects. Research findings clearly show

this inclination toward minimal compliance rather than exemplary practice (Lynch & Beare, 1990; Smith, 1990a; Smith, 1990b). The degree of compliance is often used to evaluate the effectiveness of enforcing new policies (Majchrzak, 1984). However, compliance with IEP regulations does not in itself guarantee the provision of an appropriate education in the least restrictive environment.

Furthermore, research variables tend to be a direct outcome of P.L. 94-142. Parent involvement is a case in point. Since parent-professional collaboration was productive in effecting changes in schooling for handicapped children, it seemed a logical development that legislative mandates required the parent-professional relationship be extended to collaborative development of IEPs (Gliedman & Roth, 1980; Gress & Carroll, 1985). Yet, implementing the regulation has caused both parents and professionals concern (Lusthaus et al., 1981). Consequently, the focus of much research has been on parent-professional partnerships and parent involvement.

In contrast, the child's involvement is optional. It is not surprising, then, that the IEP studies I

reviewed were not concerned with the child's role. With minimal compliance sapping the energy of the school systems, there has been little left for what is not required by law. Consequently, potentially innovative ideas such as child-professional or child-parent-teacher partnerships seem to have been left on the back shelf, unexplored.

There is also the assumption that a well planned and properly implemented IEP will ensure an appropriate education for that child. In reality, we are still in the dark about the significance of IEP conferencing and the IEP document itself for the quality of education provided. When teachers were questioned, many felt they could teach as effectively without the use of IEPs (Hartwick & Blottenberger 1986).

Finally, these studies discuss legal mandates. However, society has unofficial rules as well--social customs, informal norms of each classroom and each family, moral rules and principles, rules of each school administration--and these unofficial rules often impact children's lives as much as the official rules do. Unofficial rules influence the way laws are interpreted and enforced: policy analysis is deficient

if it does not account for the way the formal and informal rules interact (Stone, 1988). Therefore, we need studies that attempt to observe these and other dynamics that are part of the process of planning and implementing IEPs.

### The IEP as a Lived Experience

To further research in ways that will fill gaps identified above, the IEP should be conceptualized as more than a document or a set of regulations. The IEP should not be limited to a series of processes moving toward the planning and implementation of that document and, by doing so, meeting legal requirements. Instead, the IEP should be perceived as a lived experience of the children for whom it exists.

Despite the abundance of literature on the IEP, we have yet to identify the variables considered relevant by disabled individuals themselves. The IEP document is, after all, only a lesson plan cum report card for that child. It does not necessarily tell us how appropriate the educational experience was for that child. Such decisions are the prerogative of the individual who has lived through the experience.

Research on educational inequality traditionally

defined the inequality in terms of the amount of resources that were put into the educational system and ignored the unequal effects of the resources on the children (Majchrzak, 1984). To determine the extent to which a policy actually works for a child, attention and focus needs to be shifted from resource input onto outcomes. In the final analysis, it should be the primary consumer who should evaluate that outcome.

Marshall and Rossman (1989) recommended that a qualitative research design should have built into it an openness to unexpected, new findings and should be flexible enough to foster the exploration of nuances of meaning in complex, tacit processes. I turned to the literature on the disability experience for insights on such designs.

### The Disability Experience

Leaving out the disabled individual's experience and perspective has not been unique to IEP research. Most of what professionals know about living with disability has been a product of research done from perspectives outside this experience - research by able-bodied experts who give priority to their scientific theories and research techniques rather than

to the words and perceptions of the people they study (Driedger, 1989; Madge & Fassam, 1982; Schneider, 1988). The most common outsider perspectives have been medical--clinical and therapeutic--viewpoints (Barton, 1988; Schneider, 1988).

Although presently the dominant one, the medical model is but one way to understand disability. Alternative perspectives are becoming more acceptable. The human rights perspective is an alternative preferred by disabled people (Driedger, 1989). From a human rights slant, P.L. 94-142 takes on a different meaning. To Asch (1989), its best results were not the integration of the disabled with the nondisabled community, but rather, the fostering of appreciation of disabled people for one another. The law tells them that they are not required to be segregated: they are able to come together by choice, when they want to, not because they must (Asch, 1989).

The human rights perspective is in many ways compatible with the interpretivist paradigm of research. Interpretivism allows the participant's perspective to unfold more as the participant views it and less as the researcher views it (Marshall &



Rossman, 1989). Over the last few years, a new awareness of and tolerance for interpretivist research seems evident in special education (Ferguson, Ferguson & Taylor, 1992; Stainback & Stainback, 1984).

One of the central tenets of the interpretivist paradigm is that reality is a social construction (Ferguson, Ferguson & Taylor, 1992). From my review of studies on IEPs, it is evident that the dominant social construction of individualized education for handicapped children has been that of the practitioners (teachers, in particular) and not that of the practiced upon. I suspect that it was not that the practiced upon did not have their interpretations and social constructions. It was just that no one asked them to tell their stories.

Interpretivism places an unavoidable focus on discovering the multiple perspectives of all the players within a social setting. It allows the emergence of perspectives that have received less attention in policy analyses. Certainly, people with disabilities have historically belonged to those groups of devalued people without opportunity to say much about what was done to and for them by more powerful

groups within society (Ferguson, Ferguson & Taylor, 1992). Unfortunately, we know little about how disabled people of yesterday or today feel about their school experience on the whole (Asch, 1989; Madge & Fassam, 1982).

There is a lack of social science research that reports, in people's own words, any routine experiences of living with a disability (Ferguson, Ferguson & Taylor, 1992; Schneider, 1988). One of the few was by Madge and Fassam (1982). They interviewed disabled and nondisabled children about the meaning of disability, home and school experiences and hopes for the future. To facilitate projection of feelings and views, 6 hypothetical pictures were also used. They drew four general but very clear conclusions: (1) valuable information on attitudes, experiences and needs of most physically disabled children could be gained by asking the children direct questions; (2) although the children would clearly have preferred to be nondisabled, they were realistic about their condition; (3) there is no such thing as a "typical disabled child"; and (4) the disabled and nondisabled children were not really all that different. While these are

conclusions that many of us have tacit knowledge of, it is significant that this study verifies and documents what would otherwise remain as intuitive hypotheses.

Madge and Fassam cautioned that their findings were based on comments made by the children at a single point in time. Life histories and case studies do more justice in this respect. For example, Olson's (1986) case studies of two women were derived from 25 hours of in-depth interviews. Both had mental retardation and cerebral palsy and both experienced special education classes throughout their educational careers. The major difference between them was that one went to school before PL 94-142 and the other started in the year it was implemented. Both felt that school did not prepare them for the real world and shared that they were still struggling to adjust to working life. Although this account was only a preliminary one of an on-going study, it offered insights that can be used to evaluate the educational services provided for handicapped children.

There is a much larger collection of autobiographies than of research studies (e.g. Zola, 1982a). Such a body of knowledge about the disability

experience is valuable in its own right. Personal accounts are compelling and powerful because they are real. If they were to be directed by systematic inquiry, questions and issues that have emerged from current policies and practices could be addressed. Thus, systematic inquiry that retains the authenticity of personal accounts can stimulate and challenge policymakers and educators to think in new ways about old problems.

Disabled Peoples' International (DPI) advocates for disabled people being their own best spokespersons and judges of their own needs and concerns (Driedger, 1989). Yet, the disabled person is rarely considered the best consultant for disability research. Zola (1982b) pointed out that although having a disability did not automatically qualify one as an expert witness or writer, those who have lived with a disability were often in a better position to write about what it was like. Being disabled can have its advantages for a disability researcher: Asch (1989) observed that being blind herself was helpful because "my own experience shapes my reflections on what I have heard about the social lives of disabled young people today" (p.195).

Therefore, to explore the disability experience to the fullest, more disabled people have to be involved as researchers.

### Summary

The review of research on IEPs pointed to a focus on either the IEP as a document or a process of planning and implementing the plan. The research outcomes overwhelmingly identified more weaknesses than strengths in the current policies and practices of the IEP. Instead of aiming for exemplary practice, minimal compliance with the law seems satisfactory in many situations. The research has almost totally excluded the disabled child's experiences, has tended to focus on individual factors at single points in time, and has been predominantly influenced by the deficit model.

Research on IEP content and procedural compliance has reached a point of diminishing returns. What we need at this stage is a shift in focus--a revisitation of the IEP dilemma but with the spotlight on the children themselves. To this end, literature about the disability experience revealed the value of researching lived experience with disabled people as researchers using a human rights perspective within an

interpretivist paradigm.

This review gave me insights that were instrumental to decision-making about the design and substantive focus of this study. As the third chapter will bear out, each observation made in this chapter was taken into account.

## Chapter III

### Methodology

#### Design

This study operated from an interpretivist paradigm. The project was done in two phases. In the first phase, life stories were collected through retrospection. The data were used in the second phase when each participant critiqued the IEP policies and practices.

The rationale for this research strategy was informed by psychoanalytic theory. Following Spence (1982), the reconstruction of memories was treated as an aesthetic experience (as opposed to being an exercise of determining historical truth). Aesthetic experiences have a strong emotional component as the individual relives feelings evoked by the memories. The aesthetic experience also has a powerful conceptual component as images from the past are visualized in the mind's eye. The feelings and images that are part of this aesthetic experience define the analytic space created in the mind in preparation for the interpretation of experience. In my study, Phase 1 provided the aesthetic experience that prepared the

participants and myself for Phase 2.

### Participants

The important qualifiers for participation were that the person must (1) have had IEPs when in school, (2) be between 21 and 25 years old and (3) anticipate being able to work with me. The age range included people who were old enough to be above the age of having IEPs developed for them and young enough to have had the IEP regulations in effect when they were in school.

### Activating the Grapevine

An invitation to participate was made through a circular (Appendix B). Copies were distributed to potential subjects through agencies that provide services to young adults with disabilities. Attached to every circular were stamped, pre-addressed postcards so that interested individuals could reply. Only five postcards were returned and none of the senders met the criteria.

Speaking informally to people yielded better results. I talked to rehabilitation service providers, mail deliverers, pastors, my drycleaner, librarians and others who knew the community through their work. As a



result, several potential participants contacted me.

### Selection Process

I explained the significance and nature of the study to potential participants over the telephone. If the individual was interested and met the criteria, we had to decide whether we would make a compatible research team. That was an intuitive process and I felt I had to meet each person for it. During the meeting, I reviewed the purpose of the study, exactly how it would be conducted and why. Expectations in terms of time and effort were stressed. Before committing themselves, I wanted them to be aware of my expectations of them. I hoped this would reduce the chances of attrition.

As it turned out, everyone who was willing to meet me for that initial encounter was also suitable and highly motivated to participate.

Brianne (a participant): People think of disabled people as fragile little people sitting at home doing nothing. I feel privileged to be able to do something that'll show people that that's not true.

I had originally planned to have six participants. The first five (Brianne, Caroline, Olivia, Pam and Tiger) participated to completion. Meanwhile, one

after the other, four individuals started as the sixth participant and then discontinued. One moved out of state. Two said they could not spare the time: one got married, the other bought a house that needed intensive repairs and also had a baby. The fourth was too upset because he lost his job. At that stage, using five participants was considered sufficient because a great deal of data was collected and potential referral sources were exhausted.

#### Profile of Participants

All five participants grew up and attended public schools in the state of Virginia. Brianne was blind. Caroline had spina bifida and a learning disability. Olivia had dyslexia. Pam was born with missing hip joints. Tiger had cerebral palsy. He was the only male. More details are presented in the introductions to their lived experiences (see chapter 4).

When we first made contact, none of them knew about IEP regulations. Only Tiger and Brianne were certain that they had had IEPs. Caroline did not know what an IEP was and said, "If it's a test, I've had it." She and the other two made inquiries to confirm they had had IEPs before we started.

I make no assumptions that these five individuals were in any way "typical" of people who had IEPs planned and implemented for them. None of their lives or views should be generalized as being representative of others who are similarly disabled.

### Nature of Participation

The participants performed two roles. They were the primary informants and my co-researchers.

Pam: Being a co-researcher allows me to tell you exactly how I feel about certain things that we've talked about. As subjects, I think the persons being interviewed are sort of left out of the whole thing. They read it, they may not like it and if they're just the subjects, you can choose whether to take it out. Whereas, as the co-researcher, I can say 'I want this out' and it will be taken out.

The involvement was fairly intensive. I met each participant individually. Caroline had 4 sessions. Olivia had 5. Tiger and Brianne had 6 sessions each. Pam had 10. All of them had assignments between sessions. Sessions lasted about an hour each.

### Data Collection and Analysis

Brianne, Olivia and Tiger chose to have the sessions in their homes. Caroline had her first session at a fast food restaurant and Pam had her first three in one of her college meeting rooms. Then both

women decided their homes would be more convenient.

All sessions were audiotaped and transcribed.

### Phase 1: Compilation of Life Stories

This phase consisted of two to three sessions per participant. Each person was asked to tell me 'anything and everything' he or she could remember about childhood and school: to share specific incidents; to include feelings, moods, and thoughts that were part of the experiences; and to recount memories linked to IEPs in particular.

Caroline: It makes the co-researcher think way back and it brings out lots of hurtful things that set off more memories. It asks for details. You're a person and so, to talk to you makes me remember so much. It's like a snowball. When we first started, I didn't remember half the stuff I'm remembering today.

I chose to have more than one session of retrospection and at least a week apart from each other. Providing enough incubation time between sessions allows our minds to reconstruct memories and dwell on ideas so that richer questions might evolve (Marshall & Rossman, 1989).

Pam: If you do the life stories in one day, you're missing out on a lot of people's true lives because people are going to give you the overwhelming, dramatic parts first. They're not really going to delve into their souls and think about what their lives have been like. The way we

did it allowed me the chance to look back at my life and take things apart.

The invitation to share life stories was compelling. A great deal was recalled within those sessions. The stories told were slices of the teller's reality but constructed didactically within the social sphere that both teller and I shared for that moment. The telling of the stories was as important as the stories themselves "for it is in 'the telling' that both a speaker and an audience are implicitly included, and that is where interpretation comes in" (Ferguson, Ferguson & Taylor, 1992).

I stressed that, at this stage, the participants did not have to worry about mentally censoring what they wanted to share because they would be able to edit their own scripts. I tried to ask questions that would help to explore the whole experience to the fullest. For instance, there were times when I asked for concrete details about place, time, and sequence of events so that I could follow the rendition more clearly.

I also asked them to use the time between sessions to research on their own any aspects of their past that they wished to find out more about. They were

encouraged to talk to parents, siblings, former teachers and so on. They could use resources such as their own IEPs, diaries, photographs, letters and any other material to illustrate and/or substantiate the narrative. Tiger gave me copies of his IEPs and a letter his mother had sent each new teacher. The other four participants chose not to use their IEP reports. Pam used her high school year book. Olivia and I looked through a folio of all the art she had done over the years. Caroline showed me photographs of the important people in her childhood.

#### Editing of Material

The tape of each session was transcribed verbatim. I extracted the participants words. From them, I deleted repetition (unless it was deliberately done to stress a point) and false starts where the participant started to phrase thoughts in one way, stopped and rephrased them in another. The language was left unedited. When parts of the same incident were recollected at different sessions, they were knit together to make the account more cohesive. First priority was given to how the participant framed and structured memories. It was like putting together a

complex jigsaw puzzle but with many pieces missing.

Before each session, the participant was sent the draft transcription of the previous session. All drafts were printed with six inch right margins to be used as working space. Using different colors on our respective drafts, the participant and I highlighted parts we thought should be deleted. We wrote questions and comments in the wide margins. When we met for sessions, we compared notes and, thus, decided on the editing of the drafts. Because of her visual handicap, Brianne and I worked in the same way but with a disk that we passed back and forth. She used the disk on her voice-synthesized computer.

Finally, all the material from the two or three sessions of Phase 1 was combined and re-arranged in a loose chronology for each participant. The resulting script was used with that participant at the start of Phase 2.

### Phase 2: Collaborative Analysis

A week before the start of this phase, the participant was sent a copy of the script that resulted from combining and editing drafts from all his or her Phase 1 sessions. At the first Phase 2 session, I

also gave the participant a copy of the IEP regulations (Appendix A). This first session was used to plan how we wanted to proceed. Pam said she would like to try not being taped and that both of us could write down what we discussed. We tried this for one session and both agreed that audiotaping was much easier than not. The other five preferred to continue the audiotaping of sessions.

I asked the participants to review the IEP policies in relation to their life stories. I suggested that they step out of themselves and reflect on their memories by consciously allowing their new knowledge of IEP policies to color their thinking.

Caroline: When you think about experience first and talk about the laws after that, you can give good points about the laws. Just talking brings it out. Thinking about my life stories and then reading the laws means I switch back to my life and use that. It makes me really think of my own opinions.

We worked our way through the regulations and constantly referred to the script of life stories, using the working space to make notes. Once again, after each session, the tapes were transcribed verbatim and a copy was sent to the participant for editing. In this way, we edited successive drafts of the Phase 2



script. Interpretations were revised and statements reformulated. The process of writing and rewriting actually served as a methodological device. It facilitated a recycling of concepts and perspectives.

Participants demonstrated both insight and analytical capacity but to varying degrees and with differing styles. Each brought his or her perspective to the exercise. I brought mine. Although the primary focus was on using her views and interpretations, there was the interactional effect of our frames of reference. Our collaborative analyses were influenced by that interaction.

#### Presentation of Findings

Phases 1 and 2 were not distinct units: Material from Phase 1 was acted upon--and, consequently, transformed--through the procedure of Phase 2. Thus, the outcome for each participant is in the form of a single script. Each is presented as an intact section in chapter 4 so that you may appreciate the views and opinions of Brianne, Caroline, Olivia, Pam, and Tiger within the context of what they have experienced.

