# ONE CHILD'S USE OF ASSISTIVE TECHNOLOGY

by

Bonnie Nelson

Dissertation submitted to the Faculty of the

Virginia Polytechnic Institute and State University

in partial fulfillment of the requirements for the degree of

DOCTOR OF EDUCATION

in

Special Education Administration and Supervision

APPROVED:
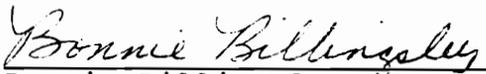
_____          _____
Bonnie Billingsley, Co-Chair              Jan Nespor, Co-Chair
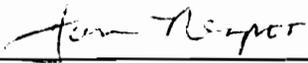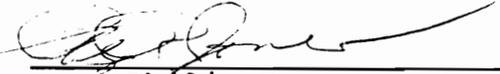
_____          _____
Philip R. Jones                           John Burton

_____
Lewis Romano

November, 1992

Blacksburg, Virginia

# A STUDY OF

# ONE CHILD'S USE OF ASSISTIVE TECHNOLOGY

by

Bonnie E. Nelson

Committee Co-Chairmen: Bonnie S. Billingsley and Jan Nespor
Administration and Supervision of Special Education

(ABSTRACT)

This is a qualitative study of one student's use of assistive technology in the public school system from preschool to fourth grade. The data collected for this case study include interviews, participant observation, field and diary notes, video tapes, and other documents including school records and a teacher memoir. Throughout the study, the goals were to stay open to and reflect emerging patterns rather than to fit data into previously determined categories. The report describes how Michael--with cerebral palsy that affects his speech and prevents his standing or holding a pencil--used computers, augmentative communication devices, and other electronic technology. On one level the report becomes the story of a student who moves from a separate special education facility into an elementary school where he is integrated fulltime into a fourth grade class. Discussion and conclusions explore (1) types of support he required, (2) barriers to technology use as well as problems of "abandonment" of technology acquired, (3) the effect of integration into general education on his use of

technology, and (4) how providing assistive technology
influences and changes teachers' roles.

*We shall not cease from exploration,*

*And the end of all our exploring*

*Will be to arrive where we started*

*And know the place for the first time.*


*T. S. Eliot*

## ACKNOWLEDGEMENTS

I would like to express my appreciation to those who encouraged, helped, and supported me throughout the writing of this study. I want to thank the members of my committee Drs. John Burton, Philip Jones, Lewis Romano, and especially the co-chairs, Bonnie Billingsley and Jan Nespor, who provided intellectual support and practical guidance at crucial times.

I wish that I could thank the student, teachers, and others by name who participated in this study. For confidentiality their names had to be changed, but I will always remember working with and learning from them. My hope is that John and I, even from a nursing home, will still be assistive technology buddies, searching out another project to tackle, another wheelchair to complain about.

For their wonderful, intelligent, and immeasurable support, this dissertation is dedicated to my husband, Walter James Miller, and my parents Clay and Elizabeth Nelson.

# TABLE OF CONTENTS

*Although most people view a wheel chair as a sign of disability, I see my wheelchair as a symbol of ability. With my wheel chair, I am an independent traveler, a man in motion as the song (St. Elmo's Fire) says. I think that the perception of a poor helpless person confined to a wheel chair is ridiculous. And the idea that the person in a wheel chair is only half a person is conceived from people who think from their waists down. I call such people bottom-down thinkers!*

*Rick Creech, <u>Reflections from a Unicorn</u>*

# CHAPTER I

## INTRODUCTION

Man is an animal suspended in webs of
significance that he himself has spun.

Clifford Geertz


## The Investigator as Narrator

This is a qualitative study of one student's use of
assistive technology in the public school system. An
important tenet of qualitative research is that the
investigator cannot be separated from what is being
investigated. The epistemological and methodological
implications of this will be discussed later. Since my
perceptions, situation, and points of view are a crucial
component of this study, I will start with my story. In the
end, my hope is that my story of Michael's story will
enlarge people's understanding of students with severe
disabilities. One of the most important things I have
learned in this endeavor is that "the goals of research are
perfectly compatible with the discovery of good stories"
(Ferguson, Ferguson, & Taylor, 1992, p.1).


## My Story

I entered public school education in middle age with a
Bachelor's degree in Philosophy, a Master's degree in
English literature and work experience as a free lance

1

writer and sometimes college English teacher. What precipitated this career change was a severe illness—or rather the discovery that I might never get back my energy if I didn't do something that I loved to do, that I was good at, and that I believed really mattered. Within a year of this decision, I was on the road to Montessori teacher certification. I loved it and was energized. Eventually I was certified to teach on many levels in public school from preschool handicapped to elementary and secondary levels of general education. Ironically, while I was hard at work becoming "an educator," certification professionals in education were deciding that a humanities background, such as I already had, was perhaps the first step in this process.

I first worked with students with severe disabilities in Preschool handicapped classes in public school. Initially I was turned off by being drooled upon. It wasn't just a matter of "present" drool but also of "past" drool dried into clothing and the thought of "future" drool to be encountered at lunch. After awhile, however, the drooling or "severeness" of a student's disability was not my major focus. It became a matter of the disabilities forcing us to go a different path to get human needs met. It became a matter of a relationship with a person.

It was here that I learned the meaning of multisensory contact. Lifting, holding, wiping, watching eyes for meaning, supporting an arm for stability, retrieving my clutched clothing or hair from hands that could grasp but not release, listening closely to a small repertoire of sounds for meaning--all this created a unique closeness, a unique exhaustion, and often a total immersion in daily needs issues.

But I also remember sitting on the floor with guitar and children in my lap as we waited to sing our part in some play we'd "written." The props were frequently a product of some zany art project--still drying. In the midst of it all I would ask myself, "Where else in this culture can you sing, produce art, hug children, and know that your job also requires every talent you can muster for human relations, insight, courage, and intellectual pursuit?"

It was here that I learned most about the social and political implications of what it means to be disabled. It was here that I met parents who helped me understand that a teacher's or administrator's way of viewing their child could be a limited and self-serving point of view. It was here that I also met Michael, the subject of this study.

Because of the severity of his physical disabilities from cerebral palsy (cerebral palsy), I believed that the only way Michael could write or show what he knew was

through access to technology. This insight started me on the road to using computers and electronic technology with my students. This story is reported in depth in "One Teacher's Beginning Experiences with Assistive Technology in a Public School Setting" (Appendix A). There I explain in detail how I worked with and assessed Michael in preschool.

Because of my interest in special education technology, I eventually left preschool after 13 years to work and study at the university. Presently I am an Assistive Technologist at the Technical Assistance Center (TAC) in the College of Education at Virginia Polytechnic Institute and State University. I work with teachers and others learning to use technology with special education students of all ages in southwest Virginia. I like what I do, but I sorely miss the music, the art, and the children in my lap.

## The Story of the Study

I initially decided to do a qualitative study of Michael's use of technology because I perceived this research approach as more meaningful--more meaningful because of the emphasis in qualitative inquiry on the importance of context and "the inescapable contextuality of our knowledge" (Ferguson, Ferguson, & Taylor, 1992, p. 295). In addition my personal philosophy and views are more in line with the qualitative interpretivist view which

emphasizes multiple perspectives rather than mathematical truth. My interests are more "describe, interpret, and understand" --goals of interpretivist research--than they are "describe, predict, control" --goals of objectivist research (Ferguson, Ferguson, & Taylor, 1992, p. 6).

I really do not think anything can be understood free of a perspective or a particular context. This is a relativist orientation in contrast to the objectivist orientation of logical positivism. The objectivist paradigm (supporting quantitative inquiry) that reality is out there to be known independent of a knower and that facts are discovered (can be deduced) contrasts sharply with the interpretivist paradigm supporting qualitative inquiry.

It is important to understand that the interpretive explanation of qualitative analysis does not yield knowledge in the same sense as quantitative explanation. The emphasis is on illumination, understanding, and extrapolation rather than causal determination, prediction, and generalization. (Patton, 1990. p. 424)

My leaning toward the qualitative perspective, actually, was largely a matter of personal view and philosophical tendencies. My own knowledge of interpretivist research and qualitative methodology was in the neophyte stage. I had yet to learn the truth of

Patton's assertions about the "in depth living with the data" that this research requires (1990, p. 410). I actually spent a lot of time trying to escape this "in depth living" because I perceived that my graduate school situation might not financially support the time that a qualitative study could require. Fellow students kept reminding me that I stood a much better chance of finishing faster if I pursued the quantitative route. There were lots of reasons for going this route, not the least of which was time, money, and an education faculty in which qualitative researchers were not significantly represented. I kept looking for a quantitative study and trying not to be impractical. As more than one person implied, a dissertation is not a "magnum opus" but "a thing to be gotten through."

I think if my students were not disabled I might have found a quantitative study or survey that I could live with. But what I see everywhere are changing definitions, layers and layers of perspectives, and complex intertwining circumstances of students with disabilities. I agree that many aspects of disability are "a social phenomenon--created, maintained and exacerbated as much by public and professional interpretations as by any type or amount of physical anomaly" (Ferguson, in press, p. 8)--a qualitative interpretivist perspective. I couldn't figure out how to

6

reduce the complex process of an assistive technology user to working definitions and eventually come up with a number or a score--a quantitative, objectivist perspective.

I have a world view and experience that says numbers don't often tell us much about a student like Michael. He's the one, originally with the "very low" IQ, who is now reading and word processing. He's the one who is "untestable" because of the way standard tests are set up. He's the one whose ability to speak or vocalize on a particular day may depend on what medication he's given. He's the one that cannot word process or indicate an answer choice if he is positioned improperly in his wheelchair. In another day and age he is the one who wouldn't even be alive; our current social views of the meaning of disability have changed from earlier times when such a child would have been left to die on the hillside (Hahn, 1983).

I'm not quite sure when one stops being a neophyte qualitative researcher. I do know that it would have been much better if, when I started, I knew as much about qualitative research as I do now. This journey was long (almost two years). First I started with Guba (1978) and Lincoln and Guba (1985). Then I took up Lofland and Lofland (1984), Bogdan and Biklen (1982, 1992), and Stainback and Stainback (1988, 1989). Later I discovered Patton (1990) and his wonderful stories, and finally  the artistic Eisner

7

(1984, 1991).  The hardest part was the crazy quilt of
methodological approaches which can be used with qualitative
inquiry, not to mention the many labels from
"interpretivist" to "hermeneutics" applied to this research.

There are, for example, those who believe data or
results are more "credible" or "confirmable" if this and
this is done.  Then there are those who believe that even to
use the words "credible" or "confirmable" is to buy into the
quantitative objectivist paradigm requirements of internal
validity and objectivity in a way that misunderstands the
qualitative interpretivist paradigm.  Thus a "paradigmatic
debate" gets mistakenly transformed into "a discussion of
methodological variations" (Smith & Heshusius, 1986).

At this point I was both paradigmatically and
methodologically confused.  To anyone who gets into a
similar state, I highly recommend the fascinating article by
Smith and Heshusius (1986).  They helped me understand that
one could use qualitative methods and still not be doing
research grounded in the qualitative interpretivist
paradigm.  Their distinction between "techniques employed"
and "logic of justification" is most helpful.

Discovering Diane Ferguson (in press) and Ferguson,
Ferguson, and Taylor (1992) was a wonderful and sanity
making experience.  Reading the research selections in their
Interpreting Disability: A Qualitative Reader (1992) gave me

8

a better sense of the variety of approaches possible in interpretivist research. Before discovering them I was not openly admitting that I was "telling stories." I was confused about why former literary skills and sensitivity to point of view issues were coming to the fore again while I was trying to write up the data. Reading their discussions of the role of interpretivist research in disability studies helped me better understand and value the process I was going through.

Generally my response to them was, "Ah ha! This is my perspective too." It was also a relief to read good writing and to see articulated so well things I was only beginning to get into perspective. All of this led to a renewed confidence in my perspective that helped tap old energies for writing that I hadn't been able to summon earlier.

## The Problem

The past decade has seen a dramatic growth in the sophistication of assistive technologies for individuals with severe disabilities. Along with a growing awareness of the potential uses of such technologies, legal mandates have created powerful pressures for making appropriate technologies available to students who can benefit from them. The challenge is that everyone from administrators, teachers, and other service providers is being required to

plan and make decisions about assistive technology when little is known about the technology or its current usage in educational settings.

There are no formulas or standard procedures by which special education students with severe disabilities become assistive technology users. Each individual effort faces a series of questions:

1. Who determines what technology a child can benefit from: how are physical and cognitive needs and capabilities of the child assessed?

2. How are funds for devices obtained?

3. How do teachers, family, or appropriate staff learn how to use the technology; what are their challenges?

4. What organizational support is provided (a) for training teachers and others to use the technology, (b) for needed planning and communication among staff (c) for keeping the technology in working order, (d) for making purchase decisions and keeping up with changes in the field.

5. How are students taught to use the technology and for what purposes -- academic learning, communication, mobility or what? How do student's families perceive this process?

6. What happens when a child using technology goes into a general education environment?

This study uses qualitative inquiry to look at one student's use of assistive technology in the public school system. This research approach assumes that "meaning and process are crucial in understanding human behavior, that descriptive data [are] . . . important to collect, and that analysis is best done inductively" (Bogdan & Biklen, 1982, p. 55). The case study explores how Michael became a competent user of technology. The study follows Michael from his entrance into the school system up to his present fourth grade class in a general school setting.

Though design elements and additional avenues of interest emerged as this inquiry progressed, the initial focus of the study was:

1. The story of how he became an assistive technology user.

2. The support and decisions that got him to his current level of technology expertise.

3. What happened to him in this process as he moved from a segregated special education facility into a general education class.

4. How providing for his assistive technology needs influenced the roles of his teachers and service providers.

Additional study questions developed are in Appendix B.

Michael's case is not presented as a typical or representative example of assistive technology use in the public schools. Rather, it serves as a point of entry into an analysis of the complicated web of issues in which all decisions about assistive technology must be made. That is, while the particulars of Michael's case may not be typical, the general issues it raises are.

## Background on Assistive Technology and the Schools

The Individuals with Disabilities Education Act (PL 101-476, formerly The Education for all Handicapped Children Act, PL 94-142) and accompanying state laws and regulations have been a major influence on technology usage in special education. In an effort to provide an "appropriate education," teachers and rehabilitation specialists are helping their students use adapted computers as educational tools and as personal assistive devices (Provenzano 1987/1988; Scarlato, 1988; Thorman, Gersten, Moore & Morvant, 1986). This assistive technology makes it possible, for example, for a person without speech to communicate with voice synthesizers. Students with cerebral palsy who cannot control a pencil can word process or paint pictures with devices at their head, eyes, feet, etc. Even a person with disabilities so severe that (s)he can voluntarily control

only an eyebrow can operate a computer. For some the same small computer on their wheelchair speaks and orders lunch and later in the classroom provides access to word processing and environmental control (Behrmann & Lahm, 1984a, 1984b; Crowner, 1984; Cosden, Gerber, Semmel, Goldman & Semmel, 1987).

Assistive technology has the potential to make a powerful difference in the way people with severe disabilities are educated and integrated into society (Behrmann, 1988; Foulds, 1982; Meyers, 1990; Parette, 1991; Smith, 1989). Most students with severe disabilities attending public school have, until recently, been served in self-contained classes, often in special schools or isolated wings within regular schools (Campbell, Bricker, & Esposito, 1980; Cavalier & Mineo, 1987; Cobb & Horn 1986; Guess, Benson & Siegel-Causey, 1985). The current emphasis on mainstreaming and integration, occurring at the same time as breakthroughs in assistive computer technology, is leading to the integration of more students with disabilities, even the technology dependent ones (Berlin, 1984/1985; Scherer & McKee, 1991; Shell, Horn, & Severs, 1989). Little is known about these students' use of technology (El-Khatib 1980/1981; Hofmeister & Friedman, 1986; Parker, et al., 1990; Semmel, Charles, Kinzer, 1987). Even less is known

13

about how use of technology affects integration of the student with general education peers (Dutton, 1986).

The term "assistive" has often been used interchangeably with "adaptive," "rehabilitative," "augmentative," and "alternative." Recently the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (PL 100-407) defined "assistive technology device" to mean "any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (U.S. Congress, 1988, p. 1046). Assistive technology devices can be low tech (mechanical as in a gripper to open a jar) or high tech (electronic or computerized). Adaptive or assistive computer technology usually means hardware that has been adapted or completely redesigned so that the individual can access the computer in a different way, for example with a head switch or a large flat keyboard mounted on a wheelchair table. Software can also be adapted for changes in feedback as well as method and rate of access. Assistive technology discussed in this study is of the high tech variety, for example, computers for word processing, augmentative communication devices with voice synthesizers, and electronic wheelchairs.