Strauss (1987) warned against overloading the report with too much descriptive material included just

because it was colorful or interesting to read. We tried to select only illustrative data that were directly pertinent to the study.

### Focused Synthesis

While the intra-case analyses were proceeding, I continued reading literature on IEPs and special education issues. My search was guided by the foci of the participants. Following Majchrzak (1984), I did a focused synthesis by reviewing, reflecting upon and integrating the literature, my past experience and the intra-case analyses. The discussion in Chapter 5 presents that focused synthesis. It is prescriptive because "research that only attempts to describe our present arrangements, not to challenge them, may serve to maintain the inequities (Higgins, 1992, p.121).

### Soundness of Design

Respondent validation on an ongoing basis is inherent in the procedure of the study itself. It is of no great concern whether a certain experience actually happened in exactly that way because we are more concerned with the plausibility of an account than with its factual accuracy.

Likewise, expressing the fundamental or overall

meaning of a text is a judgement call: Different researchers may discern different fundamental meaning. That does not make one interpretation necessarily more true than another (Manen, 1990).

"... our social investigations cannot be aimed at capturing absolute truth. There are too many competing visions for that. Instead, they must be aimed at developing understandings that help us for the moment transcend the present competing perspectives and practices" (Higgins, 1992, p.121).

### Ethical Considerations

Permission to use human subjects was sought and granted prior to the start of the study. Each participant was asked to grant informed consent by signing the form in Appendix C. All participants were ensured anonymity. If requested, disclosed information was kept confidential.

Reciprocity was not as easily achieved: I asked them to suggest ways in which I could reciprocate for giving of themselves. None did and so, I reciprocated by contributing to the disability movement: I volunteered technical assistance at the Center for the Independence of the Disabled for three months. The participants appreciated that.

Brianne: Volunteering your time to help other disabled people is a great way to show me that you

appreciate what I'm doing with you. It makes me feel good because, actually, those people are benefitting from what I'm doing.

A final consideration was the care and maintenance of myself as the research instrument. When scheduling sessions, I tried to consider my own energy level and wellness as much as those of the participants. As for my emotional health, I maintained a log and reflected on my writings from time to time. Transcribing the tapes also helped. When with a participant, I was so engrossed in the moment that my feelings were put on hold. In contrast, the monotony of transcribing the dialogues gave me the time and space to work through my emotional reactions to them.

#### Limitations of Study

The focus of the study was very broad. Any of the more specific IEP components--the meetings, the document, due process procedures, classroom practices--could have received more in-depth treatment if the study had limited its focus to one of them. However, being the first study of its kind, I felt it was more important at this stage to discover what variables would emerge for further in-depth study.

A second limitation was the amount of time per

participant that the design called for. To conduct exemplary research, researchers must devote large amounts of time so that they are able to stay with the phenomenon until it is understood (Frost & Stablein, 1992). The potential for reflection on their scripts had not been exhausted when we stopped. The collaborative analysis could have gone on for much longer than was practical and, therefore, I sought closure when the primary purpose of the study was met.

Thirdly, the lived experiences are dated. IEP regulations have not been changed since the period when these participants were in school. However, regulations about individualized programming have. Today, individualized programming in the form of IFSPs is mandated for disabled children from birth or the time of disability detection. Policy analysis of IEP regulations should be supplemented with perspectives of people who have had both IEPs and IFSPs.

## Chapter IV

### Results

Presented in this chapter are the scripts that emerged out of the process described in the previous chapter. Each is a piece of policy analysis of individualized education programs as lived experiences. The sessions were conducted over a 14 month period from 1991 to 1992.

#### Introduction to Brianne

When I first met Brianne, she had recently returned from a training program with her newly acquired Seeing Eye dog. Soon after, Brianne began her internship as a medical transcriptionist. The internship turned into a full-time job. Because of her blindness, she used a speech synchronized computer at work. Brianne lived with her parents and sister in a small town and commuted to work in a nearby city with Mindy, her best friend.

#### Brianne's Lived Experience

When I was in first grade, on the first day of school, the teacher made everyone get around the edges of the room in a line. She counted till three and at three, everyone had to find a seat and that's where

they would sit for the rest of the year. That's fine if you can see where you're going. I just stood there because I couldn't see any seat or see where to go. The insensitivity: It's that sort of thing that is really hard. She should have taken me aside and said, "Well, you sit here". She could've just given me a seat.

Kindergarten through my first year in third grade were miserable, miserable years and I don't even know how I survived. I really don't. I didn't have any friends. The teachers were insensitive. They didn't help me. Those first four years were really bad for me.

Just little things like trying to find a place to eat. In kindergarten, we were learning colors and shapes. We got our lunch trays and the teacher went down the roll book and assigned all the students like, "You go to the blue table with the blue circle shapes in the middle and you go to the one with the orange square and you go to the one with the yellow rectangle." I went to each table and I tried to find out what it was. No one helped me.

Recess was a horrible time. I can remember

sitting on the sidewalk while everyone else played. The teachers were too busy talking and the students didn't really want to have anything to do with me. Some of the students were cruel. Sometimes they would pick on me. That really hurt.

My mom is definitely my support from the family. She's really great. My sister was born when I was 5. I couldn't wait because I've always loved babies and my mom being the person she was, she let me take care of her and let me feed her and hold her. It was really nice to have someone to play with because at that time all I had was my mom. Now she's 16 and she's absorbed in her make up, hair and clothes although I know if someone made an unfair remark about me, she would take up for me.

Mr. Halm, the vision teacher I had from kindergarten through third grade wasn't worth nothing....nothing. When I was in third grade the first year, he had these little picture cards for me to play with. It was like a memory game where you turn them face-down. Then you turn up one and try to find its match. I couldn't see the pictures. No one would tell me whether I got it right or wrong. The teacher



was there teaching the class. They had cursive writing. They had multiplication tables. All this stuff and I'm sitting here in the corner just totally alone...absolutely alone. I could listen and try to absorb it but there would be no explanations. I wasn't learning anything. No one bothered. I had to do my cards.

Mr. Halm's idea of teaching me was taking me to the cafeteria and sitting there at one of those long, hard benches for four hours and just saying, "Two plus two is four, four plus four is eight." I didn't even know what the numbers looked like.

I was in third grade twice because the first year they decided that they were going to send me to a residential school for the blind. I was there only a week and decided that wasn't for me. I did not like it down there. It was too strict about certain things that didn't make a difference. Like eating - you had to eat everything on your plate.

If you need something, it's in braille or on cassette or in big print. The teachers were great. You know, it's stepping into a world that is just for people who are blind. The campus is perfect: All

right angles and with little posts that you can hit with your cane so that you know where you are. It's got braille on the drink machines. It's got braille on the snack machines. The room numbers, they're in braille. There's nothing confusing about it. Someone comes to your table and announces what you're having for dinner. It's just really great and it would be nice if the rest of the world were like that. It just isn't. The real world isn't designed for blind people. We have to fit in wherever we can. I'm really glad that I didn't stay in that school. It would've been easier, I know. As long as I was there, it would've been fine.

I'm just really glad I came back to public school. Public school was definitely a challenge. There are so many things you've got to work through. It just made me feel normal--I hate to use the word "normal" because there's nothing wrong with me. In public school I got to prove to myself that I could do it. I graduated from high school with a 3.98 and college with a 4.0.

When I came back to public school for the second year of third grade, I got a new vision teacher, Cate. She was the person who saved me.

She got me a C.C.T.V (a close circuit television). It magnifies print really big. I could see well enough to use it. We had to catch up on a lot of things. I can remember her taking my fingers and showing me what an inch was. One day, we went outside and instead of doing academic things, we practiced kicking a ball so that I could play kickball with the others.

She got me an aide who came three days a week. She was integrated right into the classroom. She copied words down for me off the board. She pretty much acted like the readers now. We would go over multiplication tables. If we had to read a story and then were going to discuss it in an hour, she would read it to me. She would just be a part of the classroom and she would have a chair that was right beside mine. She would read tests to me. Basically she would help me do really simple little things that you wouldn't think of, like turning to the right page and setting up the book under my C.C.T.V. and that would save me time. At spelling tests, I would tell her how to spell it and she would write it down for me. And I had an aide in fourth grade who did the same thing. My school life really turned around and so it

was really wonderful.

I was in the regular classroom but my desk was always put in an out-of-the-way place at the very back, in a corner. I preferred it that way. One year it was at the front of the room. I felt like I was on display and people were watching me because I was doing things differently. Then, when I got the aides, of course, it was more convenient in the back of the room where our talking, or shuffling around, wouldn't disturb other people.

It was like wasting four years of life before Cate came. I should've been able to use that C.C.T.V. all that time. It had been there all along. And tutors had been there all along. Things like that had been there all along and I just sat there with my little cards with pictures I couldn't even see.

So, Cate really turned my life around. It was at that point when I started to feel like a person. I started actually being part of the group. I did homework like everyone else because she got me a C.C.T.V. for home. I actually made a friend that year. That was an accomplishment. When we went outside, I had someone to play with.

A lot of it was just the type of people I was with because when they held me back that year, it was a totally new set of people. They were always willing to help. I made friends and it was incredible to have someone who wanted to walk with me through the lunch line to help me get my lunch. It was astounding. And there was always someone willing to tell me what was for lunch and willing to dump my tray for me or walk to class with me or anything like that.

It sounds awful but the people I was with before just didn't want anything to do with me because I was different than they were. If the teacher said, "Brienne is going to play kickball and I want so and so to run with her", they would do it because they were told to but that would be it. Then they got ahead of me when I got held back a year. I was always glad that I wasn't in that class any more.

So when I came back to third grade the second time, it was a combination of having Cate and then these great classmates. I'm really glad that it worked out the way it did. Really, really glad.

Things really picked up for me after then. I met my best friend, Mindy, in sixth grade. We're still

best friends. She was in the same college program as me and now works with me. And she's one of the most important people in my life.

I remember once when I was in 5th grade, someone accused the teacher of grading me differently because I couldn't see as well. The teacher said, "This is not true. I graded her the same as everyone else". Because I got A's, they thought, "How could she get such good grades? She's different from us. I got a B and she got an A and she can't even see."

I was not graded differently. I worked twice as hard as some of those people did for my grades and I can remember coming home at 4:00 and spending till 10:30 at night in front of the C.C.T.V.. My neck hurt. My eyes would ache and there was nothing I could do for them. A sighted person would've probably taken a couple of hours because obviously they're going to be a lot faster than someone having to use the C.C.T.V.

I didn't like gym. From sixth grade till eleventh grade we had gym every year. Everything they did I couldn't do. And that was just like sitting on the bleachers or the ground for 50 minutes every day.

It was team sort of things: Stuff that I can't do

now and I'll never be able to do...period. I mean, I can't play volleyball and I never will. It just made me jealous of all the other sighted students who could do all those things. I really think that if I could see I would enjoy tennis and basketball and stuff like that. But just sitting there watching people doing what I couldn't do, not being able to see what was going on, waiting for someone to say, "Okay, I'm going to walk you to lunch now". It was really hard for me.

Well, actually, in tenth grade, the gym teacher did try to get me to participate. They had a tennis unit and she rigged up this thing. It had a string with the ball at the end and it's taped to it and you hit it and it bounces back. I felt like a fool doing that. I think I'd rather have stood by the sidelines. I had to hit the ball and then I had to find the string and trace it back to find the ball and hit it again.

I was standing there doing this and one girl, without watching what I was doing, hit me on the forehead with her tennis racket. I had 10 stitches from that. It was really quite disgusting with blood everywhere. After that, I got to sit back down. So that teacher didn't do anything with me any more but I

have to admit she did try.

And believe it or not, they made me take driver's ed for two months before they let me out of that class.

Geometry was one of my biggest challenges. I spent many hours after school with that geometry teacher. She would take the magic markers and draw things big and color them in so that I can see the stuff. She was great. I've got to give some of the other teachers credit, too, because some of them were really wonderful. They just went out of their way to make sure that I felt a part of the class and would do anything that would help me.

The whole time I was at school, the guidance counselor would work with Cate and they would make a schedule and she would say, "She needs a teacher who's going to be understanding." And when I was in 9th grade, they still had the meetings to make sure I got good teachers but let me go around and meet all the teachers even before I went to school that year. They worked together. Sometimes what they thought was good wasn't my idea of good but for the most part they were really good.

In my junior year, I took office technology. The



teacher really did not want me in that class. Her argument was that she had never had a blind student before and she didn't know what to do. She just really was not receptive.

At 6 weeks, we had to do the cut and paste thing. I just can't do that. There's no way. There are some things that I can't do and obviously that was one of them. I did everything else that 6 weeks and I had an A average and she tried to give me a B because I didn't do the cut and paste. It's not fair for her to give me a B because I cannot do it. I talked to Cate and to the high school guidance counselor. They talked to her and she ended up giving me an A but she really didn't want to.

We had IEP meetings but I didn't know what they were called then. At each meeting, we had Cate, me and my mom, the head of the Virginia Department for the Visually Handicapped, my rehab counselor from that department, and my guidance counselor. When I had a single teacher (like 3rd. and 4th. grades) that teacher would be there. Cate was definitely in charge.

These meetings were different every year. I remember you've got all these people talking about you.

And you're sitting there and you feel really small. Because, well, you're younger than they are and, in a way, they've got your future in their hands and they're talking about you. Then after they've discussed everything that they want to do to you, and do for you, and do with you, then they turn around to you and say, "Is that okay?" And you're like, "Woe" because you've got ten billion things they want to do to you and you can't even remember what the first one was.

It was okay. It was okay because my experience was that I had this group of people who cared about me. Every one who was ever at any of these meetings cared about me and what happened to me. So it was nice and I was glad because it was a way to get into focus. Usually, they had it at the end of the year and a lot of talk was in retrospect about grades, what was going to happen next year, and what classes I should take.

We would talk about equipment that I might need for the next year. For my junior year, I needed a computer with a speech synthesizer. So that was discussed in great detail at my sophomore year meeting. Everybody was there for me but everybody represented a different department. Cate would say, "She needs a

speech package to go with the computer." Then you've got my rehab counselor would say, "Okay, she qualifies. I approve of getting this." And then the state department head would say, "I need to check to see if the funds are there." So it's like a process.

Everyone knew exactly what was going on when we come to this meeting. I would relay all this to my mom and so we would all get together and every body was finally in the same room. It was at the meetings that everything got carved into stone. It's like a finalizing thing. My mother pretty much just listened and then they'd ask her, "Is that okay with you?" It was very casual. We always laughed and joked around the table. It was really laid back, really informal.

It could have happened without me or my mother and the same thing would've been accomplished. So it's not like I was ever a big player or mom was ever a big player but I was glad I was there. I didn't have to do anything that they suggested. I had to be there and plan my schedule. I had to be there because it was about me. They needed my input and my okay on things. But it could've happened without me as far as what I did actually input. The key players would be Cate, my

rehab counselor, the state department head, and the guidance counselor. Those were the key players because they knew what they could do and couldn't do for me. I just knew what I wanted. They knew what was realistic and what wasn't.

I never realized till now that it was lawfully required that we meet every year. I just thought that it was something nice that they put together to give me some sort of direction to work towards for the next year.

I am really impressed with the details that they went into in the IEP regulations...like the fact that they have to keep records of getting in contact with the parents if they don't come and that the home visits and phone calls had to be documented. They are pretty thorough in what they say.

I was surprised that there was that much about IEP policies. I learned a few things I wasn't aware of before. I guess I didn't think about it but I never realized it applied for all handicapped people. If only there was a way you could make sure that every one who deserved an IEP had one. I have never known anyone else who would have to have an IEP. So I would assume

that everyone would get what they were supposed to get under the federal law. If they don't, I think that's really sad. Those were the two big discoveries for me: That it was for people with other types of disabilities, too, and that it was a law that you had to have IEPs.

The IEP meeting is more than a meeting that just gets you out of class. They are really so important in shaping your future. It was at one of those meetings that I decided that I was going to go to college and that I was going to be a medical transcriptionist.

I don't remember any with Mr.Halm. If he had been there, I know that I would not be a medical transcriptionist. I would not have ever gone to college. I'd probably still be playing that game with cards I couldn't even see.

If it hadn't been for my mom and Cate and some really great teachers, I don't think I could have made it through school. When I had a bad day, my mom was here to help me. She would read to me when I didn't have my books on tapes. She would read those god-awful long chapters and she was tired, she didn't feel like it but she would do it for me. We would do spelling

words together and definitions if I had definition tests. My dad, he's a different story. He likes to drink too much. He's really nice but I don't think he'd understand.

Anything that I ever wanted started with just Cate and me. I've always, always wanted to be a doctor and if I had vision, there is no doubt in my mind that I would be somewhere like Harvard in medical school because that's what I've always wanted to be. Obviously, I don't think anyone's going to want me to do open-heart surgery on them. The only other choice for a visually impaired person in the medical field is something like a psychologist or psychiatrist and that didn't interest me.

In tenth grade, Cate and I were trying to get things together. You really need to have a jump start on it especially if you're visually impaired. She knew I was interested in the medical field. She said, "Have you ever thought about being a medical transcriptionist?" I didn't know because I didn't even know what it was. So she explained.

Well, that put Cate above the rest as far as I'm concerned. Mr.Halm's the only other one I've had to

compare her to. But there was no way that anyone could be any better because her job did not end when she left me. She would call up and say, "Hey, look, I found out that there are three blind people who are medical transcriptionists right now. Do you want to set up an interview?" This could be at 8:00 o'clock at night. She cared enough to do her homework.

It really sounded good because I have good English, typing and spelling skills. We set up an interview with the head of a hospital's transcriptionist department to find out if it would be realistic for a blind person to get a job. We had the interview in my junior year. That's what I decided I was going to be.

Then it went to the guidance counselor: "Are there any classes she could take that could help her?" Next, it went to the rehab counselor: "What can the vocational rehab department do for her after she graduates?" And then it included the state department head: "What will the state do for her?" And then it all came together at the IEP meeting.

The IEPs never got read to me. There was really no point. The IEPs were just pieces of paper that I had

to sign. They did not mean anything to me. The meetings did. They gave me perspective. Every one came out with something that they had to do.

Someone like Mr. Halm would never take time without being made to do anything like that by law. Someone like Cate, I can see we would have done it anyway because that's the kind of person she is. I can see us getting together with all these people regardless of whether there's a law or not. Someone like Mr. Halm, there is no way. Obviously. Look at what he had me doing - playing with cards I couldn't even see. Why would he take the time to care about what was going to happen next year if he didn't care what was happening the present time?

Some teachers grumble about the amount of paper work they have to do. Well, I would rather be in their shoes than have to live as an IEP recipient. They might want to look at it that way. Just be thankful that all they're doing is filling out the paperwork and that they don't have to actually be a disabled person.

I think that everyone mentioned in the regulations should be at the IEP meeting. They said one representative from the state agency. Well, I always



had two. I had the person who would be taking over my case once I got out of high school and the person who was responsible for it while I was in high school. So I was really covered.

I was really impressed with the completeness and thoroughness of the regulations. I mean, they could have just slapped down that every handicapped child needing special services should have an IEP and that's all they had to say. But they had the different regulations with so much detail.

I honestly believe that if it weren't for the IEP law, handicapped children would just be shuffled under--they would just fall through the cracks. So I think that it's really good for those people who are actually receiving them.

I really cherish all my friends. I went to a seminar in 1987. That was the first time that I made lasting blind friends. Last year, when I was twenty, I went to Seeing Eye. That was the first time I met friends with whom I had discussions about being blind. It's really a sense of relief when you find someone you can talk to about it.

When you're the only blind person you know, you

tend to feel sorry for yourself a lot more. If your friends are all sighted people, at 16, they're talking about driving and you'll never drive. You feel alone. There's no one to share it with. You can tell them how depressed you feel because you'll never drive. They'll say they understand. I don't believe they do because they've never been there. You really don't know what it's like till you've been there.

It's not that sighted people can't understand. It's just that when other blind people say, "Yeah, I know what you mean", they know exactly what you mean. They know what it's like to see all their friends get their drivers' licenses. I mean, it's a big degree of freedom. If you can see and if you can drive, then you really don't have a total grasp of what it's like not to. I'm sure it's the same way with deaf people or people in wheelchairs. It's just part of being in the minority.

### Introduction to Caroline

Caroline was a freshman student in a community college in a small town. She was managing well without special assistance for her learning disability. She shared an apartment with two friends from high school. This was her first time away from home and she frequently visited her mother, stepfather and sister. Whenever possible, she took part-time jobs.

### Caroline's Lived Experience

The first grade was very hard because I had a hard time with math and English and so forth. I really couldn't do the things the other kids could do in terms of math. It took me a long time to grasp the concepts. They said I was slow, I just didn't want to do my work and I was not applying myself. So, I had to repeat the first grade. That was hard. I didn't understand why I was not with my friends any more.

I passed the first grade the second time but I still had a hard time. When the teacher would tell me to do something in the workbook, I didn't grasp it like everyone else. I feared everyone knowing that I could not do it...like I was the only one that didn't know what I was doing.

I remember my mom trying to help me in math. She'd get so frustrated because I could never understand her. She wouldn't know how to explain it to me. My stepdad would say, "Don't bother. She's not going to listen. You're wasting your breath. She doesn't want to learn." It was so hard to listen to that. And then my mom would stop. Ever since then I never asked my mom to help me. All my life I've always tried to understand why my stepdad had to be so rough with me. He didn't like it when I was around my mom a lot. Even now, me and my mom have a really good relationship. Mom says he's jealous.

My first grade teacher told my mom to call her if she had a problem. My mom called her and said, "Caroline is having a hard time with her math." The teacher said, "Don't push her so hard." That helped.

They found out I had a learning disability. I guess I have the learning disability because of a birth defect. That's what my mom says. I was born with spina bifida with an open spine on the back of my neck. They thought I wasn't going to live. Somehow I did. I don't really understand the full part of this but they had to cut the nerves in my neck so that they could sew

up the hole. The doctor told my mom, "We really don't know what that'll affect until she gets older." Now, I'm more numb on my right side. My neck is very sensitive. When I get sick, I get sharp pains on my left side.

I'm not as coordinated as the average person. Especially when I was little, I fell down a lot. Riding a bike, I would fall. I was always clumsy. I was born with astigmatism in my eyes and I'm 60/20 and I have reading glasses. I had six toes on each foot. They cut the extra toes off. My right leg is much smaller than my left leg. There still is a hump on one foot and it hurts. I'm going to have to have that cut off. My feet are crooked. I had to have them broken and then reset. I was very chubby. I wasn't as active as my sister. She'd always climb trees and I didn't do anything like that. I've always been the sick one. I always get bronchitis while my sister'll get a cold and that's it. I'm the one always needing taking care of. As a little kid, I've always been real emotional. Anything would set me off and I'd cry. If anyone called me fat or anything, she always protected me. She was really smart and I would always

think, "Why can't I do that? Why did I have to fail the first grade? Why can't I be more like my sister? Why can't I be skinny? I mean, I would run, I would play."

Once they found out I had a learning disability, I'd go for L.D. classes in science, English and math. Then, in the fourth grade I was held back again. I had special classes three times a day and then I'd get back to my other class. It was hard to come back into the regular class and catch up. Sometimes when I came back I would say, "What do you want me to do with this worksheet?" because I wouldn't know when I walked in. And Miss Truman would go, "Eat it!" I was so scared of her because she was so hateful to me. She would call me "stupid" in front of the whole class. Maybe she resented the fact that I was out of the class for so long.

I would tell my special teacher, "My teacher is being really mean to me. She calls me stupid in front of the class because I'm coming here." They made someone observe Miss Truman but they said, "Some teachers are like that."

My mom asked the principal to get me out of that

Miss Truman's class. The principal said, "No, because then everybody would want to do it." That wasn't right because if a parent asks for something like that to happen, their wishes should be respected. Then, towards the end, the principal apologized and said he should have taken me out of that class because she was so awful.

For my elementary school special education teachers, it was just a job. I feel they should have had more motivation, more eagerness about what they were doing. They should have made it more interesting for me rather than it being just a special class where you've got to do this because your teacher says you've got to do this.

In my fifth grade year, they found out that I read really well. Reading was okay and vocabulary words were okay. So I only had math in the special class. I'd have math in the regular class, too. I didn't understand what I was doing and I didn't get the help I needed in the special class. The teacher would call me to the board and say, "Caroline, I'll help you with it" and the whole class would be waiting. Everybody else knew what they were doing. I was so stressed because I

didn't like it and my mind just drew a blank. And the class would laugh. My mom would say, "Don't worry about it. You have a problem and I'll help you with it." But it was very intense. It was very hard growing up. That's what I grow up with. Those were my first beginnings.

You wouldn't think this but little kids know when you're in a special class. Most of my friends didn't have a learning disability. No one was stuck in a slow class and I was. Kids that age will laugh at you. They don't know the whole thing, they just know you're in a special class. You're not like them. All my elementary school grades, I've been made fun of because I had to go to "special ed". Their concept of it is: "You're slow, you're stupid, you're in a special class"; "You've got to look at a multiplication chart, we don't have to"; "You've got to have special help. You don't get it. You're dumb". It was embarrassing. It made me feel very insecure. I felt dumb.

I had to hide a certain part of me. I knew people knew but I couldn't say, "Look I don't care if you're laughing at me. I have a problem." Not then. And now, my good friends know that I do have a learning



disability but not Gary. We've gone out for two years.

I like him a lot but even now I hide that part.

In middle school and high school, I waited for everybody to leave the hall before I went to the special ed class. It was terrible. I would get water at the water fountain forever. Or go to the bathroom or I'd be late. They knew...everybody knew that Class 12 was special ed. I hated it. I can't really laugh about it. I try to now because I try to have a good personality but then I just couldn't.

In the eighth grade I had a boyfriend, and I think he knew but he never really said anything. As he'd go into algebra with everybody down the hall, I'd say, "I'll get some water" and I'll leave him and wait and then I'll go into my class. I just hid it a lot.

I would be called out of the regular class to be tested in the library. Everybody knew that it was special testing. And while I was taking those tests, I was so clueless about what everything was. I knew it was because I had a learning disability but I really didn't understand it.

I resented the fact that I had to be in the L.D. classes because the teachers went so slow. They even

talked slow. The teachers I had got very frustrated with me. You wouldn't think teachers would but they got very frustrated. It was mostly math. It would be something so easy and I just wouldn't understand it. I feel they could've been more patient. They could have set me on a schedule on certain chapters and followed through instead of taking so long to teach me.

I never remember working straight through the book. It was always a game or something on the board to do or a worksheet. In high school, we'd play money games. You roll the dice and move the little pieces on a fold-out board like Monopoly. That's just adding and subtracting and I knew how to do that. It was too easy and now I realize they could've taught me more.

I begged to be out of those classes. I have to honestly say that I feel, with all my experiences, that L.D. classes hurt me more than helped me because they never taught me the basic math principles. If you wanted to move up, you really couldn't. The worksheets had no direction and it would take so long for her to do it on the board. I felt they could've taught me things they knew I should learn in high school.

I was never in the IEP meetings but my mother

would come around twelve o'clock for them. My mother, the special ed teacher, the counselor who did the testing every year, and the principal were there. My regular teachers weren't because it would be going on during class and they would be in their classes.

I knew the meeting was going to take place but I didn't know what they were going to say about me. I remember saying, "Mom, mom, what did they say? What did they say?" Mom would say, "They said you're doing better." My mom would never tell me the negative parts because she didn't want to. I think they talked about my progress, what I was doing in the class and how I grasped things. I know they talked about my personality. I knew that my teachers knew that I didn't get along with my stepdad.

I would have liked to attend the meetings to know what was going on. I'm sure anyone would like to know what was said about herself. I would've liked to know what my testing revealed because they were such long tests. Some took half a day. I know it was to determine whether I was still L.D. but what's looking at a picture and re-arranging the squares going to do for me? I always wanted to know what it revealed. I

was reading one of my IEP reports the other day and I still don't understand a little chart about my aptitudes.

I was never told the test results. If they had a meeting on a Friday and I'd see my L.D. teacher on Monday, all she'd say was that I really needed to work on those multiplication tables or something like that.

The regulation says that a student may be present if appropriate. What do they mean "if appropriate"? I think it should be that we can attend no matter what. If you're a little older, I think the student should decide if it's appropriate to attend.

The student is going through all the testing--all that psychological evaluation--and needs to know what that means. Either the counselor or the teacher should say, "We're having an IEP meeting about you. You're welcome to attend. Do you want to attend? You have the right to attend." I was never told that. All I knew was that a parent, my mother, was coming to the school about my testing. I wish I had been told more.

If I had attended, I could have had a say about what was going on in the classroom. I could have let the principal and counselor know how slow my teacher

was going. I'm sure it would have caused a lot of conflict but I feel that I could have been working with the system if I'd known about it. I felt pretty blind. I was so naive about what was going on.

I asked my mom and she didn't remember getting copies of the IEPs. She says she would remember it if she had. The regulation says that the parent should be sent a copy if requested. I feel that some of the school systems don't let the parents know. Maybe they just don't want to spend the time getting the report together. They should send a note giving the report even if some parents won't like the results.

I started realizing in ninth grade, "Hey, I'm doing some stupid stuff in here." I'd finish my work really early. I couldn't stand the teacher. I didn't know why she was treating us like kindergartners. I'd ask my friends, "What are you doing in this book?" and they'd say, "We're on this chapter" and I'm like, "Oh, I'm only on chapter 3! That's not fair." So I'd get resentful. It seems like I never really got anywhere in that class. And keep in mind, I had failed two years. I was so down on myself.

I went to the principal and said, "I'll be honest

with you. I don't think I need to be in this class." He goes, "You don't? You were tested as being learning disabled." I said, "I know but I feel I can do better." He asked, "Are you on fractions?" I said, "No." He said, "Are you on ratios?" I said, "No." And he asked about algebra and I said, "no." I showed him the book. He said, "Have you got to this yet?" I said, "No." And he said, "You haven't done that?!?" Well, I think you can do better. I'll have a talk with your special ed. teacher. You need to have done more than this."

So they put me in a regular math class. I told one of my special ed. friends about what I did and she met the principal and she got out of it, too.

Then, they had a meeting about me. I don't really remember how the discussion went off with my special ed. teacher. I wasn't in the meeting to determine whether I should be out of special ed. class. My mother said that the regular math teacher said, "She's so determined not to let her handicap bother her." At that meeting they decided I was doing fine. I don't think my teacher liked it but I was able to come out of special class. What my principal and my mom realized

was that I was going at a slow pace when I could have gone faster.

But before I could go into that regular class I had to be tested. The test was like, "How many days are there in a year? How many months are there in the year?" Ever since middle school I remember: "Here's a puzzle...put the pieces together like on the cover." I was thinking like, "Please, please, don't insult my intelligence." I guess I did well.

And so in the tenth grade I didn't have any special math class. Mr. Towers, the regular math teacher, was good. He made it really interesting. I loved him so much. I visited him last week when I went home and he said, "I had no question in my mind that you could do it." So many people told me for so long that I couldn't do it.

Individualized education should mean specialized attention and the problem must be identified early. With all the testing they do, they must identify very early why a student is not doing well. I didn't like going to special classes because they labelled me as if I had a sticker on me saying, "I'm special ed".

You shouldn't take the student out of the regular

classes. I'd like it the way Mr. Towers did it. He knew I had an L.D. problem but he was willing to deal with it. He didn't take it out on me. He was very positive. His classes were not slow like my L.D. classes. First of all, I was so happy to go into a regular classroom. I knew it would be hard but I was ready to take it on. All my life I'd been labelled "L.D. in Math". Mr. Towers knew that and said he would help me. He's say, "You're not dumb. I don't ever want to hear you say that. You know what you have to get through and you're going to try. I'm going to help you."

He'd just be so enthused about helping all the students. He'd praise you if you got it right. Any one with questions could just raise your hand and he would come around the room and explain. He'd take time to explain. Mr. Towers understood what individualized education was for all children. The others didn't.

Except for Mr. Towers, I didn't have any motivators in my school-life. Now that I'm older, I know education is so important and teachers should never put down the student. To be honest, I really have such bitter feelings about everything. My



principal in elementary school knew what I was going through. Afterwards, she went, "Oh, Caroline, you're doing so well. We're so proud of you!" I hate her.

The IEP law is a good law. It gives students who have handicaps a chance to learn and grow without being in a hostile environment. It's a good law because it gives you specialized attention from teachers. The law was there for me but the teachers I had were very uncaring. The law alone is not enough. The people make the difference. I think all teachers should have an understanding of what L.D. is and how hard it is to adapt to it. I feel that all teachers--whether they are teaching L.D. or not--should be aware of all this.

Now I know that L.D. means you have to learn a different way. All along I heard about "L.D" I thought I was not like everybody else and that I was dumb. I don't want to call it a learning disability...that's so labelling. It's a problem in learning. It just means you have a harder time grasping. Sometimes I still think about those times but I stop myself and say, "Wait a minute. That's not you anymore! You're not dumb."

### Introduction to Tiger

Tiger worked at a sheltered workshop. He lived with his parents and sister in a small town nearby. During the past year, he learned golf and explored the possibility of joining a basketball team of wheelchair users. Most of the time, he used a pair of calipers and a single crutch to compensate for the physical limitations of his cerebral palsy .

### Tiger's Lived Experience

I was born in 1967, in a small town. I couldn't walk: I was walking inwards and outwards. I started using a wheelchair when I was in kindergarten. They taught me how to use it. After that, I wheeled on my own. The people at school would help me with steps--they would help me up. I also remember getting out of the wheelchair and crawling up four or five steps. They never had IEP meetings when I was little. They had a parent night.

I was in a special education classroom. There were about 8 or 9 of us. We didn't all have the same disabilities. Sometimes all of us did the same work. Sometimes we did different things.

It was similar to the regular ed. class but we

didn't do as much hard work. If I went to the regular class, I would probably fail. All that stuff is hard. I mean, I didn't go through all that stuff and it was still hard for me to know everything. I had a hard time finding out things. I had a hard time adjusting.

The special ed class was in a different room from the others. I used to have to go back to the other classrooms. Outside of special ed., I used to take art, P.E., reading and horticulture. Art was in a different room and reading in a different room and we used to go to the gym. I moved a lot to different classes. We used to have a home room, too, and we used to go to our home room before going to classes.

Sometimes the students were different ones at each place. Sometimes they're all the same. Some of them were nice. Some people talked to me and some people wouldn't. I think that's ridiculous, I mean, you know, people not talking to me. They just wouldn't say anything. There's one girl at the workshop now who won't talk to me. I don't know.

Every year, you have to choose the subjects you take. To help me to decide, I'd sit down with my parents and talk about what to take the next year. I'd

have a list of what you'd have to take. The teachers in special ed. give you a little bit of help, too.

Every six months we had the IEP meetings. The meetings were short. I went for my IEP meetings. I think it was important for me to go and know all the stuff that I did wrong and whatever. Well, I should be there to find out what it is about. I talked a little bit at the meetings. I wanted to know how I did grade-wise. I remember I'd ask, "How's my work going?" and they'd say, "Pretty good."