The Association for Persons with Severe Handicaps (TASH) defines persons with severe handicaps as individuals who require "extensive on-going support in one or more life activities like communication, activities of daily living, mobility, and education to participate in integrated community settings" (Research and Training, 1987). Around 7% of students enrolled in special education (Office of Special Education and Rehabilitation Services, 1989) have labels that are sometimes grouped together as "severely handicapped" or "other severely impaired" (Singer & Butler, 1987). "Other severely impaired" includes children classified as hard of hearing, deaf, deaf-blind, multihandicapped, orthopedically impaired, visually impaired, and other health impaired. How many of these students use technology or could potentially benefit from technology use is not known.

The development of assistive technology and its application to education are so recent that little data on the extent or type of usage are available (Malouf, Weingerber, Rieth, & Semmel, 1987; Michalowski, Roulds, Leslie, Semmel, & Charles , 1987; Parker et al., 1990). In situations where students are already using assistive technology in the schools, little is known about how teachers and administrators make decisions about the devices used or what happens to students in this process (Division

of Special Education, 1986).  In many instances pressure from parents has resulted in assistive technology services to their child in a school system that had not previously planned for these services.  Parents, as I came to realize, have often been more up-to-date than school systems on what is available--especially in services to children with severe handicaps (Creech, 1988; Glicksman, 1989; Kissick, 1984; Koppenhaver & Yoder, 1991; Messinger, 1983).

Recently schools have started integrating students with more severe handicaps into regular schools.  Some of the technology using students are also being integrated into regular education schools and classes (Stainback & Stainback, 1989; York & Vandercook, 1991).  Studies are needed to show what is happening, to explore what is possible, to look at the student and teacher support systems, and to consider the administrator's role and perspectives.  This is very new territory for administrators, teachers, parents, students, and researchers alike (Behrmann, 1984).

Issues of money for equipment and support services as well as teacher training are only recently being addressed (Blackhurst, 1989).  In 1990 Virginia received money from the federally funded Technology-Related Assistance for Individuals With Disabilities Act, PL 100-407 (U.S. Congress, 1988).  Its broad purpose is to provide state

grants to help states begin linking disabled people of all ages with assistive technology products. These funds may provide incentives to further research and provide for the needs of assistive technology users.

Legislation and newly acquired federal funds are not the only sources of pressure to study and  better serve potential assistive technology users.  A recent policy letter (dated August 10, 1990) from the Office of Special Education Programs (OSEP) clarifies the right of a child with a disability to assistive technology devices and services under P.L. 94-142.  The policy statement makes clear that if participants on the IEP team decide that "a child requires assistive technology in order to receive a free appropriate public education and designate such assistive technology as either special education or a related service, then the services must be provided at no cost to the parents" (Schrag, 1990).  This clarifies for the first time the right of a child with a disability to assistive technology devices and services.

*Some people cannot overcome their fear of the disability and are never able to interact with the person within. The speech-impaired person cannot interact with these people because they run from the augmented speaker. They avoid eye contact, mumble, shift weight from one foot to another, and show every sign of wanting to flee. In this case, the person with the handicap is not the one who uses an augmented speaking device. The handicapped person is the one who cannot communicate. (Rick Creech, 1992)*

*Rick Creech,  Reflections from a Unicorn*

# CHAPTER II

## METHODOLOGY

> To dismiss or underestimate the basic
> differences in method and epistemology
> between a laboratory experiment and an
> educational criticism is to miss the
> unique contributions of each genre of
> work.
>
> Elliot Eisner

## "Approach to Inquiry"

Qualitative inquiry has been variously labeled

interpretivist, ethnographic, phenomenological and so on.

(Bogdan & Biklen, 1982; Lincoln & Guba, 1985; Lofland &

Lofland, 1984; Patton, 1990).  From now on I am going to use

the term  "interpretivist" to indicate the world view or

paradigm underlying this method of inquiry.  The term

"qualitative" will be used to describe the methodology.

This distinction between methodology and "approach to

inquiry" (Ferguson, in press, p. 5) is also the distinction

that Smith and Heshusius (1986) make between "techniques

employed" and "the logic of justification." (p. 8).  As

others have made it, this distinction emphasizes that using

a particular method whether qualitative or quantitative does

not determine the general approach to inquiry (Bogdan &

Biklen, 1983; Eisner, 1991; Ferguson, In Press; Lincoln &

Guba 1985).  Thus, using qualitative methods and doing

qualitative or interpretivist research are not always the

same thing.

19

As Ferguson (in press) discusses it, techniques of participant observation, for example, may "complement the tenets of interpretivist" inquiry better than they do objectivist inquiry (p. 5). Likewise certain quantitative methods of measurement better "complement the essential principles of objectivist" inquiry. "Still both qualitative and quantitative methods might be used in a study grounded in either methodological tradition."

> It is not the method used for collecting data that determines the kind of study, but the approach to inquiry that guides not only the way ideas and questions are framed, but also the kinds of responses that will be judged adequate.
> (Ferguson, in press, p. 5)

Features of interpretivist research as outlined by Eisner (1991) that this study attempts to embody are:

> 1.   The study is "field focused" (p. 32).
>
> 2.   The investigator (inquirer) is viewed as "an instrument." There is "appreciation for personal insight as a source of meaning" (p. 35).
>
> 3.   The "interpretive character" of the study means that (a) "inquirers try to account for what they have given an account of" (p. 35) as well as explain what the experience means to those in the situation studied.

4.  First person point of view and "expressive language" are used (p.36).

5.  Attention is paid to "particulars."  When possible I use the words (in quotations) of informants.

## Time Lines and Access

This study of Michael began in February 1991 with a prospectus submitted to the dissertation committee.  In this month I also began writing (what became more than 60 pages) about my experiences with Michael in preschool and afterwards (see Appendix A).  Soon after, various permissions from the school, his mother, and others were obtained.  In April formal observation of him in his regular and general education class began. Interviews of him and others began in June.  Between October and December interviews were transcribed and written documents were obtained.  Coding, analyzing, and writing began seriously in January of 1992 and have continued till now.  Names of people and places have been changed to provide confidentiality.

All the above is accurate as presented.  But the truth is the observing and analyzing went on throughout the entire process.  Even bits and pieces of the written part were produced earlier.  As for the timelines, it's difficult to

say when the first thinking about the study actually began because in 1990 I made a video of Michael's use of technology. That's when I got the idea of choosing him as the subject for a dissertation.

Because I taught in the school system that Michael attended, I was able to keep up with him from preschool on. I visited the classrooms at the separate special education facility where he was first using computer technology about once a month. I am also friends with his mother and special education teachers. The school I had taught in for four years and was on leave of absence from is the same school Michael was attending when data for this study was collected. The multihandicapped classroom that he was in initially in this school was located in my former preschool handicapped classroom. His special education teacher, John, and I regularly worked on technology projects; so, for a year before and after the data collection, I stopped by this classroom every two or three weeks. Sometimes I would stay and assist with activities; at other times I would drop off equipment for John and leave after 10 or 15 minutes. For this study I had easy access to the school, the student, his family, and service providers. The advantage of this was that I was sometimes ignored, occasionally expected to assist when necessary, and generally not responded to as a stranger to get used to or perform for.

22

## Overview of Qualitative Methods Used

The data collected for this case study comes from interviews, participant observation, field and diary notes, video tapes, and documents.  This section provides a brief overview of the data collected.

I interviewed:

General Education Teacher--third grade

General Education Teacher-fourth grade

Special Education Teacher--first through fourth grade

Classroom Paraprofessional--first through fourth grade

Principal

Occupational Therapist (OT)

Physical Therapist (PT)

Speech-Language Pathologist

Mother

Michael (who answered through vocalizations that the classroom paraprofessional and others interpreted)

Appendix C contains a list of all interviews and data collected.  Appendix D contains a copy of forms used for obtaining permission and for collecting data.

Additional information was gathered from on-site observations--formal and informal, participant and non-

participant. Observation data at times provided another point of view on the information gathered from the interviews. Other information analyzed included (a) documents (school records, newspaper articles, etc.), (b)) on going diary/field notes and reflections, many based on informal site visits regularly made to his school, (c) teacher-made videos of Michael's work in earlier grades, (d) a long teacher memoir on first assistive technology use involving Michael (see Appendix A), and (e) an unpublished conference presentation on how Michael was first evaluated using technology (See Appendix E).

Throughout the study the data were continually reduced into a more manageable form reflecting the emerging categories and patterns being discovered. Always the goals were to stay open to and reflect what was emerging rather to fit data into prior expectations or constraints.

### Questions/Interviews

Throughout the study questions were asked spontaneously in the field as topics were discussed or situations unfolded. During the interviews the three basic approaches were used to gather data.

1. The general interview guide approach in which I outlined topics and issues to be explored before the interview began. This list functioned like a check

list of items to be covered.  "The interview guide presumes that there is common information that should be obtained from each person interviewed" (Patton, 1990, p. 281).

2.  For people with a particular expertise or relationship to Michael, specific items or questions to be asked were added to the general interview guide.  These were questions/topics not covered with every one. For example, his mother was asked specific questions on how he did homework; the occupational therapist was asked about activities that she did to increase his physical access to technology.

3. Informal discussions of topics in which I took part too.  We were responding back and forth in a conversational "topic format."  This particular format produced more detailed information from both Michael and John about some events that were not recent.  For example, Michael said he could not remember what happened to his pen pal, but when John started relating what he remembered, Michael provided more information on how many letters he'd written and his wondering why the pen pal had not responded to the last letter.

Most of the interviews were audio taped and video taped. I initially requested permission for a video tape because I wanted to have this permission in case I later decided to make another video tape about Michael's assistive technology use.

The general approach I used in the interviews was:

1. Briefly explain the project.

2. Obtain written permission for study and use of tapes.

3. Double check a few facts and details about how long they have worked with Michael, etc.

4. If appropriate, ask them to tell me what they do and explain their relation to Michael.

5. Begin the interview with questions developed (see Appendix F).

6. Throughout the interview respond to new information, participate in topic discussions when appropriate, and check list of questions to ask directly for any information not already gathered.

7. In conclusion, ask them, "Is there anything more you'd like to tell me about Michael.?"

8. Soon after interviews ended, made notes about my impressions, questions, responses, etc. to the interview.

9. All interviews were transcribed verbatim
and then later checked against the video tapes as
an additional check on accuracy. This was
especially important in the interviews of Michael.

Interviewing Michael first was a decision based on
circumstances rather than insightful planning. I had
thought the main value of these interviews would be to get
the views of a person about first technology use, something
that couldn't be done with a person whose speech had not
improved to the extent Michael's has. What he had to say
was interesting but not very detailed or informative in the
way I'd hoped. For example, he hardly remembered using the
PowerPad, one of the first computer boards he attempted to
use. Questions about what it was like to finally be able to
wordprocess and write letters, did not evoke a lot of data
or memories. I don't think he separated out technology that
much from all else in his life.

Once I got over not getting what I'd expected, I
realized how valuable the information he'd provided was.
His perspective also gave me useful information about what
to ask in other interviews of him and of people working with
him. For example, it was helpful to realize how much
happier he'd been integrated in third grade general
education than in fourth grade general education. It was
also surprising to discover how many of his service

27

providers were unaware of what his point of view was on many things.

In all the interviews my goal was to remain flexible, to allow the informant to shape the direction of content as much as possible. Some questions attempted to collect comparable data across participants. However, in many instances this was not possible because of such differing perspectives as that found between a peer and a parent. One of my interview goals was what Schwartz and Jacobs (1979) discuss as "recursive" interviewing. Recursion here means the information obtained or next question asked develops from  preceding information. In this context the interviewer can use "Uh huh" listener type responses and respond with questions or remarks that are generated from what the informant has just said. This did happen in all interviews, some more than others.

The personality of the informant influenced the pace of the interview and often determined what questions were asked in what order. Some informants were not chatty and had to be drawn out to elaborate more. I found myself enjoying the interviews much more than I had expected. Most of the time I found time immediately after an interview to hole up somewhere with a cup of coffee and make notes on impressions, things I was thinking about from what was said in the interview, and additional questions to ask or edit.

## Interviewing a Person with
## Severe Speech and Physical Impairments

Michael was initially very difficult for me to interview. I was surprised that this was so since much of my life I have lived or worked with people with severe speech impairments. I have often watched people be impatient and refuse to take the time it takes to get a person's meaning. I found that I was not impatient in the usual ways. However, once I watched video tapes of the first interview and thought about it, I realized that my teacher role was interfering with my qualitative interviewer role.

As a teacher I had gotten used to verbalizing choices for students to make in order to help me get at their meaning. I also spent a lot of time trying to motivate them to embellish responses and not just be satisfied with "Yea," "No," "Maybe," "Sometimes," or "I don't know." Below is an example of very poor qualitative interviewing because I am literally telling Michael what to say. However, this is a much used teacher technique to illicit information from a person who speaks little and that little takes a long time to produce whether it's by voice or augmentative communication device.

BN: How did you come up with that tune.

MI: I don't know.

BN:  Did you listen to songs and think of it?

MI:  Yea.

Later, when he spoke in more detail of how he wrote the
song, it turned out that the words not the tune came from
many different songs he'd listened to.

With Michael's first interview, I discovered how easy
it was to fall into the trap of structuring questions so he
could easily answer with a single word.  It's easy with a
person whose speech is both unintelligible and slow to
produce to start asking dichotomous response questions that
are structured to suggest a "yes" or "no" response.  Patton
(1991)  characterizes this as "using a string of dichotomous
response questions to guide the interview . . . thus
allowing the interviewer to supply the content to the
interview" (297).  Being attentive to the "dichotomous
dilemma" was helpful, but at times I was forced to ask
dichotomous questions because Michael was physically
incapable of producing all at once the amount of speech I
needed to figure out his meaning.

Because I couldn't understand Michael's speech until
the interviews were almost over, all the above remarks
attributed to him are translated by his interpreter, his
special education paraprofessional.  I had asked her to
merely translate his remarks, but at times the human urge to
explain would take the upper hand.  Also, this is her usual

30

role as a teacher/interpreter throughout Michael's school day. Below is an example of getting a fuller sentence response from Michael despite a reliance on some dichotomous response questions to get the conversation started. I didn't plan on asking him what the "hick-e-do" was because I thought he was going to elaborate more on his own. His attempt, however, was interrupted by the translator. Remarks in round parentheses are his translator's explanation of what a "hick-e-do" is.

> BN: Tell me how you learned to get that chair up and down those ramps
>
> MI: Mr. John taught me.
>
> BN: Were you ever scared?
>
> MI: Yea.
>
> BN: Did you ever have any accidents?
>
> MI: Yea.
>
> BN: Do you wanna tell me about it?
>
> MI: One day I ran into the wall and broke the hick-e-do.
>
> (He broke the rim on his tray by running into the wall.)

Michael's ability to spell was a big help in getting at his meaning, especially for the people who were regularly around him but still could not understand what he was trying to say. In the interview process, however, the spelling

31

seemed at times to cut short his attempts to explain.  Below
is an example of a spelling request from the translator that
may have had the effect of shortening his response.
Translator remarks are in parentheses.

BN:  Tell me what happened.

MI:  Sometime I went real close.  I ran over . . .

(You ran over what?  Can you spell it?)

MI:  T . . .O . . . E . . . S

(. . . ran over their toes)

Earlier I said that Michael was difficult to interview.
I changed my view on this once I realized how persistent and
attentive he was to making his meaning clear.  Once I
stopped always responding with automatic, teacher-role
responses, I was very appreciative of the fact that his was
a feisty personality, not easily swayed to another person's
point of view.  I think this is unusual for a child of his
age.  I had noticed this quality earlier in my living room
when my brother was trying to get him to change part of a
song he'd written.  After listening to my brother sing a
slightly different (and to me much more pleasing) version of
one of Michael's verses, Michael immediately objected with a
loud, "No." There he was in his wheelchair with little
functional speech, surrounded by adults (including the
musician trying to sing his song) who were making it clear
that "just this little change" would improve the song he'd

written, and he absolutely refused to consider any small change. In fact he seemed indignant at the requests. I personally felt chastened for having made the request.