I think your parents should be there. Maybe just one parent because one is probably enough. The parent should be there just to make sure everyone is getting it right and organized. My mom came. Usually my dad has too much work to do. He hardly ever came. I don't know what I'd do if I had had a mom who refused to come. That would be a different story, I guess. If she had said she had too much work, that'd be okay. I'd be able to handle it myself.

My special ed. teacher was at the IEP meetings. She's important to tell you what to do. That's it. No one else was there.

What should be in an IEP? How well you did, your

grades, what you're going to do after school. I read the IEPs when I got them at home in the mail. I think it was worth it because it helped me to remember the things that I needed to concentrate on. Well, it doesn't help any right now because I work now and don't go to school any more. No, the IEPs don't help any more.

We moved a lot. I got thrown out of school once. I got mad at the teacher and used bad words. That was something I shouldn't have done. I'm usually better. That time however, ruined me. She called my mother. I was inexperienced at that school because I had just moved to that town. It was a big change. I like the schools over here better than the ones over there. I was not in a special ed. classroom there. No, I had to be in the same classroom as everyone else. They didn't have a special ed. class. They didn't have a special ed. person in that area. That was very strange...very strange.

A lot of things were great in school here. The teachers were good, all of them. They were nice. They all worked hard. Yeah, pretty hard. I had new special ed. teachers every four years. We moved a lot and

that's hard. My mother wrote a letter to each new teacher. Here's part of a letter she wrote:

Tiger's first love is sports. Of course, Tiger could not participate in the normal capacity, but either he or his friends found a modified way. For example, in baseball, he would be up at bat on his knees and one of his friends would run the bases for him. In basketball, his friends would sit him down on a small bench on the foul line and they would run around him. Tiger was an invaluable team participant in that he almost always scored from that position, and his friends knew this, so they would pass the ball to him quite often. Also, his friends would always refer to Tiger as to what the score was since they knew he was the only one who would keep track of this.

Sometimes it was helpful for me to explain his sports interest to his teachers so that they could encompass this in their teaching techniques. For example, Tiger's reading skills were fairly good in the first grade, but his math skills were very poor. We used to play games on the chalkboard at home relating math to basketball or football games. If you asked Tiger what two plus two equalled, he could not calculate this. However, when I would say to Tiger: "If one basketball player scored and then he scored again, how many points did this make?" he would know that the answer was four.

At seven, Tiger became interested in collecting sports cards. He has them all categorized according to teams and learns all the statistics about the team members. Tiger's dad developed a game for him to use with these cards, and Tiger keeps written track of his game standings.

Tiger received a Special Achievement Award at graduation for high standard of excellence in Special Education. When he received this at the graduation ceremony, he received a standing ovation from all of his classmates, I believe not

out of sympathy, but because they truly felt he was a great asset to the class of 86.

I remember graduation time. Oh, I remember my graduation. I enjoyed every minute of it! I graduated from Blacksburg High School in 1986, June 10th. I can even prove it. I have a bracelet with the date engraved on the underside. My sister gave it to me. My graduation picture is hanging in our living room. There's one of my sister's graduation, too. I had a party here later. I thought it was great that I graduated.

### Introduction to Olivia

Olivia was a teacher. She graduated from college without any special assistance for her dyslexia. She was very involved in campus sorority activities. She was frequently on the dean's list of outstanding students.

### Olivia's Perspective

I was born in 1969. My mom was a single parent. Before I started school, when I was very young, my mother couldn't really support me and so I spent a lot of time with an aunt and uncle who had two older sons. I kind of grew up in their house. The boys were like brothers to me. I remember trying to keep up with two older boys. They taught me how to climb trees, shoot little capguns, and go fishing for tadpoles. I would spend the summers at my grandmother's. She had huge yards and gardens. It didn't have the jungle gyms and stuff but it was just as much a playground for me as anything else.

I started school in 1975. I was five. I really liked my teachers in kindergarten and first grade. The first grade teacher was really neat. We sat in clusters throughout with desks facing each other.



Well, she had to change the seating about every two weeks because we would be talking too much sitting in that arrangement. I was very meek and quiet. I talked a lot with the people I knew. I mean, there were like five people I talked to and I talked their ears off but if you weren't one of those five, I wouldn't say boo.

I was always trying to be the teacher-pleaser. The whole syndrome: "Can I clap the erasers?" One day I was so humiliated. I brought my lunch but I bought milk. Milk was a dime. I swallowed my dime. Anyway, I was caught up in this thing of trying to please the teacher and here I was, I had swallowed a dime. I had created this whole hassle for her and she was not very pleased with me. The school nurse couldn't do anything so my mom had to check for it for about a week till it was passed out.

I had one really special friend. We went to school together for four years. As an only child in a single parent household, I wasn't really encouraged to have people over at the house. I really didn't get exposed to a lot of different things but I saw really different things through my first childhood friend's family. It was like...wow...somebody can have a

different reality.

The only hobby I've ever had was stamp collecting. My step father was in the secret service and would travel around different countries. He'd always have gifts but I never wanted the gifts. I wanted the stamps. He's not really my stepfather. When I was younger (like eight through about fifteen) he was the father figure in my life. I don't feel right giving him the name "father" because I have a father and so I call him my step father.

I never spent much time with my real dad. In fact, when my mom found out she was pregnant, she didn't tell my dad. She considered the way he would handle it: He would have probably tried to force her into marriage. She didn't want to be married to him. I was four when he found out that I was even alive. His parents saw me in the supermarket and said, "My, that child looks like our son." They invited my mom to dinner. He was there and they had this confrontation.

I can only clearly remember one time in my childhood when he was there. It was for parents' night at school. At the time I thought it was real hypocritical--going to a parents' night for me when he

had never really played that role. At the same time I was excited because he bought me Rocky Road ice-cream.

Second grade was when I started having some serious problems. We went to a more open classroom. We had to switch rooms and had periods and stuff. It was all very discontinuous. In first grade, I knew everybody and we were all so chummy that we had to be moved around. In first grade we had only one class and in second grade we had to switch from class to class, from subject to subject depending on the time and the teachers. I had five different teachers I had to deal with each day. I had five different subjects. We had cubbies a little bit bigger than cigar boxes. That was home base...our little cubbies.

The arbitrary timing...well, it's spelling time now, it's reading time now, it's history time now. Why is it now? Because I wanted to get math over with early in the day, I remember asking the teacher, "Can I have math early in the morning, please? Just to get it over with?" So I always got into trouble in that class. I always had to stay after school for the teacher. I didn't like her, I didn't math and so it just built up. I was having problems with spelling and

history. My favorite subject was reading and I wasn't into that. I was just real down on school and I hated going. It was terrible. And so they had endless parent-teacher conferences with my mom. I was having some problems at home and I couldn't deal with it. I don't remember what.

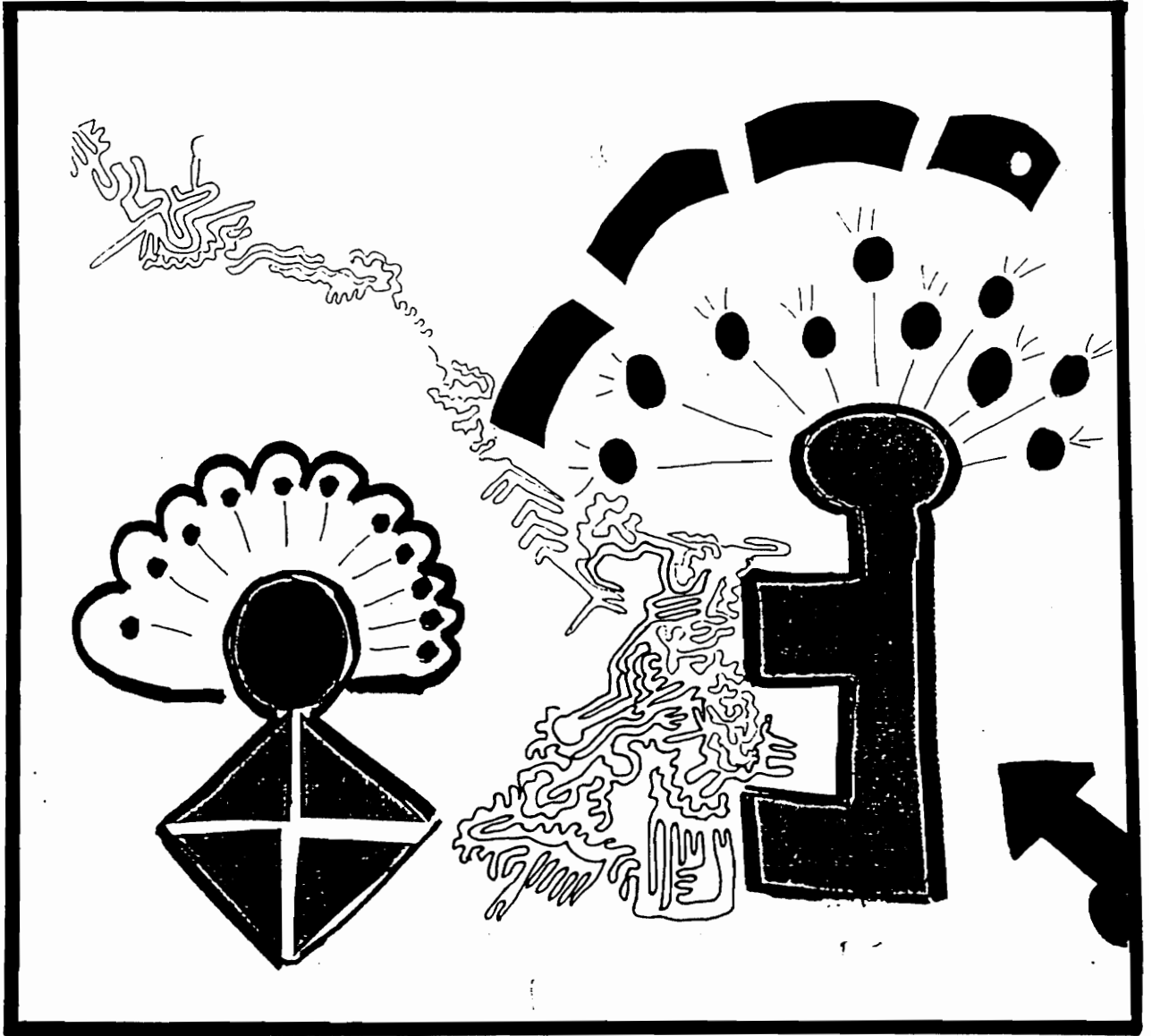
It was so frustrating for me because it seemed like everything was so meaningless. Halloween...it showed up on every spelling quiz endlessly from September till June. Every single spelling quiz. The teacher just decided that children love to spell Halloween. I always missed the 'O' in the middle. Always. Always. Always. Now, here I am. I am twenty-one and I can spell Halloween. Thank goodness, you know. And I still don't see the relevance of it. So spelling seemed obnoxious and not relevant to what I needed to know.

Now I have all these ideas about individualized education--how I can make all these things relevant to my students. I have the kids make up their own spelling lists by going through their own writing. "What did you misspell? What do you need to learn how to spell correctly?" If kids could do that it would

mean so much more than picking a list out of a book. I never understood where they got those lists.

Handwriting: That was another thing I could never get. I did everything backwards. I understand now it's because of my dyslexia. They made us do these squiggles over and over and over--big tornadoes on your paper. Why? I never saw why. Why couldn't I just make the letter? Doesn't that make more sense? I hated that whole year. Nothing seemed to make any sense and it didn't seem relevant at all. The whole thing was just...ugh. The figure below shows what I felt like.

Figure 1: Copy of collage by Olivia depicting her feelings of frustration in second grade



In third grade they diagnosed me as having dyslexia. I was put in the special classroom. I don't want to say that it was all bad because I did have some really good experiences come out of it. Actually, we had two teachers who were great. I have to credit them tremendously. But people had this idea already about the world learning disabled children would have to live in. You need to know how to work with your hands because that's the future you're doomed to. So instead of learning how to read, our teacher would read to us in the afternoon while we did handicrafts. The teacher would read a chapter a day out of this mystery book and she was a good reader but that was frustrating for me because I loved to read myself.

I had a really good friend in there. We were always together. We would communicate: "This work is too easy, don't you think? Let's finish up fast and ask for a pass to the library." "Okay. Yeah, that sounds great!" So we did this constantly. They always gave us passes. We'd just have to be back in time for the next lesson.

Then I got the bright idea that if they could give me passes to the library, they could give me passes to

anywhere in the whole building. I started thinking of all the different possibilities because we had art and P.E. and music in different areas of the building. I'd go and be with normal kids. I got passes to the other third grade classrooms. I used to ask to go help the secretaries type letters. I had full reign of the whole building.

I started going to the art room almost every day. The art teacher was the art teacher for the entire school. Basically, each week, she just adapted one lesson for the different age groups to make it as challenging as they needed it to be. A lot of times it was like crayon etchings and you can do a million etchings and they'd never be the same. But sometimes it was something that wasn't as creative. Styrofoam art or something. You can do only so much. You always make a blob. It'll be a different kind of blob each time but it'll always be a blob. I was very creative and so I started helping her to think of other things to do with it. She was like, "You're not an L.D. student. What are you doing in there?"

She was my advocate. She started talking to the other teachers and saying, "Watch her for awhile.



Haven't you noticed that she's bored with your class and she leaves because she's bored? And that she goes to the other classrooms and she comes here and she helps me write my lesson plans? This isn't right. This child needs more stimulation." She started advocating with the other teachers and with my mom and the principal. She got me out of special ed.

In fourth grade, after the second half of the year, I went into accelerated learning in another school. I went through this whole new battery of testing. It was crazy.

I still had IEPs after that because I was in a gifted program with special classes. I had one counselor at school I worked with. I went to her just four or five times. She taught me learning strategies. She taught me, when I'm reading, to use a ruler and block off everything below the line and to move the ruler down as I read. I'm supposed to read slower.

Numbers, I still have a problem with numbers. With words, if you jumble up the letters, it won't make sense so it's easier to catch those flaws. But numbers are always numbers no matter what order they are in and so it's much harder to catch the flaws.

A whole section of my life is defined by one event. It happened when I was twelve. My mother was having a party and had a lot of friends at home that night. Twenty-five people. I was raped by a friend of the family. My mom didn't believe me. It bothered me that she doubted me and so, for about three years, we were not communicating well. I resented her and she resented me.

Two years later, he was convicted of child molestation by somebody else. I was asked to testify. I wanted to but my mom would not allow it. He did end up going to jail and from jail he wrote threatening letters, trying to scare me. When I knew he was going to get out of jail, I didn't want to be where he could find me so I ran away.

I went to a big city and lived there for two years. I made some really good friends. If I met them today I might have a different opinion of them but they knew I was just a young kid and they really wanted to help me. So they got an apartment for me, helped me to pay the rent and to get me some modeling jobs. That's how I paid for everything: I did cheesy modelling.

I continued to go to school. I continued on the

swim team. During the day, I was one person and when I went home I was another. I had two completely different identities and so I had one answering machine for the deals I was making and one for school and home friends. That symbolized how I lived. When I was at school I didn't really have any friends because I didn't want anyone to get to know me. People might turn me in and I was really scared of that.

I finally decided that things were getting really too rough. I was doing a lot of drugs then and I just couldn't handle it any more. The modelling people wanted me to do more and more sexually related modelling. I just couldn't do that. It was just not part of who I defined myself as. I decided the lesser of the two evils was to go home and face my mother.

We still are not close. There was such a trust betrayed at a time when I really needed her. I knew that by running away I created a million more problems but I found a lot of strength in myself although I was scared a lot when I was on my own.

It was really neat to go back because I went back to the same high school, to the same neighborhood. They knew what had happened. They were so supportive

of me and when I came back I had a huge welcome. It was such a relief to just come and be a kid.

I had an "adopted" grandmother who would take care of me after my real grandmother died. It was right about the time the cabbage dolls came out and you could adopt a baby. I made an adoption certificate and we signed this little contract and adopted each other. One of the main reasons I came back was for her funeral. I missed those two years with her and I know she worried about me. I didn't want to have a lot of contact with her because if she knew things were really getting out of control for me, she'd tell my mother.

My mother never attended my IEP conferences. She must have been the only one they thought of asking but there were other people who might have attended for me. My "adopted grandmother" would sometimes check my homework. She might have attended the IEP conferences if they had asked her. The regulations about parental involvement should consider how one defines one's family. I consider people like this "adopted grandmother" and my "stepfather" part of my family. They were my "alternative" family. Then there are members of the extended family. When parents like my

mother do not attend IEP conferences, shouldn't the school try to identify who should act as a parent in the best interest of the child? I wonder if there is a role for educational child advocates from outside the school to be at the IEP conferences.

At IEP conferences, others determine what vein the education of the child will take. Their values will permeate the goals made for that child especially when test scores underestimate or overestimate the abilities of the child. Somebody decided for me that it was important to know how to spell "Halloween". In third grade, we were read to because somebody else decided for me that for me to learn to read would not be important and that motor skills for craftsmanship were important. Shouldn't the child have some say? And while all these goals are made for the child, is there any provision made for motivating the child to reach the goals?

I've also been thinking about who should be responsible for the education of children: The society or the family. I think formal education is there to educate about civics, reading, mathematics, the ability to analyze and other marketable skills. The family

teaches the child etiquette, values, morals, religion, personal health, daily living skills, and hobbies. What happens when one or the other doesn't fulfill its educational duties to the child? In a case like mine, should the school compensate for the family? Can it? Are schools obliged to try? Those of my teachers who tried to understand my needs did try to compensate for what I did not get from my home life and so they gave me an individualized education in a deeper sense than the IEPs did.

One of my teachers in the gifted program truly understood what an individualized education meant. I was inspired to be a teacher because of her. She ran the most stimulating classroom. We designed our own curriculum. That's how she conducted our whole class. We had a core that we had to cover. We had to learn science, math, and history. If we had a question, we designed experiments, decided what materials we needed and anything that we had to do to get the answer that we wanted. I was really curious about colors. So I ended up using flashlights with different colored lenses and mixing them up and seeing. I remember doing something with the prism, refracting the light and

getting colors out of that.

The really neat part was that we made our own tests. It became such a learning process in itself. We got to completely design our own questions and to answer them. If anything, they taught me how to think and how to solve problems, which is exactly what I think a teacher's goal ought to be.

She tried to give us an awareness of what it's like to be handicapped. Our school had mentally retarded children. Many students really resented that. I remember, in third grade, thinking that it was just gross to share lunch time with them. They got food all over them. She knew that we had to have more awareness of what it is like to be handicapped. So we had a handicapped awareness day. We got to choose a handicap and live with that handicap all that day. I chose an easy one I thought: Being in a wheelchair all day. It was not fun.

She would always try and have things that were challenging and would use our creativity. One time we designed a city. We had a whole hallway to ourselves and we had an architectural project that we worked on after she left. We had to research and list everything

we needed and report about why we chose the things we chose. Then we got to actually build it. I would love to do something like that with my class today. It uses all your skills and it's fun. It's exciting. It's challenging. She always brought so much of her own personal self into the classroom and shared it with us.

I was eager to learn. I was like a sponge. She knew what we needed to know to be human to each other. She had incredible vision. The biggest thing was letting the children control their own learning, to pursue the things that are interesting to them. At that point it's just important that you're reading and you're learning about the world and making sense of the whole thing. We shouldn't say you have to learn about George Washington. Children have so many curiosities. Just let them explore them and make sense out of whatever interests them. That's individualized education to me.



### Introduction to Pam

Pam was working towards an undergraduate degree with a double-major in mathematics and English. Last year, her college employed her as a mathematics tutor. She saw this as a step toward realizing her ambition to be a mathematics teacher. She lived with her father and had started exploring plans to live independently. Pam used a manual wheelchair.

### Pam's Lived Experience

My twin sister and I started out together in kindergarten. We went together for two or three months. Everyone realized that one of us wasn't doing so well and, of course, that was me. Then I would go in the morning and my sister would go in the afternoon so that we wouldn't be compared. They hoped that that would be better. It was but I felt isolated.

It took them until I was 6 years old to actually figure out that I was handicapped because doctors kept saying that I was slow and that was all. My mother kept saying that there was something else wrong. But I don't think she really dealt with it until I was about ten, after several surgeries. She kept hoping that some miracle would come along.

I heard the doctors and my mother talking about my handicap. My doctors talked circles around me, sure that I was not going to understand. At the time I was young but I think I knew more than they thought I did. They never wanted to tell me. I had to ask them. And even then, they beat around the bush. My mother was really the one that told me all about it.

I'm lucky that my mother told me about my disability. Well, she didn't tell me as early as I would have liked to know about it. Actually, I thought they should have started telling me when I was about 5. I think they should start at an early age so that we can understand our disabilities and what we need people to help us with. They told me when I was about 7. They explained it in detail. But before that, I knew something was up. I knew I was different.

I knew that they classified my handicap as cerebral palsy but that's not what it is. I was born without hip joints. Due to the fact that I haven't been able to use the muscles, it acts like cerebral palsy.

I learned quite a bit about my handicap. I would tell people about it. It didn't bother me and I think

it only bothered me when I got to school because all the kids were doing all these things and I couldn't do them.

Children and adults always asked me questions about my handicap. They would ask, "How did you get that way? Were you born that way? Was it some disease or what?" Although I was shy, I would talk about it but I really didn't want to so I would let mom and dad take over when they were there.

If people ask me questions and I don't know about my disability, I can't tell them. You feel lost. That's what you feel like. When a child is told she has a disability, I think she should be told exactly what that disability is and the limitations.

Knowledge about your disability should be part of your individualized education. I really think it should be. A lot of children with disabilities don't know about their disabilities and they feel they have been cheated in some way. If we had lessons on our disabilities, we could understand the handicap to the point that we could answer questions from people more clearly.

In elementary school, I ran into problems because

they never wanted to accommodate me. I got through the first three grades all right. I probably didn't apply myself as much as I could. I wasn't able to make As and Bs until mid-junior high. I started applying myself more.

I was pretty much able to do everything but they put me in special math class. As I worked through that class, I made A's. I proved that I didn't really need special math class but they thought I needed it. Now that I think about it, I really can't hold that against them because they didn't know me well and never took the chance to get to know me. I've been thinking about that a lot and I really think that it would help to use IEP meetings to let teachers, as well as others who might be there, know what you mean by a handicap and just exactly what that means in terms of limitations.

I think they thought that if the so-called normal people got wind of the handicapped people being in class, the school would lose its enrollment. So they tried to separate us. As the years went on they got better about it.

They didn't put me in special math class until I was in 4th or 5th grade. That really hurt. If they

had done it earlier, then it wouldn't have affected my ego as much. I really resented that at that time. I thought they were picking on me. I still have that what-the-hell-you-stuck-me-in-that-class attitude though now it doesn't bother me.

At that time, classes were fairly simple so I didn't see why they were singling me out at all. Back then they really didn't know how to handle the handicapped. The school I went to wanted to single out any one with a handicap and put them together as a class. They had one teacher to handle everybody.

If they had put me in special classes for everything, it might've been different but we'd always leave during math. We left about 15 minutes into the regular class. There was about 5 of us and everybody knew where we were going.

Being as young as I was, I didn't like being singled out. I feel if they were to single out people, they shouldn't have picked the students with disabilities. They should have put those children who had problems with math in a special math class. A lot of children had problems with math.

It did a lot to my confidence because when you get

out of the special math class, you feel you can't do math. That's what happened to me. Throughout school, whenever I had to take math, it was ANXIETY. I think that really hindered me from doing as well as I could've. When I got to high school, they wanted me to take algebra but I started thinking back to my elementary school when they put me in special ed. I said, "No, no, no, I can't do algebra."

In this special math class, most of the people were actually slow learners. This one guy in particular could not even tell time. I thought about it. I got a little angry. I thought, "There's no one else like me. Why am I here?" I even asked the teachers, "Why aren't there other children in wheelchairs?" "Well, they don't need this," she said. I'm like, "I don't think I do either."

I got along well with the other children in the class. There was one guy, I really don't see why he was in there. He was normal and very intelligent. I think he was in there because he was the rebellious type. To some extent I think that's what they might have thought about me because I did not speak up in class and I was more or less a loner. I did not want

to talk to anybody. I didn't really think about it then but I think that's what it was.

I like to be in a regular classroom with other children. I interact very well with other students as long as they understand me and my handicap. The adults decided that the other students wouldn't understand when, usually, the students understand more than the adults do. They really do. Especially back in elementary school. They'd ask me questions, I'd answer them. Most of them treated me like I was "normal". Teachers, I think, felt that we would be picked on.

Back then they had the racial thing, too. The Whites would not associate with Blacks a lot but, of course, I did. My best friends were all Blacks. They were more helpful than the White people were. They seemed more willing to understand what I needed. I think they were being discriminated against also and so they understood the handicapped a little more.

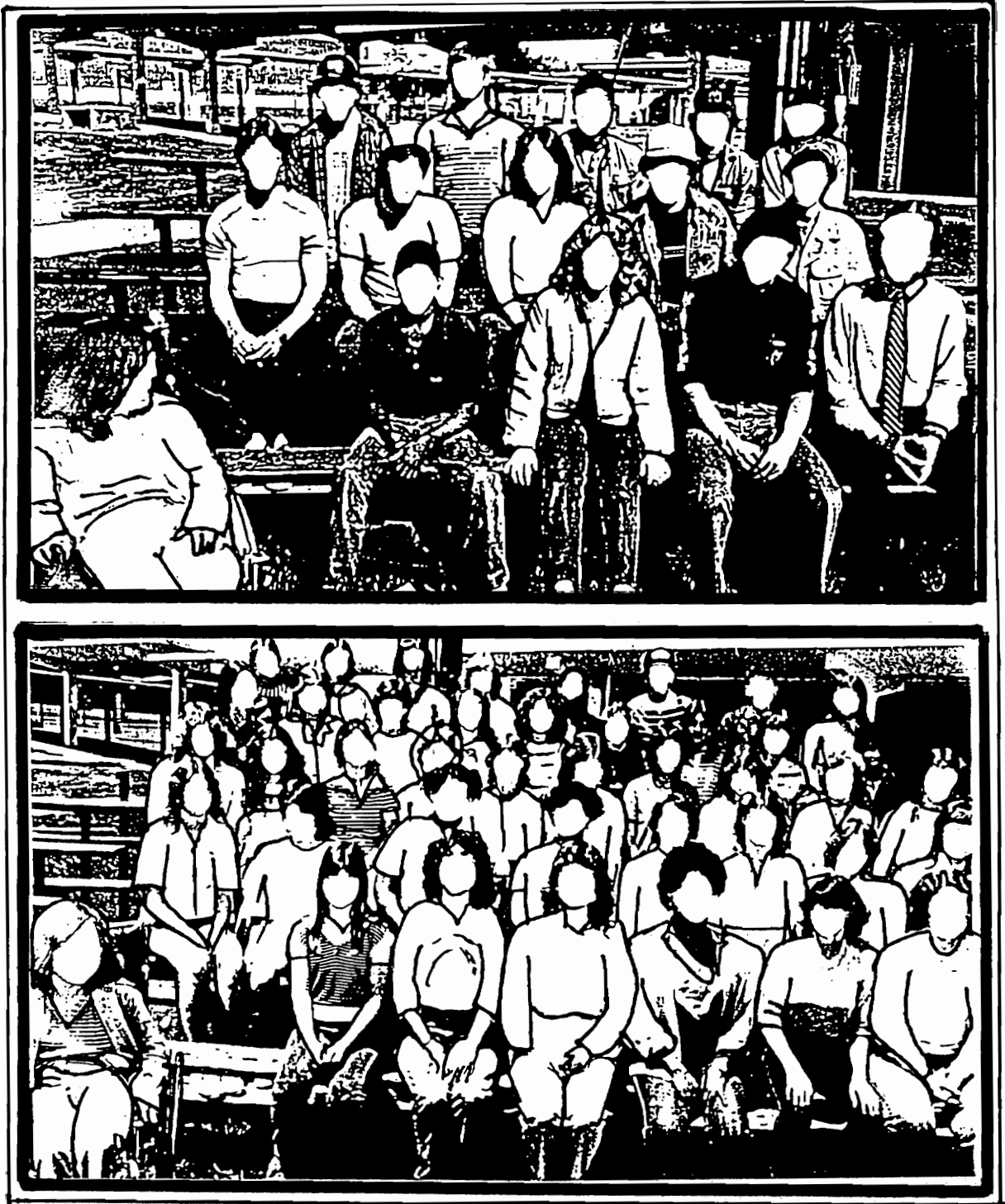
My life was kind of sheltered. Nowadays, I do everything myself. Back then I couldn't. I had no social life at that time. No one was really sure of how to handle me and I couldn't really tell them. It was real rough to transfer from my wheelchair. I would

always find that one sore spot. In school and when I went out with friends, I had to have either my sister or my brother with me because they're the only ones who knew how to handle me.

These two pictures (see next page) from my yearbook show you what it was like. I didn't realize it till you pointed it out but I think that to some degree that symbolizes the separation because I don't think they understood the handicapped person's feelings. It does play an important part: The closeness of a student to other students. It was not intentional. I don't think they realized it. I told them I'd transfer as much as I could but they said not to do that. So the result makes it seem like I was constantly being separated.



Figure 2: Photographs from Pam's high school yearbook



Other children learning about my handicap should be part of my IEP. They should include that in their lessons--questions about things that they would like to know about that person with a handicap and how they should deal with these handicaps--because if my classmates know about my handicap then they know exactly how to treat me and exactly how I want to be treated. It helps me. And if they can't deal with it the way I would want them to deal with it, then maybe I can help them understand.

As a child, I was very shy. I usually whispered. In elementary school, I would never speak out in class. And if I spoke up and got something wrong, I was like, "Whoops." So I just kept to myself whether I knew the right answer or didn't. I found it really rough when teachers started at one end of the room and called on us. I was like, "Please give me an easy question!"

I find that many handicapped students are afraid to go to their teachers. I was one of them. A teacher should make the first move and meet with that student. The teacher needs to sit down with the student and find out what she needs and what she doesn't need. For example, when teachers talk to me, they tend to bend

down. You don't need to do that. I'll make the adjustment. I'll back up and look up at you.

Telling teachers how to handle you should be part of your IEP because the student may not be able to tell the teacher what may be needed. If the student does not succeed, the teacher may have no idea what went wrong. If you are willing to let them know what you need, teachers can become your best friends.

Parents need to tell the teacher when the student can't do it herself. A lot of times, the student is just learning what she needs. Parents have the child at home more and they pretty much know what will be needed and can tell all the teachers this. It may be something as simple as sitting in front of the classroom so that you can see but a lot of times, the parents just assume that the teachers will know these things. I think that is a major problem. They assume the teachers know. No, you have to tell the teacher.

We moved a lot when we were young. I must say, as we moved, the schools were more equipped for the handicapped. I think it's actually because of government regulations. Then the schools started getting a lot better at making the changes for the

handicapped. They always had to make changes before I could come to that school. We had had to let them know about 6 months in advance. Then the changes they made were sometimes makeshift: "Let's get by until this student gets out of here". But the makeshift changes ended up having to be improved because other handicapped students followed me.

At my second school, I had a nurse who worked with all the handicapped students. She became like my second mother. I could talk to her. At the next school, we had a nurse, too, who took care of the handicapped students. We were put in the same class as the other kids. That's where they really began to understand more about the handicapped because of the nurse. She would come to the class and say, "Well, this person needs this." So the teacher would know and so would the other students which helped us out a bit.

Teachers were really nice at that school. The students were more friendly. They had this system where if you had a friend who had a different lunch time from what you did, all you had to do was ask your teacher to go have lunch with that other student. They felt that the interaction between the students was good

and they allowed it.

If you had trouble with math, no one would know except the teacher. After the class, he would say, "Can you stay for a few minutes? I want to talk with you." And the other students would never know and that's what I liked. It was quite different. I enjoyed it more because I felt as if I was actually being treated as an equal. The teacher would say, "All right, you do number one on the board, you do number two..." If you got it wrong, he'd dare the class to laugh at you. With me, he had my brother in elementary school so he knew me. "I know you can do this. I had your brother. I know you can do this!"

I have two sisters and a brother. I think that's where a lot of my problems came out of in school. I was always being compared with either my brother or my sister. I know that now. It's really been that way all my life through school.

Teachers had this thing about twins being almost exactly alike. Well I've got news for them. We're not. I have completely different interests than my sister. My mother would tell my teachers, "Well, her sister does this." And my teachers would expect the

same thing.

Now I've changed quite a bit: I accept my abilities. I used to try to be just like her. I don't think I realized it till now but I think that's what it was. Oh, it ticked me off. Why did I have to be exactly like her? Maybe I could be a little bit better than her.

Mom had a drinking problem. When we were teenagers, whenever my mom got really angry, my sister and I took refuge in our bedroom. She really didn't bother me that much, I guess, because I was handicapped. She sheltered me. I always had to do things with my brother and sisters.

When my mother would yell and send us to bed without our night-time snack, my father would sneak in with it. He was the soft one. Before I started school, my mother used to work and my father would baby sit because he worked the night shift. You'd never think that dad makes a good baby sitter but he does. It was fun with my father when we were little.

My mother and my twin sister argued over me quite a bit. My sister was always for my becoming more independent. My mother was always the one to say, "No,

no, no. She'll get hurt". And my sister is like, "You're not going to be alive forever". You know, I myself think about all that now. When mom died, my life changed. We were more of a family when she was alive. She drew us all together.

When I was little I spent a lot of time in the hospital. I was always missing school because of surgeries. For about four to six years, I missed days and days. I used to walk with a walker and then I had so many surgeries that this leg is completely stiff. When I was 9 years old they did surgery and left the cast on too long.

At the hospital, I got to know several kids. We used to play games, racing down the hallway in our wheelchairs. I was very outgoing with children my age but felt shy around the people who could walk.

I ended up being homebound for awhile when I was about 8 years old. Being home-bound was rough on me because I missed the classroom. I felt depressed.

When I was in hospital, my parents got a list of what's to be done and gave it to the teacher. She would teach me what I needed to know. Basically that's really what slowed me down. She was a good teacher but

when you're in a hospital, you really don't feel like learning anything. Doctors are always interrupting to try some new treatment they think might help.

For example, one time, in order to try and stretch the muscles in my leg, they put me in traction. So I had a pin through my knee. They didn't tell me they were going to do this. They told my mother but she would sort of use code words like, "Oh, when are you going to do 'it'?" I knew something was going on. I didn't know what.

The day they did it, my mother was going to bring my walker so that I could get up and exercise but the doctor came in wheeling this tray. I was about six years old then. He used the hand drill and he did not put me to sleep. He gave me a shot in the knee. It didn't help. You know, the pin went right through the bone. It was traumatic. That put me in bed for six months. I was very upset with my mother after that.

Actually, when I was having surgery, they never had one doctor working with me. They'd always have to change the lesson times to suit the doctors because doctors always seem to come in at different times. So when they switched doctors it was hard.



When I got back from the hospital, if I had done anything wrong with the work, the teachers would say, "Well, you need to redo this". As long as I wasn't in the hospital, it didn't really bother me if I had to redo something.