This behavior of insisting on his own meaning was evident throughout the interviews whenever I misunderstood his meaning. Once when his teacher in a teasing voice tried to get him to change his response to one question, Michael responded as follows ("JH" is his teacher):

JH: (In a teasing voice) You're supposed to say, "The most important thing is not the grades but what I learn." Next time, say that, alright.

MI: (Loudly and emphatically) NO!


## Unique Interview and Transcription Issues

I am going into detail about my experiences interviewing Michael because I encountered situations that I had not foreseen and because I have found nothing published on this topic. One of the first things I realized as I tried to transcribe his interviews was that it was a good idea I had video tapes as well as audio tapes. Using a dictaphone facilitated transcription of the audio tapes. However, I soon discovered that more of the meaning than I'd realized was visual. There were spots on the tape where I couldn't tell whether Michael had assented or dissented. This problem got worse as I started understanding his speech

better and less of it went through the interpreter. Three
or four times for each 30 minutes of interview time, I had
to consult the video tapes to see how his head nodded or
what his demeanor was. Frequently he either said nothing
and let a nod be the answer or his vocalized responses which
I'd understood during the interview were not clear to me
from the audio information alone.

In an important way the above transcriptions do not
give a flavor of how the interview actually went. These
transcriptions are accurate to content but not to how the
content was delivered. Basically Michael would vocalize
word-like sounds singly or in clusters. At the end of each
word or cluster, he would wait for the interpreter to say
what he had just said; he then continued only if the
translation was accurate. The following example is a more
accurate written representation of how Michael actually
delivered the sentence, "I have to bug people to help me."
IN stands for interpreter.

    BN:  Well tell me, Michael, what you do when she's
    not in there?
    MI:  (vocalizes one word)
    IN:  I . . .
    MI:  (vocalizes one word)
    IN:  have . . .

MI:    (vocalizes three words in a pattern
       suggesting the first two words are one word;
       interpreter at first says the first two words
       together until she realizes they are two separate
       words)

IN:    tobug . . . to . . . bug . . . people

MI:    (vocalizes three words )

IN:    to . . . (pauses to think) . . . help . . . me.
       I have to bug people to help me (looks at
       Michael to confirm that the whole sentence is
       interpreted accurately)

MI:    (nods head indicating that this sentence has
       been interpreted correctly)

The above pattern of producing sentences with one word,
a second word, then two or three words in succession was
very typical of the way Michael delivered many of his longer
sentences.  At times he seemed to be pacing his words for
the interpreter to finish interpreting.  At other times the
pace seemed to be determined by what it took for him to
physically summon the breath he needed to produce the
sounds.  Frequently two words vocalized together were
initially tackled by the interpreter as if they were one
word.  This often led to stopping in the middle of a
sentence for him to spell the misunderstood word/sound
combination.  At all times Michael was persistent and

35

patient with the interpreter and me in our efforts to get his meaning.

One last example below gives an indication of how the interviewing changed from the beginning when the interpreter mostly interpreted (see above examples) to the final interview where Michael started taking responsibility to spell without being asked when he noticed the interpreter was slowing down or looking quizzical. Also, he and the interpreter realized that I was more used to his speech, so the interpreter would let short answers go uninterpreted. At times I even helped interpret.

Transcription in instances such as these required distinguishing when Michael was speaking directly for himself without going through the interpreter. The interpreter's role became more complex as the interpreter (a) interpreted for Michael, (b) asked Michael direct questions about his meaning, and (c) made remarks reflecting his/her own views about the topic. JH is his teacher who is also interpreting here. Remarks in square brackets were not in the original transcript but were added here as additional commentary.

BN: Okay, thank you. Michael, do you have any questions you want me to ask you that I haven't asked? Something important about you or technology or whatever

that I should ask so people would have more
information.

MI:  You could have asked if they would . . . (sees
JH's quizzical expression, so switches to spelling) . .
. r . . . u . . . s . . .h through a book. [Here JH is
directly interpreting for Michael exactly as Michael
vocalized it.  The actual sentence to this point,
however, was vocalized in three separate word-clusters
with pauses between each cluster to allow for JH's
interpretation]

Rk:  (questioning Michael) You mean like a school book?

MI:  (nods)  [This was not evident from the audio
tape alone]

BN:  Is it hard for you to rush through a book?
[Here I asked a dichotomous response question when
it would have been better to have asked, "Tell me
about rushing through a book."  Actually I started
this question below but was interrupted and never
returned to the question.]

MI:  Yea (Michael answers for himself)

BN:  Do you have to rush through books?   [Another
dichotomous response question]

MI:  Yea (Michael answers for himself)

BN:  Tell me about . . .

MI:  I have to do a whole . . .(JH interpreting)

JH:  . . . story? (checking his interpretation
with Michael)

MI:  no (Michael answers for himself to indicate
that JH's interpretation is wrong)  . . . chapter
(BN interprets; Michael nods)

JH:  Oh, "chapter" . . . (checking the accuracy of BN's
interpretation with Michael)

MI:  . . . chapter in one night.  (JH finishes
the sentence he started interpreting for Michael
twenty-six lines above)

In Michael's case I think a simple transcription of a
single sentence without all the word-cluster pauses
accurately portrays his meaning because I had a video to
check back on the exchanges that were confusing.  On paper
there seemed to be no value in the extra punctuation or
reporting of the back-and-forth checking between him and his
interpreter.  In addition his personality is an important
factor in my belief that my transcriptions reflect his
meaning.  His persistent unwillingness to let his meaning be
taken wrong may even have mitigated somewhat the effect of
my use of dichotomous-response questions.

Now that I am completely finished with the
interviewing, I feel that I am beginning to understand how
to interview and transcribe what is said by people with
severe speech and physical impairments.  I try not to burden

38

myself with the thought, "Oh what might I have learned if I had known beforehand what I know now." When I read the transcripts now, I wince in places where I slipped unnecessarily into dichotomous questions or failed to follow up with a request for more information on some thing I had not noticed enough at the time it was said. I also find myself remembering good questions or follow up remarks that I intended to make but somehow forgot in all the spelling requests and exchanges of remarks between Michael and the interpreter. Sometimes I console myself that given the time I had and the energy Michael had, maybe I got as much information as could be gotten. But, alas, I only believe this on Thursdays. I had really not thought the interviewing would be so challenging for me because of my years of prior experience working and living with individuals with severe speech impairments. But I realize now my very experience exacerbated the teacher role dichotomous question dilemma.

My advice to people interviewing people with severe speech impairments is, first observe, hang out with, and communicate informally with the person a lot before attempting the interview. Then plan a series of short video-taped interviews to warm up. Look at the videos over and over until you feel at ease with all the many interruptions that occur when suddenly the informant's word

cluster is interrupted with interpreter requests for additional information that may or may not take a long time to get. It's easy to lose your train of thought about how to respond or what to ask next in this environment full of complex interchanges that sometimes require several minutes to get the meaning contained in one sentence.

It's also easy to become so involved in the mechanics of obtaining the meaning that you lose a natural flow for how to respond to the meaning finally obtained. Now that all is said and done, I strongly suspect that one of the reasons I got the best information from Michael when John was interpreting is that John cracked jokes and teased Michael as he usually does. John said some things in a playful or witty way that may look weird or awful transcribed on paper when the tone of the exchange is missing. I am sure this is also true with transcriptions regardless of whether the person has speech difficulties or not. While humor, no doubt, influences the tone and information gathered in all interviews, in Michael's case, John's humor had the additional effect for me of breaking the cumulative and at times sobering effect of listening to a person who has difficulty producing sound. Generally, John's irreverences helped create an atmosphere conducive to better and more indepth information exchange.

## Analysis

Content analysis is "the process of identifying, coding, and categorizing the primary patterns in the data" (Patton, 1991, p. 381). Steps that I followed in this analysis are outlined below:

1. Labeled the various kinds of data, xeroxed multiple copies, and filed for ease of access.

2. Read through transcripts and other data.

3. Lightly penciled possible topics in margins; made a list of these topics and decided which ones to keep initially

4. Read through transcripts again marking topics as they appeared adding to the topic list.

5. Coded the topics names by number.

6. Read through transcripts marking topics by number and penciling notes when subject didn't seem to fit the coded topic.

7. Reworked coded topics to include new insights; more precisely defined some codes but generally let what was included in a topic evolve as I worked with the data.

8. Xeroxed multiple copies of the coded data and grouped by topics.

9.  Continued categorizing and analyzing data as I started writing it up by topic groups.  Outlines of how it might all fit together as a report began to emerge.

Some topics that emerged were never coded directly on the transcripts or data.  As I worked with the data and kept categorizing and making notes, I noticed, for example, how much of the information on integration into general education of a student like Michael was not simply dependent on his being a technology user.  So I separated out a category of integration issues for students like Michael that were technology specific and others that would be an issue simply because the student was severely speech and physically impaired regardless of whether the student used technology.

Qualitative researchers refer frequently to the flexibility of the design and the possibilities of going where the data leads (Bogdan & Biklin, 1982; Lincoln & Guba, 1985).  I certainly never foresaw taking this study into analysis of literacy skills or lengthy discussions of interview and transcription issues involved.  These topics evolved from "indepth living with the data" (Patton, 1990) in ways that I could not have foreseen before hand.  These were interesting and at times exhilarating discoveries.  The less exhilarating part was trying to figure out how to write it up to meaningfully reflect perspectives and situations.

When I did finish most of the writing, it was discouraging to realize that "analysis finally makes clear to researchers what would have been most important to study, if only they had known beforehand" (Patton, 1990, p. 371).

## Interpretation and Point of View Issues

Interpretation within this paradigm assumes an understanding of the role of the investigator. In the writing and interpreting, as I faced point of view and presentation issues, I was acutely aware that this was my view of others point of view. "I shall argue that the data inevitably represent perspective rather than absolute truth. Getting close enough to the situation observed to experience it firsthand means that evaluators can learn from their experiences, thereby generating personal insights" (Patton, 1990, p. 475).

I did my best to stay open to the data and to acknowledge my circumstances and changing perspectives. In addition I attempted to present "solid descriptive data" so that "others reading the results can understand and draw their own conclusions" (Patton, 1990, p. 375). Feedback from others has provided critical input and, in the case of some informants, a chance to double check that they agree with my presentation of their point of views. John's feedback has been particularly helpful. On methodological

43

issues I have gotten feedback from my committee and others who understand interpretivist research and qualitative methodology.

Other actions that, according to Lincoln and Guba (1985) will make findings more credible are:

1. "Prolonged Engagement:" Sufficient time was invested in both the data collection, analysis and presentation to build trust, begin to understand the context and become "open to multiple influences" (p. 304).

2. "Persistent Observation:" Because of prolonged and persistent observation, it was possible to achieve a depth of familiarity and hopefully insight that led to identification of "characteristics and elements in the situation that are most relevant to the problem or issue being pursued" (p. 304).

3. "Triangulation:" I used multiple methods of data collection (interview, observation, collected documents) and multiple sources from which data were collected.

Just as there is no one way to do interpretivist research in a prescribed sequence, so there are no closely prescribed standards for writing up and presenting the results. According to Ferguson (in press) interpretivist research "accepts many presentation styles from the nearly

fictional . . . to the densely academic." (p.11).  Initially
I was so fascinated with data immersion details that I did
not fully comprehend the significance of issues about how to
write it up, or  what framework to choose that best reflects
the circumstances and informant's points of view.

According to Ferguson, Ferguson, and Taylor (1992),
"establishing an authorial style becomes part of the
interpretation, even if that means occasionally drawing
attention to the writing itself" (Ferguson, Ferguson, &
Taylor, p. 299).  An issue for me throughout the study has
been how to present perspectives with the least distortion
and, when possible, to reflect the context of these
perspectives.

*Writing is all very well, but there are some emotions that cannot be conveyed, that cannot be "felt" through the written word alone.  Writing may be immortal, but it does not bridge the gap between two human beings as the voice may, and oh, I would rather have an hour's fierce argument with a pal or a few moments of soft chatter with a girl than write the greatest book on earth.*

*Christy Brown,  My Left Foot*

# CHAPTER III

## MICHAEL'S USE OF ASSISTIVE TECHNOLOGY

> The value of telling stories is that
> that is precisely how one discovers what
> the social constructions are.  Indeed,
> what we mean by the term "story" is
> simply one person's or one group's
> social construction of "what happened."
>                          Phillip Ferguson
>                          Diane Ferguson
>                          Stephen Taylor

This chapter provides a brief background on Michael and tells the story of his assistive technology use chronologically.  It begins at age 6 with his technology use at a special education facility.  It concludes at age 11 with his fourth grade year in a general education facility when he is fully integrated for the first time.

## Background on Michael

### Through Preschool

Michael was born in 1979 with cerebral palsy (cerebral palsy).  Because Virginia was one of the first states to provide preschool handicapped services to students as young as 2 years old, he was enrolled in a local preschool handicapped program at a public elementary school in the southwestern section of the state.  Services provided regularly and free of charge were educational instruction, occupational therapy (OT), physical therapy (PT), and speech

47

therapy.  He lived with his mother in a trailer with an
older brother and sister.

In his last year of preschool at age 5 when I was his
teacher, Michael could indicate yes and no with his head and
occasionally say a word that was understandable in context.
He couldn't stand and had generally poor motor control of
all extremities.  He  could not hold a crayon, cut with
scissors, or reliably point to or pick up objects. By his
last year of preschool, he could indicate whether or not he
needed to use the toilet.  He could not lift himself from
his wheelchair or transfer himself to the toilet.  He still
does not toilet independently.

His alertness, determination, and general good humor
were often interpreted by people who worked closely with him
to indicate average intelligence. When his speech therapist
and I adapted a scanning light board for testing him, his
scores indicated he was not retarded.  His initial use of
switches, light board, and computer technology occurred in
preschool.  For an indepth discussion of his activities in
preschool see Appendix A.  Appendix G contains a brief
chronology of Michael's years in school.


### Four Years at a Special Education Facility

For the next four years (age 5 to 9) he was placed at a
separate special education facility in Southwest County.

His special education teacher, John, decided that the only way Michael could show what he knew was through access to computers. The principal and PTA raised funds for classroom computers. John and I teamed up to teach ourselves assistive computer technology and to raise funds for devices as well as further technology training. These were the years Michael went from being a novice computer user to being able to word process and write letters home. Appendix H contains a chronological listing of technology Michael used.

## Third and Fourth Grade in an Elementary School

When Michael was 9, he and John were moved to Southwest Elementary School. The first few months he spent most of his time in John's multihandicapped class where he word processed using adaptive computer equipment on an Apple Computer. In January when he was 10 years old, he was integrated into third grade for language arts. He wrote the words and music for a song which he presented at The Very Special Arts Festival during spring of his year in third grade. The next year he was integrated full time into fourth grade where he made the A-B honor roll.

His classmates and teachers say that they can understand  a lot of what he says after they have been around him awhile. He still lives in the trailer with his mother. His older siblings have left home. Because his

power wheelchair is too big for the trailer, he leaves it at
school and transfers to a smaller non-motorized chair for
the trip home.

## First Computer Use

This section describes Michael's use of technology from
his first experiences through learning to word process and
eventually to write a song.  His efforts to use technology
for communication are also discussed.

### Getting Positioned

When asked about his first attempts to use the computer
with a switch or adaptive keyboard, Michael says, "It was
hard. I knocked it around."  His hands flailed about his
head or flashed downward with a force that often broke or
sent a device flying from his wheelchair table.  John,
Michael's special education teacher since kindergarten,
describes their first unsuccessful attempts to get 6-year-
old Michael access to a Powerpad, a large flat adaptive
computer keyboard also used by other students in his
multihandicapped class:

> Well the first thing [is] you get this brand new
> shiny equipment and you immediately want to hook
> this individual up to it and you expect them to
> immediately adapt to it no matter what their

impairment . . . . We started out with a piece of
software that we have since found out was useless
but we didn't know.  It was bright and colorful
and has a cute little bear on the screen . . . .
We just set the Powerpad down on his lap tray.  So
here was Michael and his feet were kicking out . .
. . his lap tray was kind of wobbly . . . . He
would swing back and around [with his fists] and
finally he hit the thing and knocked the Powerpad
off.

According to John his first insight was that "the first
thing you have to do to access a child like Michael with
computers is to have good positioning."