Oh boy, it was real hard to comprehend what was going on each time I returned to school from hospital. Yes, it was extremely difficult. I liked being back in school but... And I think that was part of why I was never able to do as well as my sister. I was always behind a little bit or trying to catch up. That's why I attended easy classes. That's why I never attempted algebra or algebra II or anything. It's hard to feel comfortable in hospital doing all this stuff especially since I was in pain. I didn't feel like working.

The hospital teacher gave the tests. The teacher that had the class should've given the tests. I was used to my school teachers and I knew the way they taught. I don't think the tests that were given to me in the hospital allowed me to show my ability.

They need both the hospital teacher and the school teacher to get together and discuss the student. It should be part of the IEP planning. The teachers at

the school should have had a more active role when I was in hospital. They gave me assignments but I think they could've given more explicit directions. If I had known exactly what had to be done, then I could have concentrated.

If teachers would get more involved with the one at the hospital, then they can build the lesson plan according to what the teachers at the school want. Instead, the school teachers may say this or that has to be done but they don't really say how it should be done. Initially, I think they do but once the student has been in the hospital for awhile, the teacher at the school loses control over how the lessons are done. I think they need to be able to gain that control back as the student progresses.

The IEP allows the student who is put in hospital to compete with the other students. It allows the teachers to set up a more organized plan for that student who is in the hospital. When you are in the hospital, you really don't know what's going on as far as your education goes. Whereas, if you have your IEP there, you know what you're going to be doing. It does help more than if you're a student not in hospital. My

IEPs had nothing to say about my hospitalization.

You know, I never went to the IEP meetings. I never knew what was planned. I think the student really needs to know so she can be prepared for doing what needs to be done. A lot of students don't attend the IEP meetings and so they have their lives run by other people. The student needs to have more active involvement because I think you'll find a completely different perspective from the teachers' views and the state's views. That's what's being left out: Taking into consideration what the student thinks.

Most of the meetings that were for me, one parent--my mother--went. My father sort of let my mother be the one to deal with school. I didn't really know what went on unless they said something against me and then she would come home ranting and raving.

I really think they should try to include the parents more. They leave the parents out. They talk around the parent. My mom was always an outgoing person and would've liked to be included in the discussion. They talked to her as if she were a child: "Now, Mrs. Munroe, you can't do this!" They never suggested anything nicely. It was always, "You will do

this, you will do that". They never consulted with her about what was needed. Well, actually, the only school that communicated with us on what I needed was the third school. They worked with us as well as they could.

There was always a health nurse who come home to check on me. She was always the type to tell my mother, "Well, you shouldn't have her doing this." She did not like the health nurse telling her what to do. My mother would have me exercise and the nurses would say, "She really shouldn't be doing that type of exercise". She told my mother what type she felt was best for me. Basically, we just stopped doing everything. It may have been to my benefit to keep doing the ones the health nurse suggested but I didn't like it and neither did my mother.

I agree with a lot of the IEP policies. It's helpful for children who are hospitalized. The rules themselves, I don't think there's much I would change. They are good rules. The way they are enforced could be changed.

They should really challenge the person with "what can you learn" instead of "can you learn?" I like a

challenge. I think they are not really challenging the student with the IEP. The IEP should be a contract between the student and this group of people. If the student has that contract, it's an incentive to do better. Students like to know that they are succeeding on their own and not that somebody is making concessions for them all the time: "Okay, you can't do this...let's take this out". I think that eventually a student, if willing to learn, will learn.

I, for one, would definitely have liked to attend the meetings. I'd like to know what they're thinking of doing with me. They should include you in there because you know more about what you think.

Well, when I was in elementary school, I was shy. I'm not really sure it would have done that much good to have me there but, you know, at least they could've asked my opinion. I realize now that I should have told them exactly what I wanted but I didn't at that time. Even if they don't ask the student to come to the meetings, they should tell the student what's going on. They never told me. They just put the plan into action.

The policies say that, if possible, the physical

therapist and people like that should be there. They never were at my meetings. I really think an occupational therapist would have helped. When I was in high school, I wanted to study computers and get into business. They didn't think that was best for me. Occupational therapists could've given the people some ideas about how to accommodate equipment.

All in all, I'd say I had a pretty good childhood. It's rough at times but I can't say I didn't enjoy it. I did. I had experiences that have given me the confidence to do what I want to do. I think that's the main goal of an IEP: To increase confidence because if you're doing things that you succeed in, you feel more confident about your abilities. When people say, "You're not good at this", I say, "Oh, yes, I am!" When I was young, I didn't think I was good at English or math. Now in college, I'm majoring in both. Individualized education in my life has allowed me the freedom to do what I want.

### Summary

Brianne, Caroline, Olivia, Pam and Tiger told stories to interpret their IEP experiences for us. The stories illustrate these individuals' opinions and suggestions about the IEP policies and practices.

To varying degrees, the stories are of exclusion at certain levels, inclusion at others; rejection by some, acceptance by others; isolation, at times; and stigmatization in a variety of ways. The stories are also testaments of having survived school systems to become well adjusted and optimistic young adults.

All five were of the opinion that the IEP policies were sound. Brianne was impressed with their thoroughness. She, Caroline and Pam had reservations about their implementation. Caroline stressed that laws alone cannot do much. It is people who make the difference.

To Tiger, the IEP document was as significant as his graduation ring and photograph. They were artifacts of an education he was proud to have received. He was the only one who had his IEPs filed away carefully. Even Brianne, who referred to IEP documents as worthless pieces of paper, recognized what

they represented. She wished there was a way to make sure everyone who ought to receive one did. All five participants stressed the importance of the disabled child's participation in IEP meetings.

Specific recommendations dealt mainly with the implementation of the regulations. One common concern was about who should make which decisions. A second revolved around the quality of service delivery. All five gave rich descriptions of exemplary teaching practices that illustrate individualized education. In contrast, many instances of poor service delivery were also described.

Each participant's unique experiences illuminated the analysis from a different angle: Pam's hospital experiences; Olivia's experience of first being classified as learning disabled and then as gifted; Brianne's stint in a residential, segregated institution; Tiger's positive and encouraging school experiences; and Caroline's experiences of continuous taunts and teasing. In addition, their lives outside the school are a reminder that children operate within unique sociocultural settings that extend far beyond the four walls of classrooms.



Pam reconceptualized IEP curriculum development to include organizing the child's social environment by educating classmates and teachers about the child's handicap. Olivia dwelt on the philosophy of the law and raised some pertinent questions about children's education in today's world. Brianne explicitly referred to the social minority experience and the others reflected that perspective, too, when they implied that they were handicapped more by being different than by the actual disabilities.

Some of those experiences might have been direct outcomes of IEPs planned for them. Others might have been there regardless of whether these five individuals had IEPs. All, however, are part of the total IEP experience as recalled by each person.

## Chapter V

### Discussion, Recommendations and Conclusion

As a framework to structure my discussion, I use the components of PL 94-142's promise: That each handicapped child has the right to a free and appropriate education in the least restrictive environment possible. First, I address the appropriateness of these five individuals' school experiences. Next, I dwell on the school environment. The costs of their education follows and, finally, the empowering of disabled children so that they may enjoy their rights more fully.

#### Appropriateness of Education

The appropriateness of one's education may be evaluated in terms of the outcomes (what the child has learned) and the input (the curriculum developed for that child). The outcomes commonly attributed to formal curricula include the retention of academic knowledge and demonstration of academic skills. Important as these are, there are other lessons being learned: Lessons about oneself and about one's world. Not all of it occurs within the school facility. When it does, the learning is not always intended by

curriculum developers. Such learning is as important to a child's development as the academic learning.

### Learning about Oneself

When Caroline listened to her stepfather telling her mother that she was wasting her time trying to teach Caroline, when a teacher called her "stupid" in front of the whole class, and when peers called her names, she was hearing messages about herself in terms of how others perceived her. She was learning about herself. We define ourselves using the feedback we continually receive from those we relate to because

the definition of a person is to be found in the relationship between the definer and the defined, not determined either by personal characteristics or the abstract meanings attached to the group of the which the person is a part (Bogdan & Taylor, 1989, p.136).

In many cases, that relationship is influenced by the definer's misconceptions of a disability and the abstract meanings attached to having that disability. All five participants experienced treatment by others that reflected such misconceptions.

In order to develop positive self esteem, children need feedback that affirms their individual strengths as human beings. To this end, Pam's recommendation may be a first step: That IEPs include the child, the

classmates and the service providers learning about the child's disability. Once misconceptions about disabilities are cleared, both the child and those relating to the child may be able to see beyond the disability and appreciate the child's strengths.

### Learning about the World

An important part of education is learning about the world. Brianne was glad that she returned to public school because she felt the best way to learn about surviving in the "real world" was to live in it. Education in the mainstream (nonresidential, integrated public school) gave all five participants ample opportunity to learn about the nondisabled majority culture and vice versa.

Their experiences gave them some mixed messages about their worth to society. On the one hand, our society embraces the notion that every member is equally valuable. On the other, these disabled children were devalued consistently in school through the stigma attached to special education. The stigma goes deeper than contagious name-calling by peers. Ferguson (1987) believes there are more subtle forces at work:

Generally students assigned to a regular/resource room combination leave the regular class during academic instruction. Less important experiences from the school's point of view, such as art, music, gym, shop, and home economics, fulfill the LRE requirements. The not-very-hidden message of these status-of-knowledge distinctions is powerful indeed (Ferguson, 1987, p. 97).

When Caroline, Pam and Olivia were taken out of special classes and integrated fully into regular classes, they did as well as (if not better) than before. The onus was on them to prove that they deserved to be taken out of special classes and be allowed to remain in regular classes for academic subjects. The nondisabled child is not vested with the same responsibility. Such differential treatment reflects that we are placing the blame for having a disability on the child.

For a disabled child, everything that is in addition to the regular curriculum for the class is to be planned at IEP meetings. Participating in IEP meetings enables the child to contribute to the planning. At the least, by attending their IEP meetings when they were older, Brianne and Tiger were able to seek clarification of and gain insights into plans made for them. The other three would have appreciated such opportunities. Even as an adult, Pam could not fathom why she was put in a special

mathematics class. Caroline did not understand why her teachers went so slow. Olivia saw no meaning in learning the spellings of teacher-selected words. Being included in IEP meetings may have reduced the number of unexplainables haunting them. Children deserve explanations for what is being done to and for them. Those explanations help them make sense of the adult world and how it operates.

Inviting children to observe and contribute to group decisionmaking would give them the opportunity to directly experience democratic processes at work. Since participatory democracy at the grassroots level is a core value for many of us, it is important that children experience it in their daily school lives. I believe such learning is especially crucial for children who have been marginalized by society. When they become the next generation of adults, these early experiences may provide the impetus for their visions of educational reform.

### **Individualized Programming**

Picture little Brienne sitting day after day, all alone in a class of strangers, overturning cards she could not see. This instance of intra-class

segregation illustrates the power that adults have over children. However well-intentioned they may be, the Mr. Halms and Miss Trumans of the world personify the risks in individualized programming. Only when Cate replaced Mr. Halm did Brianne start "to feel like a person".

The appropriateness of a child's education depends to an extent on the curriculum developed for that child. Schools peer through a deficit model which is so powerful that irrational decisions may be made (Gliedman & Roth, 1980). Pam's is a case in point: A child has missing hip joints; she is placed in a special mathematics class. The message the school is giving such a child is that the world sees his or her disability before anything else.

The IEP regulations should include a statement about the inappropriateness of the social pathological model for educational planning. The medical paradigm does not have a place in education. Its pervasive influence should be counteracted. Legislators should take a stand clearly against the use of the medical paradigm in schools. Teacher educators should be directed to address the influence of paradigms on

teaching practices and facilitate heightened awareness of personal biases in their use.

**Assessment** Caroline complained about a curriculum that aimed at learning through games instead of going through regular chapters in a text book. Perhaps, the teachers were trying to make learning fun and meaningful. The real problem, then, might have been a miscalculation of the level of challenge that would be required to stimulate her. When the level of challenge is too low for the level of skills the player has, the player gets bored (Csikszentmihalyi, 1990).

To evaluate a disabled child's skills and design learning experiences that offer the right degree of challenge calls for perspective-taking. Teachers who have difficulty taking the perspective of a disabled child are more likely to plan curricula that does not meet that child's needs. The early school activities planned for Brianne were totally inappropriate for a child who could not see. Assuming her teachers meant no harm, Brianne's first teachers seemed to have had difficulty taking an insider's perspective of a blind child.

Teacher education programs should place a strong



emphasis on developing the generic skill of perspective-taking. Perhaps, student teachers need simulated exercises like the ones that Olivia had in school to help them take the perspectives of children with disabilities.

Also worth pursuing is Caroline's recommendation that teacher education should include learning about disabilities. However, one can learn about only a finite number of disabilities and, in terms of the social minority model, can learn only about a finite number of minority cultures. It is more important that teachers learn how to locate and utilize information about social minority groups (including children with disabilities) as and when the need arises.

For accurate evaluation, the evaluator has to try to gain an insider's perspective of the child by getting to know the child. Pam reasoned that she was misplaced in the special mathematics class because they didn't know her well enough and didn't take the trouble to get to know her. An outsider's perspective of people with disabilities may emphasize deficiencies and incompetence (Goode, 1991). Goode found his definition of a middle-aged man with Down Syndrome was transformed

by attempting to adopt an insider's perspective through interviews and videotaped observations. Olivia's art teacher knew the golden rule: "Watch her for awhile." Pam suggested another: "Ask 'What can you learn?'" instead of 'Can you learn?'"

**Curriculum Content** There are several issues here that should be studied closely by schools and policymakers. Firstly, we have to think about who is responsible for which parts of the disabled child's education. Today, there is general consensus that, as far as possible, the needs of disabled children should be met by services provided for all children. Olivia posed an important question: Between the family and the school, if one does not fulfill its role in educating the child, should the other compensate?

Secondly, what should the goals of education be for disabled children? The IEP documents often have numerous goals and objectives in very behavioristic language (e.g. Appendix C). Caroline's teacher was probably referring to one such objective when she told her she should work harder at her multiplication tables. This kind of individualized programming does not promote education as an intrinsically motivating

process of discovery and mastery.

Highly specific, minutely fragmented, quantifiable goals and objectives commit students and teachers alike to experiencing education as a process where students attempt to come as close as possible to teacher anticipated outcomes. An important risk of this brand of individualization is that the burden of failure rests squarely on the individual students in classic 'blaming-the-victim' fashion (Ferguson, 1987, p. 101).

At the other extreme, we have Olivia's recommendation for a totally child-directed education: Let each child explore whatever that child wants to. This becomes a problem if there is a common body of knowledge and set of skills that children have to master to function effectively in society.

We know, at least, that there is a certain amount of knowledge and some skills that have to be mastered before going on to the next stage of education or employment. Caroline found it very difficult when she entered college because she had not covered basic mathematics principles in school. We must examine closely the world in which today's children will live as adults to anticipate what that common body of knowledge and set of skills might be (Cain & Taber, 1987). Unlike the teacher who decided that Olivia should learn handicraft skills instead of reading,

teachers have to be aware of new employment possibilities for people with disabilities.

Grading A third issue is whether the disabled child should be penalized for what he or she is not able to do because of the disability. Brianne felt she should be given an A for the class on office technology and should not be penalized for what she could not do because of visual handicap. Following that line of reasoning, then all children should get As for all their classes as long as there is proof of effort. The question then becomes who should decide if adequate effort was exerted. If teachers were to decide, then with the exception of Mr. Towers' class, Caroline would never have received an A no matter how hard she had tried.

Besides, grades that indicate only the student's degree of effort will be invalid as indicators of the student's mastery of skill and knowledge in that area. Such grades would be problematic on two counts.

Firstly, the grades would have limited use for educational institutes and employers making decisions about who to admit or employ. In the selection process, evaluation results are the currency they work

with. When such decisions are related to future service provision, more complications arise. Current licensing and certification procedures rely on competency-based evaluation. Consumers, in turn, use licensure and certification to guide their choices. In the final analysis, I would have serious reservations about a surgeon operating on me if I knew he or she was certified because of earnest efforts to learn rather than competence.

The second and more immediate concern is that grades would be meaningless as planning indicators to guide curriculum development for that child. It may be argued that conventional tests and measures of academic competence were never very accurate either when used for disabled children (Heshusius, 1982). Heshusius attributed this to the fact that schools operated through a mechanistic world view. She suggested an alternative way to develop IEP goals and objectives:

The importance of each unique teacher-child relationship must be established as influential for making decisions about both goals and means. What do the particular teacher and the particular student have to offer each other at the level of what is meaningful and worthwhile? (Heshusius, 1982, p.11).

Pam's recommendation that IEPs be contracts between

teachers and students complements this proposition. Attractive as it may sound, our public school systems would have to be revamped before such a suggestion could work. Teacher-child ratios would have to be reduced. Teacher education would have to be reformed. In addition to being highly skilled knowledge-brokers, teachers would have to be thinking, feeling perspective-takers capable of making meaningful connections with each child. Adequate administrative and teaching support would have to be given to the teachers. At first glance, these expectations may seem impractical. On closer examination, they are not impossible. Ironically enough, they are the very same changes that are often recommended for curriculum development that is guided by conventional competency-based evaluation procedures. Therefore, regardless of the philosophy of IEP development, teacher education and the enhancement of high quality teaching should be given top priority.

### School Environment

Disabled Peoples International (1985) defined disabled people as people who have a physical, mental or sensory impairment and their handicap is the loss or

limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers. The traditional focus has been on the physical barriers--the physical facility and adaptive equipment. The social environment has not been scrutinized with quite the same intensity. Yet, the social environment can be as restrictive as the steepest flight of steps confronting a wheelchair user.