Just getting him [seated] properly required a
multi-disciplinary approach.  You get physical
therapists, occupational therapists, rehab
engineers involved, and in Michael's case, we went
through the Children's Miracle Network and he had
to be transported to Charlottesville to get him
fitted there.  I had to take a day off from school
to go down there with him.  It was a long drawn
out process just to get him to a point where he
was in the position where he had enough control of
his upper extremities to utilize the expanded
keyboard.

51

Getting the proper chair with the proper seat insert was the beginning of additional tasks that John had to solve because the rehabilitation engineers in Charlottesville had not counted on Michael's extremely strong kick while seated in a chair. "The type of cerebral palsy that he has, his feet were constantly moving and you had to be careful. You couldn't get anywhere near Michael because you would get kicked, of course, unintentionally."

Because of Michael's strong kick, John had requested of the rehab engineers that the new wheelchair have a foot plate that his feet could be strapped onto. When Michael arrived from Charlottesville he'd kicked so hard that he'd bent the foot plate as well as the back of his chair so that he was sitting not up-right at a 90 degree angle but backward at 130 degrees.

> We asked them if we could drill it [the chair] and
> bolt it so that it would stay in position and they
> said no, we could not do that, it would void the
> warranty on it. But there was no way to keep him
> in that wheelchair system, so finally we just went
> ahead and drilled it and bolted it, and they told
> us to put lock-tight on the set screws, because
> Michael was just too strong. We couldn't get them
> to understand. Also, his foot rest . . . he was
> so strong, he broke the foot rest within about two

or three days.  They wanted us to send the
wheelchair back on a Greyhound bus, and we said,
"Well that's really nice, but where are we gonna
put Michael if we send his wheelchair back."

As John later remembers this story this was the first
time his teacher role started expanding to include what he
considered to be a rehab engineer's job, a job that in this
instance the engineers asked him to complete.

So they sent us a foot rest and we put it on.  We
had to adapt the straps.  This was all new to us
also, we had never done any of this stuff.  When
they finally saw the way we had drilled and bolted
the seating system, their engineer up there sent
me a note saying I was using inferior bolts.  I
sent him a note back saying, "it's a good thing
you didn't tell me I had inferior nuts."

### The Road to Word Processing

#### Unicorn Keyboard

The Powerpad was little used by Michael because of the
limited software available for it and because the board was
not very adaptable.  Michael's next alternative keyboard was
the Unicorn Keyboard, a flat adapted keyboard that can be
set up for simple yes/no responses or for complex and total
access to a computer with 128 "keys."  Unlike the Powerpad

this keyboard had an internal card (The Adaptive Firmware Card) that allows this board to access any software.

The Unicorn Keyboard could be divided into one or 128 sections. Michael initially used it divided into 32 sections (a 32-section overlay). With this overlay each section of the flat keyboard board was about 4 inches by 4 inches. If his fist, palm, or finger struck anywhere within the four-inch section, the computer would print "A" or what ever letter he'd chosen. His major problems were (a) knocking the board on the floor despite it's being anchored with a commercially available holder, (b) needing the board at a special angle in order to see what he was choosing, and (c) choosing the wrong square on the board because of poor fine motor control.

## Adaptations That "Made All The Difference"

Most ready-made keyboard holders have a way to secure the holder to a person's wheelchair lap tray. The mechanism that holds the keyboard to the keyboard holder, however, was not strong enough to prevent Michael's pulling out the Unicorn Board from its holder and crashing the board to the floor. This motion which was not voluntarily controllable by Michael would often have the additional effect of loosening the moorings of the holder and it too would crash

54

onto the floor--a potentially expensive disaster considering the price of these items.

John finally designed and made a board that solved all these problems. He called it the Expand-A-Stand. Eventually the parent of a student made the board which because of requests from other teachers was made for sale on special order. All proceeds went to purchase technology equipment for Johns's class. The board not only locked tighter to both the wheelchair tray and the Unicorn board, it also provided more choices of positions at which the board could be angled.

Now Michael was stable and the keyboard was stable. He could choose areas on the 32-section overlay--a limited overlay without enough choices to have full access to a computer. At first John "thought that was as far as [he] could take him."

> The next breakthrough came with the use of a
> keyguard--a thick plastic sheet with holes that
> fit on top the Unicorn Keyboard. Very quickly, we
> found with the use of a keyguard . . . . he could
> actually put his hand down on the keyguard and
> slide his hands across and then access through
> holes in the plexiglass keyguard, a smaller area.

The keyguard basically meant that after Michael's hand dropped heavily down on the Unicorn, he still had not made

his choice of a letter or number until his finger reached down through the hole in the keyguard to choose a particular letter.

> We got it to where he could actually input anything into the computer that anybody else could on a regular keyboard. He could do it on the Unicorn Keyboard. That opened him up to word processing which is primarily what we did with him. The first thing he wanted to do was to write love letters to his girlfriends.

Michael's access to the computer through the Unicorn Expanded Keyboard is considered "direct access" in contrast to scanning, a method of "indirect access." See Appendix A for more information on scanning, "indirect access," and why his teachers originally thought Michael would never have direct access to a computer.

## Access Difficulties

At 7 years old Michael was able to use the Unicorn divided into 64 two-inch sections. This gave him access to numbers, all letters of the alphabet, punctuation, as well as a few computer and printer control commands. When I asked him to tell me about his first Unicorn use, he said it was "hard," but I queried him further to get more information on what was hard.

BN:  What's hard?

MI:  It's hard.

BN:  Learning how to use the keyboard, is that what's
hard?

MI:  Playing the keyboard is hard.

BN:  Is reaching the key that you want hard?

MI:  Yea

BN:  So when you want to write a word like "hello," is
the part that's hard reaching the H or deciding what's
the first letter?

MI:  Reaching


## Writing Letters

At age 7 and 8 Michael could word process at three or
four short words per minute.  John recalls that Michael's
initial interest and energy was for writing.  "Word
processing [was] primarily what we did with him."

He started off writing letters and in writing
letters, he found out he had to learn how to spell
some words so he started working on his spelling
and when he got a little more sophisticated, we
got to be a little stricter about his grammar and
he had to learn to punctuate his sentences.  We
got a little more sophisticated on that, it was
like doing it as he needed it.  That was very

57

highly motivating for him.  He wasn't learning

something and not realizing why he was learning

it.  He realized that he needed to learn it, so he

learned very quickly.

See Appendix I for a discussion of "Skills Acquisition

and Literacy issues."  This appendix explores (a) literacy

acquisition issues for people with severe speech and

physical impairments, (b) literacy instruction given Michael

in school, (c) Michael's skills acquisition in other areas,

(d) how Michael's circumstances reflect or don't reflect

current research findings on literacy acquisition.

## Augmentative Communication

Students with cerebral palsy and others with severe

speech disabilities may use computers as augmentative

communication devices.  Augmentative communication is all

communication that  enhances or supplements speech

(Vanderheiden & Yoder, 1986).  This includes everything from

pictures and word cards to communication devices and

computers with synthesized or digitized speech.  Much

augmentative communication research has concentrated on rate

enhancement techniques that might enable the person to

communicate more rapidly and efficiently (Beukelman &

Mirenda, 1992; Blackstone et al., 1989; Light, Lindsay, &

Parnes, 1988).  Little research has been done concerning the

social relations of augmentative device users.  Indications
are that listeners have significantly more positive
responses toward persons who use technology (communication
devices with synthesizers) than those using non-speaking or
non-electronic approaches (Gorenflo & Gorenflo, 1991).

## Acquiring the Touch Talker

At age 8 Michael's speech was becoming gradually more
understandable in context to people regularly around him.
His repertoire of different sounds, however, was very
limited and his longest utterances were usually clusters of
less than five words.

> His speech was, unless you knew him and was used
> to his speech, it was unintelligible.  And even if
> you did know, even his mother had difficulty
> understanding everything he said.  Well he's very
> talkative, especially to the younger and prettier
> teachers (laughter).  Well we kinda condoned the
> flirtatious behavior too because we thought it was
> kind of cute.  It got him into situations where
> people would interact with him that wouldn't
> interact with him otherwise. (John)

After demonstrating to the "head of the Speech
Pathology department at Kluge Children's Rehabilitation
Center that Michael could actually, with better than 95%

accuracy, hit the hole that he wanted" on the Unicorn

Board," John reports that Michael was considered eligible

for funding for a Touch Talker.  This device made by Prentke

Romich is basically a small computer, the size of many

portable computers.  It is specifically designed for

augmentative communication but can also be used as a

computer interface.  Or in John's words, "this is a $3500

device which speaks with a robotic voice which doesn't work

right now."  Now that Michael was acquiring more devices and

depending on them technology breakdowns were becoming

important issues in his functioning.


## Using the Touch Talker

John tells stories of how Michael's first Touch Talker

synthesizer with robotic speech was not always understood by

listeners.  "I would grab people out of the hall and bring

them in and say...'Do you understand this?'  Very seldom did

they understand it but then we upgraded the [Touch Talker's]

speech to Smooth Talker and that was much more

understandable."  John's experiences are reflected in

research on the qualities and effects of speech synthesizers

used for augmentative communication (Cavalier, van der Walt,

& Mineo, 1990; Mirenda & Beukelman, 1987).

Since the Touch Talker required even finer motor

control than Michael needed to use the Unicorn board, the OT

custom made a pointer from polyplast to fit in the palm of his right hand.  This made pointing down into the keyguard easier since he could not always get his finger at the correct angle to reach down into the holes of the keyguard on the Touch Talker.  Unlike the Unicorn which is much larger and is attached to a computer, the Touch Talker is portable and is designed with social interaction in mind.

At first John set it up with messages that Michael dictated and could use in various situations such as asking "What's for lunch?" or  saying "Hello, my name is Michael." These were pre-programmed and to activate them Michael had only to press one or two places.  More spontaneous on the spot responses requiring him to spell or use communication icons took so long that, according to John, this "never became a good workable augmentative communication device, but it got him into interactions that he wouldn't have had otherwise and experiences he wouldn't have had otherwise."

John says that the Touch Talker, augmented with Michael's attempts to vocalize, became a stepping stone to communication that Michael had never experienced before.

> When people saw him using [the Touch Talker] all
> of a sudden they realized that this child in the
> wheelchair that had the bright smile and
> everything . . . that not only did he have a
> bright smile but he was also pretty intelligent.

It made people look at him a little bit
differently and they would be more apt to try to
engage him in conversation, knowing that he would
use this.  Seeing how hard he would struggle to
use this and everything, they acquired a little
different viewpoint of Michael, a little more
positive viewpoint.  Then they would wait long
enough to try to interpret his broken speech.

## Michael's Song

### Significance

In third grade Michael completed a long project
involving the composition of a song that he got sung,
recorded, and entered in the Very Special Arts Festival.
Later he used an adapted camcorder to help tape scenes for a
video story about his song.  This song is an example of the
level of technology expertise and literacy skills that
Michael achieved before being integrated full time into
regular education.  This is also a story about the level of
assistance Michael required in order to accomplish a complex
task.

All of Michael's technology accomplishments described
to this point occurred in the special education facility
which Michael attended from 5 to 9 years old.  In 1989 when
Michael was 9 years old, John's multihandicapped class was

moved to a general education elementary school. From September to December Michael remained in John's class except for occasional socializing in a third grade class. In January he was integrated every day in this third grade for language arts class. The next month he told John and his music teacher he'd written a song. The music teacher suggested he get it produced and enter it in the Very Special Arts Festival in April.

An important reason for going into detail about this song project is that it is the last technology milestone he accomplished before his relationship and access to technology changed as he was integrated the next year full time into fourth grade. "Michael's Song," as it was eventually titled, influenced some of the reception he initially received in his third grade class. Hopefully, the details of this story will also give a flavor of Michael's personality and the effect he sometimes had on others.

## Getting the Words

According to John, Michael became noticeably interested in music at 9 years old when he announced that he preferred K92, a local rock station, to the country and western music his family usually listened to. "He started talking about rock and roll music." Sometimes he would tell us "raunchy

lyrics" and "would look for our response."  Then "he started saying that he would like to make up words for songs."

So we had him dictate some words of songs and then we had him to actually write on the Unicorn board which was very motivating for him.  His most efficient input on the Unicorn board was when he was trying to write words to his song.  He got a little bit frustrated.  Number one, with his inability to spell the things he wanted to spell, and two, the fact that he would have to do a lot of deletions and changes as he went along--as he made erroneous input.

Originally the purpose of his "song" writing was to practice his literacy skills and use the technology. Without the music these productions were more poems that songs.  However, after his music teacher began talking to him about the possibility of actually putting a song to music, he started asking John to help him get one ready for the Very Special Arts Festival.  He personally could not hum or produce a note of music, but he insisted he had the music in "my head" to accompany the lyrics of his latest song. The BIG challenge for the adults assisting him was to figure out the tune.  Michael had no experience writing music and wasn't able to indicate the tune by using any of the class' music software.  John called me for help and discovered that

my music software was no better than what he'd already tried
to use with Michael.

## Getting the Tune

While John continued searching for a high tech solution
with music software, a special education paraprofessional
discovered a lower tech solution.  As John tells it, one day
she "came in and brought a portable, battery operated
keyboard."

> She actually got on the keyboard and said, "Okay
> Michael, this is middle C, do you want the first
> note to be this note or do you want it higher . .
> . or lower?".  He would say higher; she would say,
> "Okay, this high?"  He'd say, "No, lower," and she
> would say "This note?"  And he would say, "Yea,
> start with that" . . . . They went through this
> little tedious process to the point that they got
> some music to match the lyrics, one note per
> syllable.  It came out pretty good.

She made a tape of the tune after Michael worked out
how long to hold each note.  At this point the Very Special
Arts Festival was only 10 days away. John called again for
help from the Technical Assistance Center (TAC) at Virginia
Tech.  As the Technology Coordinator for TAC, I came in at
this point to help only to discover that what was needed was

65

not an assistive technologist but a real musician.  To make a long story short, John, Michael, his mother, and my brother Mickey, a musician, met at my house one evening to try to translate the tape of the keyboard tune to a tape of Mickey's singing that tune with guitar accompaniment.

The major difficulty--as the musician soon discovered--was that even Caruso in his prime could not span the octaves of this song.  Michael who couldn't sing himself had written a song that couldn't be sung.  Another major difficulty was that he wanted absolutely nothing changed.  Also Michael was not at first pleased to hear the guitar version of his tune--the part of the tune that Mickey could actually sing, that is.  At times Mickey would sing a phrase over and over to prove to Michael that the tune <u>was</u> Michael's tune but pitched at a different octave.

John felt that the issue here was Michael's "very strong ownership of this song."

It was probably the biggest product . . . creative product of [his] life.  This was his song and when Mickey suggested changes to . . . make it more singable or marketable or whatever, Michael didn't want to change it . . . . He was very adamant about it, and the only changes he really allowed were those that allowed Mickey to sing it within a range of his voice.

## At the Very Special Arts Festival

John, his family, Michael, Michael's mother, as well as
other students who were entering the festival went to
Radford University on April 21, 1990.  Michael presented his
song at The Very Special Arts Festival in two versions--a
robotic, sing-song version that John had programmed into his
Touch Talker and a polished taped version of Mickey's voice
and guitar.  Here are the words to the three verses of his
song.

Let's rock and roll all day long

And do the locomotion.

Wherever you go, what ever you do

I will be right here waiting for you.

----------

I will never let you down.

What did I do?  What did I say

To win your love?

I am your angel, going my way.

----------

Knowing the way you treat me.

You are my angel.  I am yours.

Oceans apart--day after day.

And that's the way we are.

Lyrics, of course, never convey the sense of a song
sung.  In the above case, however, the discrepancy is

67

greater because, as the musician told me privately, "the tune is superior to the lyrics." According to John it's a mushy love song that Michael probably wrote for a third grade girl in his language arts class. Michael can't be penned down about who the song is for, but he doesn't outright deny that the song is for his third grade friend. About composing the tune and lyrics, Michael said, "It took a long time." When asked where he got the tune, he answered, "my head." When asked where the words came from, he responded thus.

MI:  Heard them on the radio.

BN:  So you put them together from several songs or from one song?

MI:  Several

BN:  Several songs.  Well that's an interesting way to write a song.  Let me see if I've understood you. You heard parts of it from one song and parts of it from another song?

MI:  Yea.

## Response to the Song

The paraprofessional assisting Michael in third grade said his classmates "were somewhat in disbelief" that he had written a song.  When the story came out in the newspaper, "all the children were clipping it out and bringing it in."

While "kudos came in from all over for Michael and his accomplishments," what pleased John the most was "there was actually a little bit of envy among his peers, which . . . how wonderful is that?"

Here are kids envying Michael rather than the other way around. Among the faculty and staff here at school, it was a true awakening to what we have been telling them all along--that this really is a very bright young man. You know . . . the orthopedic impairment does not necessarily suggest that he is cognitively impaired.

Michael played his song for many people. One day in May after he had been integrated part-time for over four months, I walked into the school and saw him and a group of boys coming toward me in the hall. As I watched Michael maneuvering the motorized wheelchair with the boys on each side, I had the distinct feeling that "something is different here?" Later John explained that after lunch, Michael was regularly taking some of his third grade peers to the multihandicapped classroom to listen to his song. What was "different here" was that I had never seen Michael look like he was moving about in a group with his peers. The boys were not pushing his chair or "being helpful." They were just going down the hall with him to hang out and do something together. Most children I've seen moving down

school halls in motorized 150-pound chairs do not give the effect of hanging out with peers on each side of them.

When he played his song for a school board meeting, his mother said she was "proud of him." "He's not like me," she explained. "He don't mind a bit getting up in front of people doing things." John acknowledges that Michael gets attention for more than just his song. "Everybody is visually impressed with Michael because he is a bright, good looking young man, and they are drawn to him because of that and the fact that he is in a wheelchair."

## "Michael's Song:" A Video

The next technology project, the making of a "music video" was not so much Michael's project as mine and the Technical Assistance Center's at Virginia Tech. The original plans called for Michael to help tape some of the video shots to be used in the final video story. This required figuring out how to mount a camcorder that he could operate with a head switch. A hand switch would not work because he needed his hand to operate the wheelchair.

Eventually Michael was able to operate a video camera that moved about with him on his wheelchair. With this he helped tape scenes from his school day to accompany the video of his song. With the camcorder mounted on his wheelchair just above the lap tray (using Ablenet's

Universal Mount), Michael had off/on control of the video camera through a head switch mounted at the back of his head (Ablenet's Switch 100).

He could not hold his eye steady at the view finder, so a small battery operated TV was placed on his lap tray. The TV, connected to the camcorder, acted as a viewer to show him what he was taping as he wheeled about. His favorite taping activity was to run up near people and get an enlarged close-up picture of their nose or some body part. He would then laugh and back up his wheelchair, only to move in again on the hairs in their nose or  maybe part of an eye ball. When he could, he did this over and over. This was probably the first time in his life he could directly view how a lens changes perspective in this way.

Because of battery problems, only a few of his taped scenes were used in the finished video made by the Technical Assistance Center. The seven-minute video, titled "Michael's Song," tells the story of his song--how he wrote it, presented it, and helped with taping the video. During the last two minutes, his song plays while scenes from his school day dissolve in and out.

## Michael as a Model

Michael was the first student to use technology in John's classes at the special education center. When he and

John moved to the elementary school, their class was mixed
with other students who were already technology users,
including two former students of mine. In John's view
Michael functioned as a role model for other students with
severe disabilities in this multihandicapped class.
Students have indicated that Michael influenced them to want
to learn to operate a computer or control a power chair.
Michael "gives 'em hope."

> They look at him as someone . . . who, despite his
> speech and language impairment and his orthopedic
> impairment, is making it. . . . It gives some of
> them, possibly, an attainable goal. At some point
> in time just about every young boy wants to be a
> Michael Jordan or Bo Jackson or something and for
> kids in wheelchairs, of course, when they are
> mature enough realize that's an unattainable goal,
> but here's Michael giving them an attainable goal.

John believes that the related service providers as
well as parents view Michael as a model of what's possible.

> Michael is setting up a path maybe some of these
> kids can follow. Every child is different. Of
> course their disabilities are different, but it
> gives them something to aspire to also. When these
> kids come home with the idea that they would like
> to have a power wheelchair or something like that,

you know.  The parents look at Michael and say if Michael can do it, why can't my child?"

The big problem as John sees it is "Michael is serving as a role model for other students with severe disabilities but he really doesn't have a role model for himself."  This is because not many people in southwest Virginia use this technology and because the technology hasn't been around long enough to provide many models of it's usage--especially not students in general education (Blackstone, 1989).  John tries to foster friendship between his students and adults who visit his classroom in wheelchairs.

Finding a model who also uses a computer or Touch Talker has been more difficult. Because these people usually do not travel without special vans and attendants (expensive travel costs), he has resorted to using videos.  He shows his students videos of two acquaintances Lake Kissick (1984) and Rick Creech (1992), two authors using augmentative communication devices that he first met at technology conferences.  He also shows his students any videos he can find of students and adults using technology for recreation, work, and learning.

## Technology Access Decreases

As Michael became integrated full time into fourth grade, his access to technology decreased.  The initial

reason for this was that the Apple computer and Unicorn Board he used belonged to the multihandicapped classroom and were used by other students in that class. Also, the board and computer were not portable, and there was no computer of any kind in his general education classroom. Because the Touch Talker is built for portability, John's plans initially were that Michael would use this device in general education with a portable printer mounted on a shelf attached to his wheelchair.

According to his general education teacher in fourth grade, "we tried to get his printer going" so he could use technology more with written activities. "But he didn't practice that often with it . . . there were problems with it . . . . By the time he typed out, it was just very slow at that point. So he didn't use it a lot." She further explains that "he never used it to do his talking . . . . Either myself or one of the other children knew what he was saying."

At this time, Michael was still having trouble physically accessing the small board of the Touch Talker. John and the occupational therapist designed a plastic collar to fit around the bottom to enlarge the surface for Michael's palm to rest on. After the collar was completed the portable Diconix printer broke down. When that was repaired the Touch Talker broke. After the manufacturer

repaired the device and all was in working order, the collar broke again. Then the Touch Talker, which is generally considered a sturdy device with few major breakdowns, untypically broke down yet again. John, who often praises Prentke Romich, the maker of the Touch Talker, for their "support and repair service, "began to suspect that in this case Michael's Touch Talker was "a lemon."

These were more glitches and breakdowns than usual. This time, however, they were occurring when Michael was trying to keep up with the requirements of a general education environment. The general education environment also influenced his use of speech feedback from the speech synthesizer inside the Touch Talker.

When I asked Michael to tell me about using the Touch Talker in fourth grade, his first remark was, "the teacher tells me to turn the speech off." His paraprofessional explained that "he can't see what letters he hits, so he needs the speech on so he can hear what letters he hit and the teacher tells him to turn the speech off so it doesn't disturb the class." Using headphones solved the problem of letting him hear without disturbing others, but created the additional problem of his not hearing what the teacher was saying when the headphones were on. According to the paraprofessional, she and John worked out another solution-- to use a small earphone in one ear. This way he could both

hear the teacher and hear the speech feedback from the
device.

In further discussions of the Touch Taker Michael
explains, "I am too slow," meaning that it took him too much
time and effort to use the Touch Talker for written
assignments. The paraprofessional assisting him took over
the role that technology might have filled in the general
education environment. "Right now he thinks it's a whole
lot easier to just tell somebody to write for him." By
"easier," the paraprofessional is referring to Michael's
rate of input into the Touch Talker not the equipment
breakdowns.

John, too acknowledges that "technology is not helping
him as much now because he is more fully integrated and
utilizes a paraprofessional to a lot of his things that
technology did for him before." Now instead of Michael
typing out his own words he dictates them to a
paraprofessional who writes for him.

What I would like to see him do is utilize
technology a little bit more so that he can do
independent writing rather than dictate. We're
kind of at a cross roads there . . . . What might
happen next year is he may have a dedicated
computer in his classroom. When it's time for him
to write he can go to the computer and write it.

76

For a more indepth discussion of Michael's integration into general education and the influence this had on his technology use, see Chapter V, "General Education."

*Getting a SOC (speech output system) turned out to be the catalyst for what has followed.  Attending college became viable as the result of having a SOC system.  I discovered that a SOC system is not necessary in attending college;  however, the regard for speech output is such that before I had one, no one in authority, including myself, considered my attending college as an option.  After I used my SOC device a while, some people in authority started thinking that if I attended college, I might graduate.*

*Rick Creech,  <u>Reflections from a Unicorn</u>*

# CHAPTER IV

## ASSISTIVE TECHNOLOGY: SUPPORT AND ISSUES

> Still, the fact that all linguistic
> expression is and remains "metaphorical"
> expression is proof that the capacity
> for objective representation can never
> become completely dominant in the domain
> of language. Metaphor constitutes an
> indispensable factor in language in its
> organic wholeness.
>
> Ernst Cassirer

This chapter provides information by topics. The more narrative and chronological approach of the previous chapter gives way here to a more thematic discussion of (a) related service providers, (b) teacher training in assistive technology, (c) assistive technology and teacher's roles, (d) funding assistive technology, and (e) how technology decisions are made.

## Related Service Providers

Michael receives assistance from related service providers, some who work full time for the school (the speech-language pathologist) and some who are contracted for part time work from local rehabilitation services (the physical therapist and the occupational therapist). Following is (a) a discussion of the planning and coordination of these related services from the point of view of Michael's special education teacher, and (b) a description of what each service provider does with Michael.

## Planning Required

Providing technology access for Michael required
planing from many sources.  According to John "it as a
multi-disciplinary thing."

> You've got to look at number one, positioning,
> which is primarily the domain of the physical
> therapist.  You've got to look at fine motor
> control which is the domain of the occupational
> therapist, and you've got to look at, if there is
> a speech and language impairment, you get the
> speech pathologist involved.  So some times all
> three of those areas are involved and they've all
> got to be there.

For augmentative communication to succeed integrated
planning is required of service providers, all teachers, and
the family as well.  According to John, "Augmentative
communication requires a lot of time and it never really
became useful for Michael because we didn't have time to put
in."

> Not just the therapists but families have to be
> involved in this.  It requires a great deal of
> everybody's time and very often in the schedule of
> your therapist and speech pathologist, there just
> isn't enough time for them to do a thorough job.
> When they don't do a thorough job, then it kind of

falls back on the teacher or falls back on me to
do a little more and if I do a little more in that
area, then I have to lay off in some other area.

John considers Michael "lucky" because "he has had a
good physical therapist who worked with him for about five
years." Basically, however, it has been John's job to
explain the technology and coordinate the planning. What he
wishes is that all people involved could "sit down on a
regular basis and discuss . . . the total child." When
asked how he would characterize his current planning, John
told the following story about getting his finger bitten to
illustrate the way he meets and plans with service
providers.

A typical scene. I'm sitting in the
cafeteria. I've got most of the fingers on my
right hand covered with peanut butter and jelly.
My other hand is supporting the jaw of a child
that has a severe tongue thrust, and I'm getting
ready to jam some more peanut butter and jelly and
bread mixed in, into this child's mouth. And the
occupational therapist comes in, and says, "How
much is so and so utilizing that splint on her
left wrist?" and I'm going, "Left wrist?" And in
the mean time I get my finger bitten by this other
child and I'm hollering, and he's screaming and

81

the therapist is tapping her toes because she's on
a schedule to be at another school in fifteen
minutes and it's an eighteen minute drive.

So I say, "How much should she use it?"  And
she says, "At least twice a day for twenty
minutes," and as she walks out the door, I'm
saying, "Would you write that down for me." And
that's your typical service [provider's]
conference.

When asked how his relationship with service providers
is different when the student with severe disabilities also
uses technology, John  asserts that "if they use technology,
more is expected of me . . . . because I'm the technical
person and it requires more of my time."

More is required of the relationship.  There
isn't always the time to do it all so you gotta
set priorities-which is more important, the
orthopedic needs or the technology needs?  It has
to be evaluated and sometimes we don't agree and
that puts a little bit of a damper on things.  And
it's hard.  You're looking at it from a different
viewpoint.  You've got a physical therapist who
doesn't understand the technology or what it can
do for the individual, they're going to steer away
from it and they're going to say well we gotta

82

look at the ankle/foot orthotics or we gotta look
at these wrist splints or we gotta look at
position adaptations of the wheelchair which have
nothing to do with technology.

It's different for every child. Michael,
because he is so bright and has progressed so
quickly, has opened doors for the other kids and I
think along the way, realizing this, a lot  of the
related service personnel are putting in a little
extra time.

According to John staff turnover of service providers
is a big problem.  In the past five years Michael has been
lucky because working with him is " very motivating to the
service providers so for him, the turn over in physical
therapists and speech people has been very little in the
last five years."

Most of the children I work with, the turn over is
immense.  Somebody leaves, a new person comes in
every six months or at best, year to year,
therapist change so it becomes difficult.  So if
you have a therapist coming in who has no
involvement or experience with technology, which
still very few of them have, especially in the
speech area, it's impossible.

## Physical Therapy (PT)

The PT, while crucial to Michael's positioning that enabled him to use technology, never worked directly with the devices and computers he used. Her major goal was "mid-line arm control. We've worked on that for years and years and years, trying to get him to get his arms to mid-line and keep them there when his head is turned in a different position." Below she itemizes some of the activities they did.

> We had a small thing we worked with trying to put his hands through the center of the ring. As I moved the ring, he would have to try to follow the ring and put his hand through the ring... or working on puzzles on his tray or throwing bean bags into one of those clown faces with a big hole for the smile, set those a certain distance away and have him throw the bean bags into the hole.... things that got him into mid-line. That's the only way he's going to be able to use a computer is if he's in mid-line all the time because he doesn't have any control out of mid-line at all.

When she saw him twice a week for therapy, the "emphasis was on trying to get better mid-line use of his arms because he has severe athetoid muscle tone which causes him to have very poor grading of his movements."

84

He works more out to the side, instead of getting
his arms to the middle.  So we worked on trying to
get his arms to the middle, keeping his trunk in a
good position, an upright position, which I'm not
saying happened (laughter), keeping his head in
mid-line because he has a very severe asymmetrical
tonic neck reflex.  When he turns his head, his
arms go like this.  (She demonstrates by holding
both her hands six inches away from each
shoulder.)  So he has difficulty keeping his hand
in the middle if his head is turned.

Michael has "high tone" which is spasticity.  This
means his muscles are stiffer; "whereas low tone is the more
floppy child."  A child with low tone has "to work hard
against gravity to even get themselves upright against
gravity.  Whereas Michael has a lot of spasticity, he can
push himself up using his muscle tone against gravity."

She explains from a PT perspective why his wheelchair
seating system is crucial for his functioning.

He has a contoured seating system in both his
manual chair and his power chair.  That enables
him to hold his trunk in a nice erect mid-line
alignment, no slumping to either side.  He has the
head rest in the back that allows him minimal
support when he needs it and also I think it gives

85

him physical feedback when he touches it to know
that his head is in mid-line.  So he uses that and
then he has his lateral trunk supports that keep
his trunk erect and he has the lap belt which
holds his hips back.

She also emphasizes the importance of his being
restrained to decrease thrusting of his arms and legs.

 His feet are strapped onto his foot plate which
is at a ninety degree angle so his feet, his
ankles are at ninety degrees, his knees are at
ninety degrees and his hips are at ninety,
ideally.  His hips could be a little bit more
flexed than ninety really to break up his muscle
tone.  Even if he doesn't have his feet strapped
and he has everything else strapped and correct,
he still can't do his work because his feet are
flying out in front of him.  He has to have
everything restrained.

For Michael access to technology requires even better
positioning than would be necessary if he weren't trying to
access letters and numbers on a Unicorn Board or Touch
Talker.  "Because his muscle tone is so severely abnormal,
he has no stability at all through his trunk and therefore
he cannot do anything through his arms and legs without a
complete support to his middle."

He has ungraded movements.  [She waves her arm
above her head to demonstrate]  They are just
large, sweeping, waving movements. That's what
athetosis is.  He has no control through the
middle part of the range of the muscle.  It's all
at the end of the range, way over here or way over
here but nothing.... no quality to the movement.
Everything would look very non-purposeful, even if
he were trying purposefully to do something. If he
wasn't in a good position, it would look as if he
were throwing toys across the room.  Everything
would be very non-purposeful looking and would be
very frustrating, I think for Michael, with his
intelligence.

Because of the flailing movements of his arms and the
severity of his athetosis, she agrees that without assistive
technology Michael would not be able to write.  As he gets
older, larger, and heavier it becomes "more difficult for us
to control his movements.  Proper positioning also becomes
more expensive as he gets bigger.