### Social Environment

Whenever possible, disabled children are to be educated with nondisabled children (PL 94-142, 1975). Integration was meant to eliminate the stigmatization and victimization of segregated schooling by providing opportunities for meaningful interactions between handicapped students and their nonhandicapped peers.

The early public relations television spots about PL 94-142 showed attractive and perky little girls in wheelchairs with school friends eager to wheel them from class to class (Greenberg, 1986, p.4).

Tiger proves that such a scenario is possible. Pam stops us from taking it for granted. For many students, it has resulted in further separation (Ferguson, 1987; Greenberg, 1986).

Tiger's mother's description of Tiger playing with

his friends is a good example of how much more important it is for children with disabilities to participate in normal, everyday activities than for them to perform such activities in a "normal" way. The philosophy of integration is in the best interest of all children because education includes growing in one's understanding of, and ability to live with, diverse people. We learn through our associations with friends who like us as well as those who are not like us. Olivia's first friend was an instrument of learning for Olivia because she realized that "wow...somebody can have a different reality".

Even young children are capable of perspective-taking and moral reasoning to some extent (Eisenberg, 1992). These facilitate the forming of friendships with those who are outwardly dissimilar from oneself. Misconceptions about those who appear different may hinder such efforts. When Brianne's classmates accused the teacher of grading her differently, I believe they were trying to explain what was to them a paradox: A blind child doing well academically.

Cognitive dissonance of this kind arises when children have limited or incorrect knowledge about



children who are different. From a very early age, we try to make sense of the world by developing personal or tacit theories about events as ways of reducing ambiguity and explaining paradox (Marshall & Rossman, 1989). Friendships with disabled children may reduce the risks of forming tacit theories that set into strong prejudices as the child grows older.

Present classroom practices often resemble the experiences of Brianne and Pam when the classmates who agreed to accompany them to lunch were allowed to leave early. Adult-directed, extrinsically-rewarded, unidirectional helping relationships are being fostered instead of true friendships. How can adults facilitate true friendships between disabled and nondisabled children? There is very little literature, if any, about it.

There is a growing body of knowledge about children's prosocial behavior (e.g. Eisenberg, 1992). That knowledge could be supplemented with research findings about friendships between disabled and nondisabled children. We need research on complex, multidimensional friendship relationships of the Brianne-Mindy quality. We also need research on the

less intense but as important playful give-and-take relationships such as those between Tiger and his baseball friends. Meanwhile, the making of true friends remains a formidable task for many disabled children in the public schools. Recall Brianne's words: "I actually made a friend that year. That was an accomplishment."

We do not know very much about the effect the teacher has on how children treat the child with a disability. The contrast Brianne drew between the first class she was in and the second poses some interesting questions about the role of adults in effecting such a dramatic change. We know that children learn prosocial behavior by observing adults (Eisenberg, 1992). Ethnographic studies may shed more light on the influences of the teacher, classmates and the child itself on its social environment; and how the social environment, in turn, effects the child's learning. The knowledge gained could be instrumental in planning more comprehensive IEPs. By law, the IEP is not restricted to academic areas. If IEP conferees were convinced of the influence of the child's social environment on learning, they may see the sense in

formulating objectives about, for instance, the making of friends.

### Program Structure

Caroline, Olivia and Pam described their special classes as if they were prisoners in them. They were relieved to be taken out of them. Caroline went to the extent of showing a friend how to get out, too. The purpose of having special education classes and resource rooms is defeated if children feel they are worse off by being in them.

The participants' programs required them to leave their regular classrooms. Individualized education should not translate into being singled out. Children strive hard to belong. They are still egocentric in their perception of how others perceive them. Perhaps no one noticed the children who went into the special classes but those children felt they were conspicuous.

Tiger did not feel the same resentment but he, like the others, found the daily transitions between regular and special classes difficult. The participants draw attention to other types of transitions: Olivia gives a graphic description of the transition from first to second grade; Pam talked about

transitions from school to school; Tiger from town to town; and Pam between hospital and school.

The IEP policies address only the transition from school to school. Beyond that, service providers should explore various alternatives to ease the transitions for the child. One option could be the use of interactive communication through computers in the classroom. The student could remain in the regular classroom, participate in the ongoing class and when class is working on problems, communicate silently with a resource teacher located outside the room.

Interactive technology that is used in distance learning could be used when children are hospitalized. The child can continue to be part of the classroom even if only through a television screen. We hear of incidents where such technology is used today with children who have communicable diseases. Teachers should be given the necessary technical assistance to include such innovative strategies in their regular IEP planning.

### Costs of Education

Children with IEPs are guaranteed a free public-sponsored education. By definition, the education is

to be at no cost to the child or the child's family (PL 94-142, 1975). Ironically, if anyone anticipated the problems with such a promise, it was the president who approved PL 94 142, President Gerald R. Ford. After grudgingly approving the bill, he publicly voiced his apprehensions.

Unfortunately, this bill promises more than the Federal Government can deliver, and its good intentions could be thwarted by the many unwise provisions it contains...Even the strongest supporters of this measure know as well as I that they are falsely raising the expectations of the groups affected by claiming authorization levels which are excessive and unrealistic...It contains a vast array of detailed, complex, and costly administrative requirements...complex requirements under which tax dollars would be used to support administrative paperwork and not educational programs" (Ford, 1975)

In the years following, the federal government channelled more funding towards improving educational service delivery for disabled children. More recently, however, there has been reduced budgetary support for the education of disabled children (Newman, 1991). The costs of providing individualized education have not gone down.

When we do not invest what it takes to make individualized education work, then children pay the price. Teachers who have inadequate support are

handicapped themselves and the quality of their services suffers. When this happens, it is impossible to assign a dollar value to the emotional costs for children. The stories that the participants told spoke of anxiety, shame, fear, frustration, a sense of helplessness and feelings of being shortchanged. Unless the nation invests adequately in the education of children with disabilities, the children will continue to pay the price in a currency that does not lend itself to dollar estimates. These children are being deprived of their right to that education which was to be at no cost to them or their families. That the participants survived their early school experiences is a testimony to the resilience of the human spirit and its ability to make peace with society's shortcomings. It should not be an excuse for not investing in higher quality educational services.

The most striking examples of individualized education given by the participants were of teachers who were creative with their resources. Planning a creative curriculum that meets individual children's needs requires time and effort. Teachers who are bogged down by the administrative requirements of the

IEP policies will have that much less to expend on their curriculum development and actual teaching (Fiscus & Mandell, 1983; Weiner, 1985). Policymakers should reassess the IEP regulations to determine whether such detailed administrative requirements are still justifiable. In 1975, the IEP policies were tailored to pacify parent groups and the disabled peoples' lobby. Today, we could take a more proactive stance and work on the assumption that good teachers prefer to use their time and resources planning for and working with children rather than on paperwork.

Overworked, underpaid service providers often do not stay on the job long enough to become experienced professionals (Greenberg, 1986). Overwhelmed by the paperwork they are responsible for (Weiner, 1985), many teachers burn out early in their careers and do not have the emotional energy to be the "motivators" Caroline wished they could be. Brianne's comment that teachers should not complain about paperwork because they're better off than the child with a disability may be valid but not necessarily the only stance to take. Teachers deserve tangible support: employment incentives; aides; administrative assistance; classroom

resources; and whatever else it takes to improve service delivery. Children will, in turn, gain from the improved teaching.

If federal funds were channelled into teacher education about and support for IEP classroom practices, teachers may see the value of developing IEPs regardless of the legal requirements. Then the policing function of the IEP document could become less urgent. Less time, effort and money could be spent on administrative checks for minimal compliance and more on exemplary classroom practices.

Educational futurists predict that the use of electronic technology for administrative work will permit the school of the 21st. century more time for curriculum development and teaching (Cain & Taber, 1987). Policymakers should explore making monies available for such technology, too.

### **Empowering Disabled Children**

Disabled People's International has repeatedly stressed that they do not want services provided out of sympathy or compassion. Disabled people want programs based on human rights principles: full participation, self-determination, integration into society and



equalization of opportunity (Driedger, 1989). For all this to be possible for disabled children, they have to be empowered.

### Children's Advocates

Children are first empowered through their advocates. The genius of PL 94-142 is that the child is provided with two advocates who each act as an independent check on the other (Gerry, 1987). The parent is one. The other is the school district: The school district has a statutory obligation to be a co-child advocate. Both are equally responsible for protecting the child's best interests. When these advocates are empowered, the child stands to gain.

The mothers of Brianne, Caroline, Pam and Tiger attended their IEP meetings and put in a great deal of time and effort to help their children. What they did was commendable but not always possible for all parents. These four were fortunate to have had mothers who could be as involved as the IEP policies suggested they be. In school, Brianne's Cate, Caroline's Mr. Towers, Pam's school nurse who was like a second mother, and Olivia's art teacher were strong advocates for them. Once again, it is fortunate that these

people were there for the children. What if they had not been there? A child's probability of having a sincere advocate should not depend purely on luck.

Section 399.514 makes provision for the appointment of a surrogate parent to act for any child when the parents are unknown or unavailable or when the child is a ward of the state. Olivia's mother chose not to attend and, thus, Olivia did not qualify for a surrogate parent under the present regulation. If Olivia had been given the option, she might have suggested contacting either her "adopted grandmother" or "stepfather". I recommend that the regulations should be amended to make provision for children to request a surrogate parent of the child's choice in the event that the parents who are the legal guardians do not attend IEP meetings (regardless of the reason). The fact that there is no typical American family today (Newman, 1991) justifies asking children to identify their parent figures.

Parents' co-advocates, teachers, do not usually have advocacy listed in their job descriptions. Those aspects of the job that call for sensitivity, nurturance and understanding are not legitimized parts

of the teacher's work either. Yet, according to the participants, these are the requirements for good teaching. Teachers are evaluated in ways that do not credit them with these types of work. Traditionally, children's service providers were mainly women. The longstanding cultural denigration of much of women's work because it does not formally contribute to a capitalist economy as paid labor (Ferguson, 1987) infiltrates into "women's careers". Further research is needed to re-evaluate the meaning of various aspects of teachers' work in terms of what it takes to individualize education effectively.

### Power Sharing

The five participants felt it was important that disabled children participate in the planning of their IEPs. As part of a student empowerment program, Davis (Davis & Ferguson, 1992) prepared students to participate in their IEP meetings. She helped them understand the IEP process, identify and defend their own priorities, and develop strategies for participation that would help express their wishes and get them met. They practiced their presentations in groups and observed a mock IEP meeting. At the actual

meetings, they participated with varying degrees of success (Davis & Ferguson, 1992). Davis found that as the students became more empowered, they forgot her role in helping them and she found her own power diminishing (Davis & Ferguson, 1992). Is it any wonder then that power sharing is a democratic ideal which many adults hesitate to put into practice? Those who plan and implement IEPs would benefit from research that deepens our understanding of power sharing with children.

Service providers should be empowered enough themselves to allow children some control over their school lives. When children feel they have some control of their own education, they will be more motivated. Olivia, by obtaining passes to leave the special education class, self-individualized her education by seeking higher levels of challenge. She felt she had more control and was thrilled at the thought of having "full reign of the whole building".

### **Self Determination**

A large component of Brianne's experience of the IEP practices was encouragement to indicate preferences and make choices. The choice-making capacity to

recognize and select from a range of opportunities is critical to active, independent functioning (Ferguson, 1987). People are empowered only when they have the capacity to make choices and there are real choices to be made. Children and their families should have choices about which would be the least restrictive environment for the child: The residential school, the fully integrated classroom, the separate special education classroom or combinations of these. Disabled children should have the choice of when they want to spend time with similarly handicapped peers and when they want to be in the mainstream with other children (Asch, 1989; Greenberg, 1986). They should have the option to attend IEP conferences and to have test results and other reports accessible and explained to them if they require.

None of the participants or even potential participants knew of PL 94-142 or legislation specifically about IEPs. Many did not know that they were entitled to IEPs by the law of the land. In fact, most did not know what an IEP was. If individuals with disabilities are to become self-determined decision-makers, then it is important that they know about and

understand the laws that ensure them their rights (National Information Center for Children and Youth with Disabilities, 1991).

It is not the information but the use of information which is powerful (Cain & Taber, 1987). There is some excellent literature explaining the educational rights of disabled children and courses of action available to actively pursue those rights (e.g. Ferguson & Ripley, 1991; National Information Center for Children and Youth with Disabilities, 1992; U.S. Department of Education Office for Civil Rights, 1989). This literature is written for the parent or adult reader. Literature should be produced specifically for children of different ages. The literature should reflect consideration of developmental levels and the concerns specific to the type of handicap. We have to devise developmentally appropriate ways to educate children about these rights and how the knowledge may be used. To empower the disabled child, there should be role models in that literature which documents a repertoire of skills and knowledge that disabled children may find useful (Asch, 1989; Olson, 1986). For example, disabled people should write about their

lived experiences of IEP meetings and advise children about participating in them.

### Summary of Recommendations

#### For Policymaking

Policymakers should continue to be committed to the vision of every disabled child receiving IEPs. They should make provisions for the funding of (1) research and training programs on IEP development and implementation for service providers, parents and disabled children respectively, (2) administrative and classroom support for good teaching practices, and (3) remuneration that matches the complexity of providing services for disabled and nondisabled children in integrated classrooms.

Student empowerment should feature more prominently in the regulations. Regulations about IEP meeting attendance and receiving copies of IEP documents should be amended to specify that the student should decide about the nature of his or her participation. Regulations should specify that evaluation results and the IEP contents should be explained to the student and parents. The regulation about surrogate parents should be amended to state that

a child should be given the option of selecting a surrogate parent to attend IEP meetings in the event that the legal parents do not attend for whatever reason.

Policymakers should take a clear stand against the use of the deficit medical model in education. The regulations themselves should be amended to reflect a more proactive stance that promotes exemplary practice instead of the existing reactive approach that seeks minimal compliance.

Policymakers should contemplate the use of IEPs for all children as part of the nation's plan to meet the educational needs of an increasingly diverse student population. Monies should be channelled towards the study and development of curricula for pre-service and in-service teacher preparation for such a reform.

#### **For Service Provision**

Whenever possible, service providers should use the IEP as a contract between the teacher and the student. They should realize the potential to use IEPs to address much more than the traditional academic concerns. All aspects of the student's sociocultural



environment should be explored with the intent of providing the most conducive learning environment for an education that is appropriate and at least cost to the student and his or her family. Accurate assessment of the student's needs should be seen as integral to such planning. Teachers should be aware of their powerful presence in the student's school experiences and use that presence in ways that make the student's schooling meaningful and worthwhile.

#### For Research

All the recommendations for policymaking and service provision would benefit from further research on individualized educational programming. Future research could study the social environment of disabled students. How are friendships between disabled and nondisabled children formed and maintained? In what ways does the adult presence in the social environment promote such friendships? In what ways does it restrict them? How do adults influence the child's learning? How do peers?

I strongly recommend research on curricula for teacher education that seeks to develop highly skilled professionals capable of planning and implementing

research should be informed by the lived experiences of disabled children, their peers, parents and the teachers themselves. If I were to conduct such research, I would develop hypothetical IEPs for the child that I remember being and ask the same of all participants and co-researchers. From there, we would develop working models for IEP development and implementation.

### Concluding Remarks

The amendments to special education laws have been in the direction of greater inclusiveness as more and more types of disabilities are becoming acceptable criteria for receiving IEPs. The time is ripe for introducing the use IEPs for all children in a national effort to improve educational services. Some school systems do already provide IEPs for all their children. The trend has raised fears that the needs of disabled children will, once again, be ignored as teachers try to mass-produce IEPs (Fiscus & Mandell, 1983). I do not believe that will happen for there is no turning back now. Just as Tiger reacted to the new school which had no special services for him, we will find it "strange...very strange" when we come across a school

that ignores the needs of social minorities. I believe the IEP may be one of the only truly viable alternatives for effective curriculum planning in a country where the student population is becoming increasingly diverse in every way. However, as is the case with any powerful instrument, a high degree of professionalism should be exercised in individualized educational programming. Done poorly, it can be oppressive. Done well, it will be liberating.

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## Appendix A

### IEP Regulations (Abridged)

Given below is a summary of the IEP regulations. They are the United States Federal Regulations Code 34 Parts 300.340 to 300.349 found in the Federal Register (Volume 46 Number 12, January 19, 1981, Rules and Regulations, pp. 5462 - 5474).

#### **Reg. 300.340 Definition**

The IEP is a written statement for a handicapped child that is developed and implemented in accordance with Regs. 300.341 to 300.349.

#### **Reg. 300.341 State educational agency responsibility**

The state educational agency (SEA) shall insure that each public agency develops and implements an IEP for each of its handicapped children. The SEA shall insure that an IEP is developed and implemented for each of its handicapped children (a) placed in or referred to a private school or facility by a public agency or (b) is enrolled in a parochial or other private school and receives special education or related services from a public agency.

#### **Reg. 300.342 When IEPs must be in effect**

From 1st October 1977, each public agency shall have in effect an IEP at the beginning of each school year for every handicapped child who is receiving special education from that agency. An IEP must be in effect before special education and related services are provided to a child. The IEP must be in effect as soon as possible following the meetings under REG. 300.343.

#### **Reg. 300.343 Meetings**

Each public agency is responsible for initiating and conducting meetings for the purpose of developing, reviewing, and revising a handicapped child's IEP. A meeting must be held within thirty calendar days of a determination that the child needs special educational

and related services. Each public agency shall initiate and conduct meetings to periodically review each child's IEP and if appropriate revise its provisions. A meeting must be held for this purpose at least once a year.