Until he was integrated in regular education Michael
regularly used a standing table.  Strapped in this he was
held in an upright position and able to bear weight if each
foot was in an ankle foot orthosis (AFO).  AFOs which
resemble a thick plastic sock or a lightweight foot cast are

"designed to hold his foot in a good position while he is
standing and also help to decrease his tone" when seated.

We have found that if he does a lot of standing at
his standing table with his AFO's on, that his
tone reduces and his tone is more manageable, so
we tried to get him standing a lot last year.
Unfortunately, his AFO's didn't fit very well last
year and we kept having to make changes and they
were painful to him.

Because they had difficulty fitting him and because
they weren't sure of their continued necessity, the clinic
in Charlottesville stopped putting Michael in AFO's just
before he entered third grade. Service providers, school
personnel, and his mother question the wisdom of this
decision. Without the AFO's he won't be able to bear
weight. Both John and the PT are concerned that this might
also affect his access to technology. According to the PT,
if his toes start pointing downward and he cannot keep his
foot at a right angle on the foot plate of his wheelchair,
his ability to control his arms and reach an adaptive board
will be impaired.

We decided to put him on consultative with a home
program for his Mom to work on things at home,
activities for John to try to work toward at
school because without his AFO's he could not

stand any longer at his standing table and it
really hampered the transfers [getting him in and
out of the wheelchair].  So it's more of a matter
of lifting him up against your body and
transferring him than it is for him to assist with
his feet.  Without his AFO's, at the very same
time he gets heavier, it'll be more difficult for
him to transfer.

I told the PT how indignant some of his service
providers were that he was being taken off the AFO's.  Many
said that the clinic did it because they knew they could get
away with it--a money and personal influence issue.  The
PT's response showed concern and a need for monitoring what
happens as he tries to do without them.  Because of how
difficult it is for them to fit him properly when they make
the AFOs, she can, however, understand the clinic's
decision.

They may end up putting them back on him.  He has
blisters on his feet.  He complains of his AFO's
everyday from wearing them.  His Mom is torn
between knowing he needs to wear his AFO's and
seeing that he is in pain and knowing that the
pain is affecting his school work or could
possibly affect his school work.  So she's torn

between what to do and Michael does complain of
the AFO's everyday.

## Occupational Therapy (OT)

The OT works with Michael on fine motor control.
Unlike the PT she has directly helped him access the Unicorn
Board and Touch Talker. However, she did not assist or
provide input into decisions of what devices to purchase for
him.

To tell you the truth, I have only recently begun
to know much about Touch Talkers, and Unicorn
Boards so I wasn't in a position to really assist
much in the development of his communication
devices. John always knew so much more than I did
and I always relied on him and his decisions. I
was always interested and asked him what he was
doing, but I really didn't have much input.

When Michael was in the special education facility and
first trying to access technology John came to her and asked
for help in getting Michael out of his "usual pattern" of
holding his hands "up and out to the sides of his body."

He was having trouble with the movement from there
down to the board and back. So I tried to gear
all my activities like sponge painting, with a
sponge, or just any kind of activity. I tried to

90

gear it so we would imitate that same pattern that
John wanted to use on the Unicorn Board. I
observed a lot of times in the classroom and gave
suggestions. I think he started out with the
pointer back then for certain things. I know I
made that pointer for him four or five times
because he has grown.

Below the OT describes what she did with Michael during
direct service, once a week in third grade before he was
placed in consultative services in December.

Well we started out at the beginning of the
year focusing mostly on the self help skills
because I felt pretty comfortably that he was
doing pretty well getting about in his
environment. He was functioning well in the
classroom. So I didn't feel like I had to dwell
on any of those type of skills. But he still had
some deficits in dressing, feeding, those two
areas, and also fine motor. Those were the three
things I focused on initially.

The dressing and the feeding we got to a
plateau. He can dress himself but his clothes
have to be positioned for him. He cannot take a
pair of pants that's rolled up in the corner or
folded up in his dresser and he cannot remove

those and get them positioned for his limbs to go
in.   He just can't because of the ambulatory
component, he just cannot do it.   We tried some
adaptive equipment like dressing sticks, sock
aids, buttoners, and so forth, but again, there
had to be a certain amount of set-up done for him.
He could not, even with the adaptive equipment, he
could not do these things independently.

For feeding, she says they "tried many different things
. . .different types of cups, different types of holders,
the ball bearing feeder, all kinds of things to try to get
him to use the utensil."

The problem is that he just lacks control in the
hand-mouth pattern.   It was dangerous unless he
wore goggles and protected his face because of his
swiping, quick ballistic movements, you know, he
might be able to scoop but then he would get
excited, and any little degree of excitement just
fed right into his movements to increase [speed].

So we had to settle with finger feeding, which he
can do pretty well.   He uses a gross, swiping type of
grasp. And he anchors the food right in the middle of
his palm with a gross type of grasp, It's not anything
like a prehension pattern or like a pincer grasp.   It's
a palmer-type grasp.   He gets to the side and he has to

anchor his hand onto his cheek for stability, then he
can release it into his mouth.

When asked whether he could use an automatic feeding
device, she explained why he could not.  "He hated it.  He
just got so frustrated with it."

When you hook somebody up to that, they have to be
expecting to follow a certain track ...just like
their hand is a train or a car ... a train on this
track that goes from scooping position to his
mouth and back down again.  Well being athetoid he
could not stay on one linear path, he couldn't do
it.  He was flipping his hand all around.
They did, however, achieve a way he could drink
independently.

Of course, there is just no way he can handle a
cup and bring it to his mouth, take a drink, then
set it back down on the table.  So we got a coffee
can, you've seen those, and cut out the lid and
put an elevated cup in this weighted coffee can,
then used a straw holder.  Plus we made a long
straw and angled it towards him so that all he had
to do was reach forward and get it between his
lips. . . .  With his head, he can do it if it
doesn't involve any use of his hands and if it's
positioned right close to him so that all he has

93

to do is lean forward and clamp his lips around it. So he was really pleased with that. That's something he can do totally independently, get a drink.

She adapted his paint brushes "in a T-grip because he does so well with the t-grip" but still needs it taped or strapped to his hand "because he just has involuntary release all of a sudden that he cannot control." After adapting the brushes and being unable to adapt a ball so that he could release it for a game, she went to John for suggestions on what to work on next for Michael in third grade. This is when John asked for help with accessing the Touch Talker.

The lower left hand quadrant, he was having difficulty with. And I kind of looked at how he was using his hands when he hit the keys. He has a pointer now to aid him. I think that does work better than him trying to isolate a finger. Although, certain keys, he does just use his finger, it's the space, when he has to use the space, which is located right down at the bottom right in the middle of the key, he can do that with his finger.

He was using his left hand. There's nothing there for his left hand [to rest on]. The keys

are real close to the edge.  What we did was just
take a piece of splinting material as a trial and
cut out an extension in an L shape to go on the
left hand side on the bottom and attached it there
to see how it would do.  It really helped him out
because he had somewhere to rest his hand and then
hit the key.  The idea was that John would then
make one out of plexi-glass and attach it on to
the Touch Talker.

Like many of his service providers, she developed a
special friendship with Michael.  "This year I think he was
really successful although it started to get pretty hard for
him.  He often told me that he was sweating it out and
worrying about his grades and how he did on tests and
things."

Below she remarks on their friendship and her reasons
for placing him on a consultative basis.  She also shows
that the demands of the general education curriculum
influenced her decision.

He really enjoys working with me.  He really kind of
uses me as more of a buddy.  I feel like I'm more his
buddy than a teacher and he confides a lot in me.  Now,
since he's on a consultative basis since last
Christmas, I changed him from direct weekly to consult.
I felt like I had to do that, not only because we were

getting plateaued in certain areas and had to do it,

but I also felt it was not important enough to take him

out of the class that he was in.  He had to get there

at nine o'clock and he was in his Math then.

## Speech Therapy

In third grade the speech pathologist worked with
Michael twice a week.  In fourth grade this was reduced to
once a week because of "pullout" problems.  "We couldn't
figure out a time that we felt comfortable with him coming
out of the classroom again.  We felt like he was missing so
much that's very important."

When she tested Michael "his language skills looked
pretty strong."  Later his fourth grade teacher pointed out
to her that he was weak in comprehension.  "With the
classroom teacher coming to you and telling you what's going
on in the classroom, that's very helpful because sometimes
things like that do not show up and we need to know.  And I
did appreciate her coming to me."

Once a week she worked on comprehension activities
with Michael when she took him from the classroom to her
speech therapy room.

What I do is I bring him in for about twenty

minutes and we've been working on reading

comprehension.  He has a lot of difficulty if he

96

is reading by himself and remembering what is
read.  If it's read to him, he can remember just
about every thing you have read to him.  It's not
hard at all.

We have been working on him reading it and
then visualizing what he has read and answering
questions about what he had read, or relating back
to me what he has read.  He really had a hard time
doing that. . .

She "hope[s] that his mother allows him to read it
himself rather than to read to him because he really needs
to work on that."  She has also discovered that he
comprehends better when he reads aloud.  "Sometimes I have
him read out loud, sometimes he reads silently.  When he
reads out loud, then he remembers because he had that
auditory key as well.  When he reads silently, that's where
we find the problem."

In addition to comprehension they also worked on
vocabulary development as well as "articulation and
strengthening the oral structures."

We worked on one sound all year.  We worked
on "t." He wanted a tape, he wanted a new "Kids on
the Block" to listen to and his mother had gotten
him one and said that was all she was going to get
him for a little while. . . .  He would always

97

say, I want a cape, I want a cape.  And I said well when you're able to tell me you want a tape and you say it very clearly any time I talk to you, then I will get you a tape.

And I told him, "I'll bring a cape and a tape.  Whichever you say, you'll get."  So he got to the point where he could say his T sounds, and it was very difficult for him because he has to elevate the tongue and that's something that is difficult for Michael.  But he really did work on it which showed me that if the motivation is there and there's something he wants, he will definitely work toward that and can get it.  But it did take a whole year just for one sound.

According to her his vocabulary is "very good" and he "picks [it] up very quickly.  "I think that whatever weakness he has in that area is due mainly to lack of exposure rather than deficit because once he's been exposed to the word, he remembers it."

She used his Touch Talker with him until this year when it "was out of commission most of the year."  She knew of his interest in songs so they worked on them together and put them into his Touch Talker.  "Sometimes he would program it and sometimes I would. . . .They had no tune . . . they were more like poems I guess."

She hopes that in the future he can use the Touch Talker for written communication and that his speech will improve enough so that "he will be able to speak on his own and be understood." A trip with him on a field trip to a nearby mall however gave her "a better idea of how the outer world reacts to a child like this." After this trip she thinks "maybe he would benefit from the Touch Talker simply because people tend to be impatient, and it takes Michael a long time to get out just one small sentence."

> But I kind of felt bad for him there because I
> could see he really wanted to be able to tell them
> himself and they wouldn't take the time until I
> said--I kind of pulled them aside and said, "You
> know, if you wait and you listen, you'll be able
> to understand what he's asking you." I think they
> tend to take people like that as if they are not
> very bright. They were treating him that way,
> they were saying, 'Now how are you today?" and you
> know, just talking to him like he was just a
> little child. And it was really irritating
> because Michael is very bright.

She enjoys Michael a lot. "It's just a joy to be around him. I really get excited when it's his time because I know we're going to joke back and forth and you kind of need that during the day." But she is concerned at how

complaining and angry he is about school recently. "He's positive in his social relations and that sort of thing. He's negative in his view of what his life is going to be like." To be negative or complaining gets him attention and is "reinforcing to him for some reason." "He has this list that you wouldn't believe of things he doesn't like."

## Teacher Training in Assistive Technology

### Getting Started

One of the most demanding roles that John, Michael's special education teacher, has assumed is obtaining training in assistive technology. John initially got started by attending a workshop sponsored by Bud and Delores Hagen who also sponsor the annual international conference, "Closing the Gap." From there he developed a network, purchased a computer for use at home, took university courses, and spent a lot of time in self instruction. The following is a brief description of the different ways he obtained training in assistive technology.

### Conferences and Workshops

Initially Bud and Delores Hagen were significant influences. They conducted a workshop in Richmond where John still remembers his response to the videos they showed of children "doing phenomenal things--that no longer seem

phenomenal." After describing the tapes showing children who could not hold a pencil who were word processing, he admits that he "was kind of inspired." Later, after regularly attending the annual conference in Minneapolis, Minnesota, he says that he "learned a great deal from Closing the Gap international conference[s] which I attended."

## Self Instruction

After attending the Hagen's workshop and before getting his students into assistive technology, John decided, "Well if I'm going to learn to use a computer, I'll start at home."

> So I purchased a computer at home similar to the school computer. And I took some of the adaptive things home during the summer and worked with them to learn how to use them and then it seems like from there it just kind of grew. When you get started the initial feeling of intimidation of computers kind of went by the wayside. You just realize that you could do whatever you need to do, you just have to dig into the manuals, talk to people and try.

## Network Support

Immediately John started forming an assistive
technology network, initially consisting of me and people he
met through attending the "Closing the Gap" conference in
Minnesota. "There's kind of a network that has developed
through groups like Closing the Gap and through TAC Centers
and different individuals through the field and you kind of
draw off each other." The TACs he refers to are Technical
Assistance Centers which are federally funded in Virginia
through the State Department of Education to provide
assistance to special education school personnel. Later the
TAC's became an important source of training and networking
with other people in southwest Virginia interested in using
assistive technology. Initially network support also came
through access to Confer telecommunications though the
University of Michigan.

## University Courses

Courses and mini-courses sponsored by universities have
been sources of training. John has enrolled in these
courses but has not used them for credit toward a degree.
He considers these courses helpful but not as important as
"on the job experience."

> I've gone to five years of pre-training workshops
> that are put on by Hamline University out of

Minneapolis. I also attended, what do they call those, mini-courses from Johns Hopkins University that Dr. Bud Riser did several years ago on the utilization of the Adaptive Firmware Card. That's kind of piece meal here and there and on the job experience primarily. You learn by doing but it has taken a lot of individual time. Some of it is supported by the school system and some not. Some of it is just your own time, out of pocket expense. It continues to be that way.

## On the Job Experience

"Learning from experience" and "seeing what's not working" have been two of the most important sources of training in assistive technology for John. "Michael has been a wonderful training [ground]."

Being able to work with Michael has really helped. The information we have learned all along, because he learns so quickly, you don't get stifled by lack of cognition and not know what the next step is. There's always been another step with Michael.

## Assistive Technology and Teacher's Roles

The following section discusses how Michael's special education teacher's role changed as he first used assistive technology with Michael and later with other students. Initially at the special education facility his teaching role expanded. Later at the regular education facility his role as direct instructor decreased while his role as coordinator and facilitator increased. After an introductory overview of "Role Expansions and Changes," the various roles he now assumes are discussed under these headings: (a) Transdisciplinary, Multidisciplinary Planning, (b) Assistive Technology Coordinator/Negotiator of Services, (c) Maintaining a Support Network, (d) Fundraising, (e) Repairing, Trouble-shooting, and Liability Issues, (f) Adapting, Programming, Designing Devices, (g) Support and Training of Service Providers, (h) Advocacy and Public Relations, (i) Supporter of Parents and Other Roles

### Role Expansions and Changes

John's role as teacher of students with severe disabilities expanded when his students started using computer technology. Programming, repair and upkeep of computer and augmentative communication devices initially and most visibly changed his role. Later adapting and adjusting Michael's wheelchair to make technology access

easier with improved positioning led him into tasks that, while strictly belonging to a rehabilitation engineer, through default and geographic distance, fell to John either to do or to get done. The next roles he picked up were those of fundraiser and advocate or public relations spokesman for his student's accomplishments and needs for additional support and devices.

All of these roles, first adopted while he was in the special eduction center, meant his job expanded, often taking more and more of his free time. When he moved to the general education facility, his original teacher role also changed significantly. Here the integration of many of his students into general education for all or various parts of the day meant his role as direct instructor decreased while his role as coordinator and facilitator increased.

The principal of the general education facility says that it is different being responsible for a teacher with so many roles. "He doesn't do any of those things without communicating with me first. He realizes that I am ultimately responsible for every action that takes place in this school." The principal also speaks of possible future changes in John's role.

> As far as John's role, I would like to see the day
> come when he's just more like a coordinator, you
> know. The children start off in his room in the

morning, but then they are out there, all of his
students, are out there in the regular classroom.
But because of their physical needs, that's not
possible.  They still need the therapies and the
things, and the communications and until he gets a
hold on how they communicate to other students, to
teachers, to someone else, then he needs to work
with them to get that done before he sends them
off into the regular classroom.

John speaks of one change in his teacher role after
leaving the special education facility as giving up his
"cheerleader role" which was "sometimes overplayed."

The kid would do some minor little skill or
achieve some little skill and you would go crazy
and stand on your head and turn somersaults.  You
don't do that as much [now], but you've still got
to be the motivator and figure out ways to
motivate the kids.

After two years in the general education school, John
plans a change in the third year that would allow him to be
with Michael and other students more in their general
education classes.  In third and fourth grade it was the
paraprofessional who accompanied Michael to his classes.
John now realizes that he "needs to be more involved with
what's going on in [these classes], more of a facilitator in

integration." He also feels he should be a regular observer of what is going on in order to plan better. He plans to "put more energy into visualizing and putting together a program, in facilitating for Michael, more positive experiences and work on his independence."

While the coordinator and facilitator of integration roles were adopted at the general education facility and didn't depend on whether or not the student used technology, many of John's role expansions and additions occurred because of assistive technology. "Very often the fundraising or the maintenance of the devices is as important as lesson plans." Because Michael was the first of his students to use technology, John's role expansion coincided with Michael's use of technology. Michael was a "training ground" for roles that he now assumes with all his students in the multihandicapped classes. As John explains, "It's hard to do it all" because "it can be more than one job." If, however, "you stuck by the contract and just did what teachers are normally supposed to do, you wouldn't be doing your job."

## Transdisciplinary, Multidisciplinary Planning

One of the role changes recently proposed for people working with students with severe disabilities is the change from multidisciplinary team planning to transdisciplinary

team planning (Oreloff & Sobsey, 1991).  With
multidisciplinary team planning a speech pathologist (S)LP
remains in her area of expertise and makes speech language
suggestions often with out information from or influence on
the other team members.  At other times OT and PT service
providers may gather and write their own plans in a similar
manner.  The OT and PT do not make language suggestions or
necessarily integrate their therapy with language
activities, for example.  With transdisciplinary planning
everyone meets together and these boundaries are broken down
(Orelov & Sobsey, 1991). Providers share information and can
make suggestions across expertise domains.

For students like Michael these domains must overlap
for assistive technology to be used properly.  For example
the SLP knows which words or letters he types the most or
which vocabulary he needs for which environments, the
teacher knows which computer or augmentative device function
keys are most  needed for a certain program,  and the OT
knows how to adapt the pointer he uses and which side of the
board he can access most easily without exhaustion.  All of
this input is needed to design a computer or communication
board overlay for Michael.  If the team members don't
communicate, the board's overlay can have the very letters
and function keys he uses most on the section of the board
that is hardest to reach.

Without communication and sharing of expertise and information on a student, a teacher might, in the worst case scenario, assume a behavior is an academic or cognitive issue when it is first and foremost a positioning issue. Also, motivation and interests are especially crucial factors for students with severe disabilities. Sharing of personal information learned about a student's behavior and interests, especially what they find motivating or discouraging can be of help to all team members regardless of their area of expertise.

Ideally John "would like to see all the related services personnel and parents sit down on a regular basis and discuss each student, discuss the total child" in a transdisciplinary session. However, because there is no time or administrative structure that allows the team members who work with Michael to meet together, John fills the role of the "go-between," a sort of assistive technology coordinator. He tells the OT which function keys are most needed. She suggests their placement on the overlay and John either makes the overlay from this information or relays the information to the SLP who adjusts the overlay according to the OT's information.

This is multidisciplinary input but the team member's planning is often solitary. The sharing or gathering of

information that does occur most often occurs through talking to John.

## Assistive Technology Coordinator/Negotiator of Services

According to John "more is expected of [him]" in his relation to service providers for students who are assistive technology users. "More is expected of me because I'm the technical person and it requires more of my time." In general "more is required of the relationship" from their perspective too.

> There isn't always the time to do it all so you
> gotta set priorities-which is more important, the
> orthopedic needs or the technology needs? It has
> to be evaluated and sometimes we don't agree and
> that puts a little bit of a damper on things. And
> it's hard. You're looking at it from a different
> viewpoint. You've got a physical therapist who
> doesn't understand the technology or what it can
> do for the individual, they're going to steer away
> from it and they're going to say well we gotta
> look at the ankle/foot orthotics or we gotta look
> at these wrist splints or we gotta look at
> position adaptations of the wheelchair which have
> nothing to do with technology.

One of the difficulties of being in the coordinator/
negotiator position is that assistive technology--especially
augmentative communication--"requires a great deal of
everybody's time." When others don't or can't do the job,
then it "falls back on the teacher . . . to do a little more
in that area."

## Maintaining a Support Network

Basically a teacher of a student using assistive
technology is in "The-Buck-Stops-Here" role. This is one of
the reasons John assumes roles as diverse as repairman,
fundraiser, and systems change facilitator. When I tried to
build the scanning board for Michael in preschool, I
discovered I didn't have the needed expertise with
integrated circuits. So the next step became finding
someone who could build the board. This networking is
essential to assistive technology teachers. Not all can
solder or repair devices, but many build the networks it
takes to get an unusually diverse array of tasks
accomplished for their students (Orelov & Sobsey, 1991;
Scherer, 1991a; Wehman, Wood, Everson, Goodwyn, & Conley,
1988). This can mean anything from knowing congressional
representatives to knowing which personnel are especially
helpful at which electrical supply stores. This can mean
knowing about private health insurance companies' funding

111

procedures as well as the hoops that must be jumped to obtain medicaid funding for a wheelchair.

John's assistive technology network which he has built in the past five years since first working with Michael includes--among others--business owners, sales representatives, writers and consultants (some of whom have severe disabilities), special education and rehabilitation professionals, university professors, parents of students, social workers, mental health and home health care providers, wood workers, metal workers, electricians, politicians, college students, retirement home residents, manufacturers, inventors, lawyers, public and private school personnel at all levels including custodians, and medical personnel at all levels including doctors. The latest addition to his network is "a computer mechanic" whom he "just recently discovered."

> He's willing to do some things that normally I
> would have to figure out. He can do it much
> quicker, not necessarily cheaper. In some cases
> he has to charge us labor and in some he doesn't.
> But, you know, you look for situations like that.

## Fundraising

Teacher's fundraising activities are often governed by school policies. John has the permission and support of his

principal for fundraising which he sees as an integral part of his job.  If the fundraising is specifically for one student, he also has the parent's permission.  If someone else does fundraising for a student, this effort eventually involves John as a source of information on the student and what is needed.

Much of the fundraising he initiates when the parents' resources or insurance company cannot be the source of devices needed.  Fundraising as discussed here is not the usual request for funds from the school system or the PTA that is often a part of all teacher's jobs.  John's fundraising is for devices that the school is not required to supply such as augmentative communication devices to be used at home or for devices and equipment for which there are not funds available.

He has not been too successful with large grant proposals and spends more of his time speaking to local civic groups.

> I've written three, one sort of sophisticated, two
> unsophisticated grant proposals now and I've
> gotten no response on any of them.  You hear
> about, through periodicals and journals, sources
> of funding and you try that.  Some of these are on
> a national or regional basis so the competition is
> pretty tough.  You go to philanthropical

organizations, community service organizations.

I'm speaking to a Civitan Club week after next.

With direct appeals to local community organizations he can get funds "if you have a device that doesn't cost too much." One device, for example, recently purchased by "an organization that specializes in funding for the crippled [their words]" cost $970. Other sources of funds are regional service organizations and privately funded networks like The Children's Miracle Network at Kluge Rehabilitation Center in Charlottesville. Over the past five years he estimates that he's "been involved in fundraising either for dedicated devices like wheelchairs or technology equipment, probably somewhere around $60,000 or $70,000 worth of fundraising."

> But none of it is funded through the school
> system. It's all private donations, charitable
> donations. You just get out there and beg. It
> takes a lot of time. . . . You keep going because
> as new stuff comes on the market, you want that
> new stuff cause it's going to do a little bit more
> than what you've got now to integrate these kids
> into society.

## Repairing, Trouble-shooting, and Liability Issues

Broken cords that hang out of devices, broken switches that operate devices, or other pieces like the polyplast collar at the bottom of the Touch Talker made to support Michael's palm are a nuisance to repair and maintain. Although such repairs are time consuming and can disrupt class lessons, they're on the basic handyman/woman level that most people with some repair experience can fix. Many teachers of students in preschool and severe or multihandicapped classes routinely repair and maintain such devices and equipment. Where the non-technology specific repairs become more difficult and time consuming is with devices like wheelchairs, for example, when the rehabilitation engineers are far away or do not finish their job. With his first motorized wheelchair Michael arrived in John's class sitting in an uncomfortable, semi up-right position with his feet flailing about a broken foot plate. Before all this was remedied John had to bolt the seating system himself and obtain a new foot plate after several phone consultations with the rehabilitation engineer in another city.

The more difficult and time consuming breakdowns, however, occur when something is wrong with the sophisticated technology operating a device. Although these repairs must often be done by trained technicians, the

115

device's malfunction may at first resemble a minor problem caused by an inadequate hook-up or a programming error made by the teacher.  Assistive technology teachers have to learn to trouble-shoot minor and major mishaps in order to know when the device needs to be sent back to the supplier.

As John explains "being dependent on technology" is tough because technical things break down . . . . It's getting better.  There's not the repair work on these devices that there used to be, but it's still there."

When you have problems with devices, it just depends on what it is.  Like this Touch Talker. The problem with it now, there's nothing I can do. I've taken these things apart and I've moved micro chips around in them and done things like that but I don't have the expertise to fix what's wrong with it now.  It will have to go back and the turn-around on sending this device in to be fixed and getting a replacement device or a loaner device is sometimes three weeks and sometimes it's two months.  If Michael were really dependent on this to be his voice, it might be two more months without a voice . . . . He wouldn't be able to function.

For devices without warranties, like Michael's power wheelchair,  John feels responsible either to do it or to

find someone who will do it. He makes clear that one of the reasons he takes on these repair roles is he sees what a barrier to a student's program a non-functioning device can be.

Michael's motorized wheelchair is sitting in the classroom right now. It's inoperable. There's nobody up there to repair it but me, and it's just a matter when, and it's going to cost, not much. This particular thing is probably about $40 or $50, and that's real cheap for a wheelchair. The wheelchair's initial retail price is about $8500. There's no warranty on this device, no funding to do it, and in the meantime, Michael has to be pushed around rather than being independently mobile, which is a blow. It's like putting an ambulatory person on crutches. It's like go ahead and do everything you do normally, just do it on crutches. It's hard to do. It's another barrier to his program.

Assistive technology roles can take administrators and teachers into uncharted areas. After obtaining expensive chairs and equipment, parents expect the students to be taught how to use them. Could they hold the school liable if the students hurt themselves in the process of learning, for example, how to steer a motor controlled chair? Could

they hold the school liable if, once the chair is obtained, the school does not teach the student how to use it? Recently the school principal has suggested that because of liability issues maybe John should not try to fix wheelchairs.

Both he and John have been concerned over some recent near accidents with the chairs. In one instance John accidentally put the tray onto Michael's chair in a way that trapped the stick controller. Before John was able to turn off the chair, Michael knocked over a hall display and ran over the foot of a substitute teacher. In another instance a student almost drove the chair down a flight of steps. John understands the principal's concerns and the difficult position the school is in being responsible for what might happen if the chair is out of control. On the other hand he says, "Seems to me if I notice the brakes need adjusting and I don't adjust them, then I could be liable for not fixing them."

## Adapting, Programming, Designing Devices

Many of the computer and augmentative communication boards that Michael has used have to be programmed or adapted for him. The Unicorn board, for example, is basically a "tabula rosa" and can be as simple as a two choice board or as complex as a full function keyboard with

128 keys. Programming it is not as tedious or time consuming as programming in a computer language. However setting up the programs and learning all the levels and ways of adapting it is initially very time consuming. John purchased an Apple computer for use at home because he saw no other way to keep up. During the first semester he worked with Michael he went to John's Hopkins University for a two weekend course on how to use and make set-ups for the Unicorn board. Many of his weekends were spent working on and becoming familiar enough with this board to be able to quickly trouble-shoot minor problems during class time.

Once he was at ease with the board, he started looking for a slant board holder that would hold the board near Michael on the wheelchair lap tray without falling every time Michael's fist pounded it with athetoid frenzy. After looking fruitlessly and breaking purchased boards, he eventually designed and made his own board which he names "Expand-a-Stand." The next step was to design in collaboration with the OT an overlay for the board that would allow Michael to count and use letters of the alphabet. Each improvement in positioning that was made, each cognitive advancement meant new programs had to be set up and new paper overlays to match had to be made.

Working this closely with students who were among the first to use these devices puts an assistive technology

119

teacher in a position to provide needed feedback to people
who design and manufacturer these devices. After attending
conferences and meeting these people both of Michael's
teachers, John and the preschool teacher, became part of
consumer/user groups providing feed back on what is needed
in new devices.

## Support and Training of Service Providers

John has been responsible for training
paraprofessionals and service providers in how to use the
technology Michael has access to. Because a
paraprofessional was often with Michael in general
education, John's responsibility to the third and fourth
grade teacher was more of an informant and facilitator when
there was, for example, too much noise from the speech
synthesizer. If Michael "had been required to use it more
in the classroom and more independently when the para-
professional was not there, then his homeroom teacher would
have had to be more involved, at least understand a little
bit more about the workings of [the technology]. As the
fourth grade teacher explains it, she never could steer his
electric wheelchair but she did learn to turn it off when
necessary.

He taught the occupational therapist how to use the
Touch Talker. He taught the speech-language therapist how

120

to use and program the Touch Talker. The paraprofessional received the most training and was able to set up and use both the Touch Talker and computer at an elementary level.

The para-professional has been trained along the way and has a working knowledge of . . . the Touch Talker . . . . She knows how to store messages in the Touch Talker. She knows how to set it up so that it will speak to the computer so through ASCI code output it will speak to the printer . . . . She just kind of learned this along the way. She knows how to interface the Touch Talker with the Apple computer.

She has a limited but workable knowledge of the Adaptive Firmware Card to do a few things like change the configurations of the Adaptive Firmware Card. In other words, tell the computer what auxiliary input it's supposed to accept. For example, rather than accepting the input from the computer keyboard, it's telling the computer to accept input from the Touch Talker or to accept input from the Unicorn Board or accept input from a switch operated on-screen scanning. She knows how to change that.

For students using assistive technology this role of training others who work with the student often falls to the

teacher, speech-language pathologist, or both depending on the device used. Occasionally parents have reported taking on some of this role when they have moved to schools without personnel familiar with devices used by their children.

## Advocacy and Public Relations

John functions as an advocate for his students with people working in the schools as well as in the community. Sometimes people "expect technology to be easier to use." They expect results from the student faster than the student can respond. "As you're working with some of the adults, they very often become frustrated in trying to achieve their goals for the student. So you have to come in there and do PR for the student."

At other times the advocacy and public relations is to enable people to have a vision of what is possible. Before students with severe disabilities had access to technology, positioning was important, but it didn't always have to be as precise. No one expected students like Michael to have better control of their hands, for example, because there were no Touch Talkers or Unicorn boards for them to access. One student in John's class who was able to use the computer in class, came back from the orthopedist in a new chair so badly positioned that she could not begin to accomplish what she had in the old chair. The doctor had

sent the family to a home health provider (certified as a
Durable Medical Equipment [DME] dealer) whose job it was to
order and adjust a new wheelchair for her. This provider
knew little about the technology she used in the schools.
It had not occurred to him that this young student with
severe disabilities could word process, and when she left
his office she couldn't because of the chair and the
positioning.

As an advocate in this instance John had to go directly
to the doctor. John, the student, and her parents went to
the doctor's office with a video of what she had been able
to accomplish and could no longer accomplish because of the
new wheelchair. In this instance the doctor listened and
acknowledged that he needed to be more aware of the skills
of the DME providers who order and assemble the wheelchairs
for his patients. In this instance he was able to correct
the error. This is not usually possible once a wheelchair
has been used.

### Supporter of Parents and Other Roles

Finding adult assistive technology users who can visit
his class and serve as models for his students is a role
John has tried to fill whenever he can. Coordinating the
five weekly volunteers--parents, students, and retirement
residents--who assist in his class is a role that many

multihandicapped teachers assume.  However, because of the technology used by his students this role is more complex and in many instances, especially with college students who are interns, requires extra time.  Consultant and advisor to teachers, parents, and educators from surrounding school systems in southwest Virginia is another role that John assumes when he can.  Almost weekly parents, teachers, or local educators visit his class to observe and get information.  He often schedules these visits near the end of the day so that he can talk with them after his students are on the bus.