**Reg. 300.344 Participants in meetings**

The public agency shall insure that each meeting includes: (1) a representative of the public agency, other than the child's teacher, who is qualified to provide, or supervise the provision of, special education, (2) the child's teacher, (3) one or both the child's parents, subject to Reg.300.345., (4) the child, where appropriate, (5) any other individuals at the discretion of the parent or agency.

For a child who has been evaluated for the first time, the public agency shall insure (1) that a member of the evaluation team participates in the meeting or (2) that the representative of the public agency, the child's teacher, or some other person at the meeting, who is knowledgeable about the evaluation procedures used with the child and is familiar with the results of the evaluation.

**Reg. 300.345 Parent participation**

Each public agency shall take steps to insure that one or both of the parents of the handicapped child are present at each meeting or are afforded the opportunity to participate . The steps include: (1) notifying parents of the meeting early enough to insure that they will have an opportunity to attend and (2) scheduling the meeting at a mutually agreed on time and place.

The notice must indicate the purpose, time and location of the meeting and who will be in attendance. If neither parent can attend, the public agency shall use other methods to insure parent participation, including individual or conference telephone calls. A meeting may be conducted without a parent in attendance if the public agency is unable to convince the parents that they should attend. In this case, the public agency must have a record of its attempts to arrange a mutually agreed on time and place such as (1) detailed

records of telephone calls made or attempted and the results of those calls, (2) copies of correspondence sent to the parents and any responses received and (3) detailed records of visits made to the parent's home or place of employment and the results of those visits.

The public agency shall take whatever action is necessary to insure that the parent understands the proceedings at a meeting, including arranging for an interpreter for parents who are deaf or whose native language is other than English.

The public agency shall give the parent, on request, a copy of the IEP.

#### **Reg. 300.346 Content of IEP**

The IEP for each child must include: (a) a statement of the child's present level of educational performance; (b) a statement of annual goals, including short term instructional objectives; (c) a statement of the specific special education and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs; (d) the projected dates for initiation of services and the anticipated duration of the services; and (e) appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved.

#### **Reg. 300.347 Private school placements**

Before a public agency places a handicapped child in, or refers a child to, a private school or facility, the agency shall initiate and conduct a meeting to develop an IEP for the child in accordance with Reg.300.343. The agency shall insure that a representative of the private school facility attends the meeting. If the representative cannot attend, the agency shall use other methods to insure participation by the private school or facility, including individual or conference telephone calls. The public agency shall also develop an IEP for each handicapped child who was placed in a private school or facility by the agency before the effective date of these regulations.

After a handicapped child enters a private school or facility, any meetings to review and revise the child's IEP may be initiated and conducted by the private school or facility at the discretion of the public agency. If the private school or facility initiates and conducts these meetings, the public agency shall insure that the parents and an agency representative (i) are involved in any decision about the child's IEP; and (ii) agree to any proposed changes in the program before those changes are implemented.

Even if a private school or facility implements a child's IEP, responsibility for compliance with this part remains with the public agency and the SEA.

**Reg. 300.348    Handicapped children in parochial  
                  or other private schools**

If a handicapped child is enrolled in a parochial or other private school and receives special education or related services from a public agency, the public agency shall (a) initiate and conduct meetings to develop, review and revise an IEP for the child, in accordance with Reg. 300.343; and (b) insure that a representative of the parochial or other private school attends each meeting. If the representative cannot attend, the agency shall use other methods to insure participation by the private school, including individual or conference telephone calls.

**Reg. 300.349    IEP - accountability**

Each public agency must provide special education and related services to a handicapped child in accordance with an IEP. However, Part B of the Act does not require that any agency, teacher, or other person be held accountable if the child does not achieve the growth projected in the annual goals and objectives.

## Appendix B

### Circular Inviting Participation

(on departmental letterhead)

#### School Experiences of Disabled Children

Over the last few decades, there have been many changes in the type of education available to children with disabilities. Many research studies have also been done over the years. Most of the studies tell us what teachers and parents feel about the kind of education that disabled children are getting. However, we do not know very much about how disabled people themselves feel about their school experiences. I believe the best way to find out is to ask them directly. Therefore, I am doing a study that will use the memories and views of people who were considered handicapped children when in school.

At this stage, I am looking for people who may be willing to participate in this study. They should be between 21 and 25 years old. If you would like to know more about it, could you, please, return the attached postcard to me? Alternatively, you could give me a telephone call (703-343-7751). Thank you.

Mary Cherian

# Appendix C

## Sample of Tiger's IEP Reports

Page 1

ALYSID 304 SPECIAL EDUCATION INDIVIDUALIZED EDUCATION PROGRAM

I. Student \_\_\_\_\_ Date of Birth \_\_\_\_/\_\_\_\_/\_\_\_\_ Age \_\_\_\_ LEA \_\_\_\_\_  
 Parent/Guardian/Surrogate \_\_\_\_\_  
 Address \_\_\_\_\_ Home Phone \_\_\_\_\_  
 \_\_\_\_\_ Work Phone \_\_\_\_\_  
 \_\_\_\_\_ Expiration Date of IEP 5 12 1 86

Date of Most Recent Eligibility 11/2/81  
 Date of IEP Meeting 5/2/85  
 Handicapping Condition(s):  
 PRIMARY EMR  
 SECONDARY \_\_\_\_\_

II. PRESENT LEVEL OF EDUCATIONAL PERFORMANCE Speech/Language Evaluation (if applicable)

Academic Achievement: PIAT 9-16-83 Annual Update  
Fall Evaluation  
 4-2-89 Woodcock Read. Abnt Math- 3.8 3-19-85: Notmeyer Diag. Sp. Test. 6.0  
 Letter ID = 12.9 RR 5.2 8-10-85: Gleason Oral Read. 8.6  
 Word ID = 8.8 RC = 3.3 4-10-85 Breakthrough Math = see that  
 Word Att = 11.3 Sp = 2.3  
 Word Comp = 1.8 GI = 3.8  
 Pass Comp = 3.2 3.9  
 Pre Vocational Vocational Ability-89 Bandline (59-65) full Scale Psy IQ = EMR  
Horticulture

Social Adaptation Friendly, gets along with teachers and peers.

Psychomotor uses crutches, leaves some classes early - uses elevator

Self Help Skills Usually reliable, well groomed

Page 2

III. DISCIPLINE Name of Student \_\_\_\_\_ (2)  
 Student's behaviors affecting educational programming:  
 Discipline of handicapped students. 1) All disciplinary measures which are appropriate for the non-handicapped shall apply 2) Other measures as needed.

IV. LEAST RESTRICTIVE ENVIRONMENT

Special Education and Related Services	Frequency and Duration (per week)	Date to Begin	Anticipated Completion Date	Location/Provider
<u>English</u>	<u>50 min x 5 days</u>	<u>8-85</u>	<u>6-86</u>	_____
<u>Assessment</u>	<u>"</u>	<u>"</u>	<u>"</u>	_____
<u>Life Skills Math</u>	<u>"</u>	<u>"</u>	<u>"</u>	_____

P.E.: Adaptive \_\_\_\_\_ Regular  General \_\_\_\_\_ Special

Extent of participation with non-handicapped students

	ACTIVITIES/GRADE PLACEMENT	AMOUNT OF TIME PER WEEK
Academic	<u>Physical Ed.</u>	<u>50 min x 5 days</u>
Non Academic	<u>Computer Lit.</u>	<u>50 min x 5 days</u>
	<u>Horticulture</u>	<u>" " " "</u>
Extra Curricular	<u>Study Hall</u>	<u>" " " "</u>
	<u>Art I</u>	<u>" " " "</u>

V. MINIMUM COMPETENCY TESTING (APPLIES ONLY TO 9th GRADE STUDENTS)  
 Is this student expected to take the MCT?  Yes  No If yes, provide approximate date \_\_\_\_\_  
 (See separate form for specific MCT information)

CONFIDENTIAL: Information on this page must be maintained in the student's confidential file.



VI PRESENT AT INDIVIDUALIZED EDUCATION PROGRAM MEETING

Name of Student \_\_\_\_\_ (3)

Page 3

Date	Signature of Persons Present	Relation to Student
5-2-85	_____	Sp Ed Teacher
5-2-85	_____	Sp Ed Teacher
5-2-85	_____	Counselor

NOTE: All of the elements of the IEP (including Section B) must be complete before the signature of the parents is obtained

VII I give permission for my child, \_\_\_\_\_, to be enrolled in the special education program described in the Individualized Education Program Plan. I understand that I have the right to review his/her Individualized Education Program at any time. I understand that I have the right to refuse this permission and to have my child continue in his/her present placement pending further action. I understand the contents of this document and I have been informed of my due process rights. I have received a copy of the IEP and the procedural safeguards.

\_\_\_\_\_  
Date Signature of Parent/Guardian

*Voc. courses are subject to change*

I do not give permission for my child, \_\_\_\_\_, to be enrolled in the special education program described in the Individualized Education Program Plan. I understand that I have the right to review his/her records and to request another placement. I understand that the action described above will not take place without my permission or until due process procedures have been exhausted. I understand that if my decision is appealed, I will be notified of my due process rights in this procedure. I understand the contents of this document, and I have been informed of my due process rights. I have received a copy of the IEP and the procedural safeguards.

\_\_\_\_\_  
Date Signature of Parent/Guardian

CONFIDENTIAL: The information on this page must be maintained in the student's confidential file

SECTION B. Annual Goals and Short Term Objectives

Page 4

Student: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ School Year: \_\_\_\_\_ (4)

VII Annual Goals

1. \_\_\_\_\_ will complete all English classwork, homework, projects, activities, and tests with 70% (C) accuracy or greater.
2. \_\_\_\_\_ will complete all government classwork, homework, reports, projects, and class activities, tests and quizzes with 70% (C) or greater accuracy.
3. \_\_\_\_\_ will complete all Lipinville Math classwork, homework, projects, activities, tests/quizzes with 70% (C) or greater accuracy.
4. \_\_\_\_\_ will complete all vocational courses scheduled with 70% (C) or greater accuracy.
5. \_\_\_\_\_ will complete all P-physical Education requirements with 70% (C) or greater accuracy.

NOTE: Information on this page may be maintained in the student's cumulative file and/or teacher's file

Appendix D

Letter of Agreement

This is an agreement between \_\_\_\_\_ and Mary Cherian about our research partnership in the project "Individualized Education Programs as Lived Experiences". We may revise the agreement when either of us feels the need to.

I, \_\_\_\_\_, consent to participate in the study as a co-researcher and primary informant. My privacy will be protected by using pseudonyms of my choice for people I mention. I am aware of my right to withhold information, withdraw what I have shared and/or discontinue participating at any time. I understand the success of the study depends on my sustained involvement over a several months and so, I will try my best to fulfil my commitment.

.....  
(Signature of Participant)

I, Mary Cherian, will try to be sensitive to your needs as we work together on this project. I will meet you at times and places that are convenient to you. If you feel the need to, a session can be postponed. During sessions, we can take breaks, stop early or do whatever both of us feel would make the experience as comfortable as possible. I will make copies of your documents or seek information about you only with your consent. Before submitting my dissertation, I will ask you to validate the section we will be working on together.

.....  
(Principal Investigator)

**MARY CHERIAN**  
2737 Fletcher Street  
Salem, VA 24153  
TEL: (703) 389-5972

**Education**

- Ph.D.           Family and Child Development, present  
                  Specialization: Child Development  
                  Cognate: Public Administration & Policy  
                  Virginia Tech, Blacksburg, Virginia
  
- M.A.           Applied Psychology, 1982  
                  Major: Guidance & Counseling  
                  University of Madras, India
  
- B.A.           Psychology, 1980  
                  University of Madras, India

**Teaching Experience**

**Instructor** - Family & Child Development, VPI&SU,  
August 1991 - Present

**Graduate Teaching Assistant** - head teacher, Child Development  
Laboratory, VPI&SU, August 1990 - May 1991

**Graduate Teaching Assistant** - for course on early childhood  
curriculum planning, VPI&SU, August 1989 - May 1990

**Graduate Teaching Assistant** - head teacher, Child Development  
Laboratory, VPI&SU, August 1988 - May 1989

**Clinical Experience**

**Psychotherapist** - Self Management Program for Handicapped  
Children, Madras, June 1985 - June 1987

**Administrator & Psychologist** - Vocational Assessment and  
Placement Center, Singapore Council of Social Service and  
Handicaps Welfare Association, Singapore, Aug 1982 - May 1985

**Intern Psychologist** - Psychiatry Clinic, Government Hospital,  
Madras, January 1982 - May 1982

**Intern Psychologist** - Neuropsychology Clinic, National  
Institute of Neurology, Madras, August 1981 - December 1981

**Intern Psychologist** - Juvenile Guidance Bureau, Madras,  
August 1980 - May 1981

## **Research Experience**

**Teaching as Reflective Thinking: A Constructivist Perspective to Early Childhood Teacher Education and Development,** Blacksburg, August 1991 - present

- interviewer
- data analyst

**Individualized Education Programs (IEPs) as Lived Experiences,** Blacksburg, March 1991 - present

- Ph.D dissertation

**Self-assessment and Reflective Thinking among Pre-service Early Childhood Teachers,** Blacksburg June 1990 - Present

- co-researcher

**Resource Management in Family Day Care,** Blacksburg, May 1989

- participant-observer

**Survey on Accident and Injury Prevention for the Elderly,** Department of Public Health, Richmond, November 1987

- interviewer

**National Survey of Disabled People,** Ministry of Community Development, Singapore, January 1985 - April 1985

- developed survey instrument
- conducted training program for 200 interviewers

**A Field Experiment: The Effect of Non-verbal Teacher Behavior and Extrinsic Reinforcement on the Immediate Story Recall of School Girls,** Madras, January 1982 - May 1982

- M.A. thesis.

## **Presentations**

Cherian, M. "Including the young child's emotional heritage on the agenda of multicultural education". Preconference session at Annual meeting, National Association for the Education of Young Children (NAEYC), Denver, November 1991.

Cherian, M. "Storytelling to nurture self-esteem" (Invited presentation). Annual meeting, New River Valley Association for the Education of Young Children (NRVAEYC), Blacksburg, October 1991.

Stremmel, A., Cherian, M. & Martin, D. "Self-assessment and reflective thinking among preservice early childhood teachers". Annual Meeting, American Educational Research Association, Chicago, April 1991.

### **Presentations (continued)**

Cherian, M. & Martin, D. "If you see the wonder of a fairy tale...". Annual Meeting, Virginia Association for Early Childhood Education (VAECE), Richmond, March 1991.

Cherian, M. & Fu, V.R. "Individualized education program conferences: So much more than a meeting of minds". Annual Meeting, NAEYC, Washington D.C., November 1990.

Vogler, J. & Cherian, M. "Early childhood program foundations: Philosophy and curriculum". Annual Meeting, NAEYC, Washington D.C., November 1990.

Cherian, M. "Be good to yourself so that you can be good to the children" (Invited Presentation). Annual Meeting, NRVAEYC, Blacksburg, October 1990.

Martin, D. & Cherian, M. "Saying good-bye: Ending teacher-child relationships". Annual Meeting, VAECE, Charlottesville VA, March 1990.

### **Publications**

Cherian, M. (1983). An Evaluation of the V.A.P.C. Phase 1. Singapore: Handicaps Welfare Association.

### **Professional Membership (Current)**

Association of Childhood Education International  
Madras Psychology Society  
National Association for the Education of Young Children  
National Black Child Development Institute  
Southern Association on Children Under Six  
Virginia Association for Early Childhood Education

### **National Committees**

**Board of Executives, 1984 - 1985**  
Singapore Psychological Society

**Board of Trustees, 1984 - 1985**  
Singapore Professional Center

**National Committee for International & Community Affairs, 1984 - 1985**  
Young Women's Christian Association of Singapore

**Committee for Centralized Job Placement, 1985**  
Handicaps Welfare Association of Singapore

## **National Committees (Continued)**

**Committee on Employment Opportunities for Visually Handicapped Persons, 1984 - 1985**

Singapore Association for the Blind

**Committee on Employment of Disabled People, 1983 - 1985**

Ministry of Community Development, Singapore

## **State Committees**

**Committee on Multiculturalism, 1991 - present**

Virginia Association for Early Childhood Education

## **Organizing Committees**

**Program committee of workshop on "A National Definition of Disability", Ministry of Social Affairs, Singapore, 1983**

**Program Committee of seminar on "People, Services and Development", Singapore Council of Social Service, 1982**

## **International Meetings**

**National delegate (presented country report) - Rehabilitation International Asia and Pacific Convention, New Zealand, 1984**

**Rapporteur for Sub-commission on Vocational Rehabilitation, 11th. Asia and Pacific Regional Committee Meeting of Rehabilitation International, New Zealand, 1984.**

## **Training Programs**

**"Effective Use of Time"**

- for disabled adults, sponsored by Handicaps Welfare Association, Singapore, 1985.

**"Industrial Safety and Vocational Rehabilitation"**

- for occupational health nurses, sponsored by National Productivity Board, Singapore, 1984.

**"Selective Job Placement Techniques"**

- for job placement officers, sponsored by Singapore Council of Social Service, 1983.

**"Evaluation through Work Sampling"**

- for occupational therapists, sponsored by Singapore Association of Occupational Therapists, 1982.

**Community Service**

**Coordinator** - The Child Care Special Needs Awareness Program and The Montgomery County Respite Care Program, Child Care Resources, Blacksburg, Virginia, May 1991 - August 1991.

**Volunteer** - Center for Independence for the Disabled, Inc., Roanoke, Virginia, March 1991 - August 1991

*May Phesia*  
*15 Sept. 1992*