John insists that one of his most time consuming roles is "supporter of parents."  When asked how technology affects this role, he replies that "parents don't always want to foster a child's independence."  Another one of his roles is information resource to parents and others. Currently he is gathering information on summer camps for students who use augmentative  communication to help a parent decide which camp--if any-- might be appropriate. When new devices arrive, he is frequently the family's source of information on where to buy the best keyguard or how long and how frequently to recharge batteries.

Keeping up with changes and recent developments in assistive technology is a job "that keeps growing."

We need to put more money and time into
professional growth for our public educators.  We
cannot expect them to pay for this type of growth
themselves.  It's too expensive.  We can't expect
them to take the personal time.  It takes too much
time.  It's not the kind of thing you get a
degree, you know.  You go through a program and
get a degree and you're there, because it doesn't
stop, it keeps growing . . . that's what's
happening in the medical profession.  The same
thing is happening in education.  You don't get
out of medical school and stop learning because
new innovations are gonna come along and you gotta
keep up with them.

When asked whether he would like to reduce the number
of these roles or get more support in filling these roles,
John replies, "I would like to reduce the number of these
roles by getting more support."

I would like to become less of a physical
therapist by getting more appropriate physical
therapy in the schools. I would like to become
less of a rehab engineer by getting more expertise
in the area in rehab engineering.  Actually we
don't deal with rehab engineers right here, we
deal with rehab mobility experts.  I would like

them to get more expertise and more time to work with the students. The wheelchair mechanic role--I definitely would like to dump that. It's extremely time consuming but if I don't do it, it doesn't get done.

Actually ...the actual day to day instruction, computer instruction, use of the computer in educational process, I would like to eliminate a lot of that by getting more trained staff involved so that I could spend more quality time with the students in the actual integrated classroom.

## Funding Assistive Technology

Funding cuts across many issues--teacher roles, "bottom line" budget items, legal aspects, how professionals and institutions respond to change--to name just a few. Data collected in this study do not especially flesh out this topic. However, to better understand the influence of the funding process as well as how Michael's technology devices were acquired, the following section very briefly presents, sources of funds, I.E.P. issues, and a special education teacher's view of administrator responses to the cost/benefits of technology. A quote at the end reflects

the teacher's point of view and hints at larger social issues.

## Sources of Funds

The first switch toys and comparatively inexpensive electronic technology that Michael used in preschool were paid for by the school system. Parts for the homemade scanning board were paid for by the teacher. Also the first computer he used in preschool belonged to his teacher. This was in 1985 at a time when even the general education school had no Apple computers.

In the 1986/87 school year at the special education facility when John first started using technology the Apple IIe computer, printer, Echo speech synthesizer, switches, Adaptive Firmware Card, software, and adapted keyboards like the Unicorn and Powerpad were paid for by the P.T.A. and the school system. Each paid half of the initial costs which were around $7000. Although Michael was the first to become adept at using this equipment, this was not purchased specifically for him.

John's fundraising activities seriously started when he realized that students like Michael needed expensive devices like the Touch Talker (around $4000) that were not the school's responsibility to purchase if used at home. Money for the Touch Talker came from the privately funded

Children's Miracle Network administered through Kluge Children's Rehabilitation Center. Community and regional service organizations have been the source of funds for less expensive devices. Michael's printer for the Touch Talker, for example, was paid for from Christmas funds donated by a local church.

With other students similar devices have also been funded from parent's personal funds, private health insurance, and community funds applied for by parents with supporting letters and documentation provided by John and other service providers. John also assists Michael's mother with the lengthy process required for going through medicaid to get Michael's wheelchair. The paper work and time lines are such that Michael usually outgrows the chair long before new funds are approved.

Funds for repair and parts frequently are obtained free from John's large assistive technology network. If this is not possible, the school usually pays. When school funds aren't available, John has paid from his own pocket. Funds for attending conferences and other professional growth and training are funded about equally from three major sources--the school system, the SPH Technical Assistance Center at Virginia Tech, and John's personal funds.

## I.E.P. and Funding Issues

Because Michael is enrolled in special education all
plans and decisions about his education are written in his
I. E. P. (Individualized Education Program) developed by an
interdisciplinary team to suit individual abilities and
needs. Guidelines specifically state what the I.E.P. must
include.   In addition to the "child's present levels of
educational performance," "annual goals," "short-term
instructional objectives," and other requirements is the
following statement that an I.E. P must include

> a statement of specific educational services
> needed by the child (determined without regard to
> the availability of services), including a
> description of
>
>> a.   all special education and related
>> services needed to meet the unique needs of
>> the child, including the physical education
>> program
>>
>> b. any special instructional media and
>> materials that are needed. (Federal Register,
>> 1992, p. 4481)

More specific information on how assistive technology
relates to the I.E.P. and what the schools must provide came
in  1990 from the Office of Special Education Programs.   In
response to an inquiry about schools providing assistive

129

technology, Judy Schrag responded that (a) assistive
technology "might qualify as special education, a related
service, or a supplementary aid or service" and (b) "the
determination of a child's need for such assistance must be
made on a case-by-case basis in connection with the
development of the child's IEP" (16 EHLR 1317).  This
directive is not law but indicates that if a child needs
assistive technology for a free appropriate education the
schools will have to provide the technology.

From the beginning John raised funds for devices for
Michael and did not include their use in the I.E.P. until
the device had been acquired. When asked if things had
changed since this letter from Judy Schrag, he replied that
he doesn't "know that it's going to help."  On the one hand,
the problem is money and often it's "the child's needs that
are turned off again."  On the other hand, I can't set up an
I.E.P. "for the state to say I'll provide something I don't
have.  So it's kind of a Catch-22."

## Administrative Support for Assistive Technology

John feels the building principal in the general
education facility is "very supportive as far as allowing me
to go out and search for independent or charitable sources
of funds." When asked what central administrative support he
got while helping Michael become a technology user, John

explains that response "was mixed."  At first Michael
attracted a lot of attention "which can help with funding."
The difficult side was that families "can look at technology
as being a panacea. . . so they're asking for  more and more
equipment from the school system without them having the
money."

> So the response from the administration was mixed.
> When they need to show off to folks what was going
> on, they were very delighted with what was going
> on with Michael. . . . on the other hand they
> didn't want it to get out of hand because it ends
> up costing them too much.

> Generally this initial response has not changed.  There
is "resistance to the funding needs of keeping up with
technology, but a positive response to the fact that Michael
is able to do what he can do."  John reflects the view
expressed by several service providers that this way of
funding is short sighted.  If we get "the funding in now, in
the long run we will save money on these kids because we're
going to make it more possible for them to be more
independent and be able to do more in their adult lives and
be more productive."

## How Technology Decisions Are Made

The initial decision to use technology with Michael occurred because of his need to write and to communicate. At the time that computer and augmentative communication technology were first becoming available in schools, Michael's speech was much less understandable than it is now. Decisions about what technology he would use and in what manner the technology would be used were strongly influenced by (a) the vision of his special education teacher, (b) various experts who were consulted, (c) Michael's physical growth and change, and (d) the nature of the educational environment in which he was learning.

### Central Person with Vision

In Michael's case most major technology decisions were made by John, his special education teacher. Once a device was acquired, the service providers might help with decisions on how to adapt the device or to enable Michael to gain better use of the device. According to one service provider, "John always knew so much more than I did and I always relied on him and his decisions."

As John explains it the way he made his decisions were basically by "T and E"--that is by "trial and error."

We've gotten sophisticated enough now and when I

say "we," I mean American Special Education, that

there is a certain amount of knowledge out there
that you can draw from.  There are even some data
base centers where if you can describe the
abilities of a handicapped person, they will
prescribe certain devices to try with them, or
whatever.  You have a certain knowledge of what's
available, but very often you are restricted by
what you've got to work with.  There is so much
out there now and nobody has everything.  You look
at what you've got, you try it, and if it doesn't
work, you try to make individual adaptations to it
and if that doesn't work you look for something
else or you call somebody and say look, I've got
this problem.

## Consultant Input

Consultant input from outside experts was crucial in
decisions on which device to obtain initially as well as in
later adaptations or upkeep once the device was obtained.
Speech-language pathologists at Kluge Children's
Rehabilitation Center and from Prentke Romich Company were
particularly important consultants whose input influenced
which devices were purchased.  In order to receive funding
from the Children's Miracle Network for the Touch Talker,
Michael has to demonstrate to the Speech Pathology

Department at Kluge that he has enough fine motor control to access the Unicorn Board "with better than 95% accuracy."

## Michael's Growth and Change

Michael's changing speech frequently influenced technology decisions. Initially the plan was that technology devices would be used for written and spoken expression. However, Michael's increasing ability to make sounds and to make himself understood meant that devices were used with decreasing frequency for augmentative communication. After he was 8 years old, no technology was needed for any assessment because either the teacher or the psychologist could understand his speech enough to know what answer he was giving.

Michael's changing fine motor skills similarly influenced technology decisions. Initially his poor hand control meant that he could not use a Touch Talker. Later he could access the Touch Talker but not fast enough to keep up with the rate of output necessary to participate in and do homework independently in his general education classes.

## Environment Influence

Decisions about which devices to use and how were influenced by the school Michael attended. In the special education facility Michael seldom used the Touch Talker

because it was much more difficult for him to reach the smaller holes on the smaller keyboard. Since he had regular access to a computer in his classroom, he used the larger Unicorn Board on the Apple IIe much more than he used the Touch Talker. Generally, in the self-contained class at the special education facility, availability of computers and portability of devices were not as much of an issue as they were in the general education facility.

Because the general education classrooms were not equipped with either computers or adaptive equipment, John decided to work harder on improving Michael's access to the smaller and more portable Touch Talker that could be mounted on his wheelchair. For these reasons he obtained funds for a Touch Talker printer that would attach to the back of Michael's wheelchair. He also worked closely with the OT as they attempted to further adapt this device for faster input.

Once Michael started using the Touch Talker in the general education classroom, further adaptations were needed because the regular education teacher said that the synthesized speech was disruptive. Turning the speech off was not the solution since Michael needed the speech feedback to be sure of what he was typing. Using headphones turned out not to be a solution because with these on Michael could not hear what the teacher said. According to

the paraprofessional, "We kind of fixed that problem though. We have an ear phone that we can put into [one] ear and he can hear what it's saying and no one else can." Because one ear is uncovered, he can also hear the teacher.

Eventually, the need to provide feedback faster than Michael physically could on the Touch Talker, led to the decision not to use the Touch Talker in the general education classroom and to let the paraprofessional do all writing and translating until John could figure out what to do next. Decisions about the next technology to use will be influenced by Michael's needs and fine motor abilities as well as by integration and funding issues.

*Some people wish that they lived in another time and place, but I have three special reasons for thanking God for living in the time of the computer and in the country of technology: my alternative and augmentative communication (AAC) device, my powered wheelchair, and my microcomputer. I jokingly say that when people see me, they see fifteen thousand dollars of equipment run by an eighty-nine cent body. This generation is the first in which an individual with severe speech and physical impairments has a chance to live an independent and a productive life.*

*Rick Creech, Reflections from a Unicorn*

# CHAPTER V

## GENERAL EDUCATION

> My convictions about the value of
> students with severe disabilities
> receiving instruction alongside their
> peers and attending their home school
> have been powerfully influenced by
> seeing the actual outcomes of these
> approaches.  "Seeing is believing"
> continues to be one of the most
> successful strategies for promoting
> changes....
>
> Marti Snell

This chapter contains descriptions of Michael's general

education school and the types of integration he experienced

there.  A detailed discussion of his first fully integrated

year explores his accomplishments and difficulties in fourth

grade.  The concluding discussion attempts to place Michael

in a larger social context.


## Types of Integration

The students in John's multihandicapped classroom at

Southwest are integrated in basically three ways: (a) part

time for social and limited skills participation, (b) part

time for social and academic participation, and (c) full

time for full social and academic participation.


### Part Time for Social and Limited Skills Participation

The first type of integration emphasizes social skills

learning and some academic skills learning but at a lower

adapted level--often because the student is not cognitively able to work at grade level, even with adaptations. While in the general education classroom, there may be expectations for the multihandicapped student to behave and act as peers do, but there is no academic requirement for the student to perform grade-level tasks in math, language, or other subjects.

During a social studies unit, for example, the multihandicapped student, might observe and participate in hands on projects about the culture of the Eskimos. He might use his Touch Talker to make a presentation about the Igloo he helped make, but he would not be expected to take the tests or to complete the written assignments on grade level. Students integrated in this way may have many contacts with their general education peers who escort them back and forth to their general or multihandicapped classroom throughout the day. John, however, is definitely the teacher in charge of these students. This was the type of integration Michael experienced in his first four months of general education before he was integrated into third grade language arts.

## Part Time for Social and Academic Participation

The second type of integration--part time for social and academic participation--is what Michael experienced from

January to the end of his third grade year. Basically he spent the morning in the multihandicapped class and the afternoon in third grade language arts. He was expected to participate socially and academically accomplish third grade language work. For Michael the academic expectations were for one subject, for a limited time, and with one-on-one paraprofessional support inside and outside the general classroom. Outside of the general classroom he had full access to technology as needed in his multihandicapped classroom. He received direct PT, OT, and speech services in the morning.

John considered the third grade teacher to be Michael's language teacher. Both she and John gave Michael grades. For math she provided copies of her homework assignments and math test sheets for John to use with Michael in the multihandicapped classroom.

His third grade general education teacher reports that Michael "got along well with his peers. They accepted him. But what I was most impressed with, they accepted him as another child, not as a handicapped child. At least, that's the way it seemed."

> Well during break is when you see more of the
> interaction. They would have him participate. We
> used to play a game called speed ball during break
> and even though it would be real hard for him to

play, they would play anyway with him and they
would throw the ball and help him to catch it and
that type of thing.  They really wanted to be his
friend.

Michael's third grade teacher remembers only one time
she had to remind Michael of the class rules.  It happened
when he was first integrated.  The paraprofessional who
usually assisted him was walking out of the class, and he
was being left for the first time.  "He just shouted out ,
'Where's Marsha?'  And I said, 'She left the room but from
now on please raise your hand if you want to say something.'
And he always did after that."

### Full Time for Full Social and Academic Participation

The type of integration Michael experienced during
fourth grade was full time for full social and academic
participation in all subjects.  Physical education was the
class he usually missed in order to receive speech.  Other
related services were provided on a consultative basis.  The
fourth grade teacher was responsible for all of Michael's
grades.

For his fourth grade teacher, who was in her second
year of teaching, Michael was the first physically
handicapped child she'd taught.  "I knew that he would have a
full time aide so I wasn't real nervous about what if

141

something were to happen to him physically."  It took about a month before "I was comfortable with [his speech]."

He's very patient with people . . . .  Sometimes he would say things and I would say okay, now say it one word at a time.  And if that didn't work, and I would repeat after him so he would nod so that I would know that I got it right.  And then sometimes he would say words that I had no idea and I would say okay, now spell it And then when he would start to spell, we could come up with it, either myself or another child .

When asked how he did academically, she responded, "Pretty well.  He made the A-B Honor Roll."

According to her, the accommodations made for Michael generally were not disruptive.  "As a matter of fact, it didn't even bother the other children or myself when Linda and Michael would talk real quietly to each other sometimes. Even during tests, when he would have to be answering [out loud]."

"Sometimes he did go outside with us for our classroom PE. . . . He especially enjoyed using his wheelchair out on the play ground to referee and play dodge ball."  The children accepted his calls as a referee.  "He used to position himself behind the kicker in kick ball and he would call the fouls or when people came in, he would call the

runs or things like that. He did, he enjoyed being out there."

One of the role shifts that some proponents of educational reform advocate is that the regular education teacher take responsibility for all special education students (Gartner & Lipsky, 1989; Stainback & Stainback, 1989). From her discussions of Michael, it is clear that his fourth grade teacher took responsibility for him and considered him to be her student--not John's, not the paraprofessional's. For example, when she noticed that he was having difficulty with comprehension, she talked to his speech-language pathologist and made suggestions for comprehension activities such as having him read a paragraph silently and report back what he'd read or answer content questions. Although a battery of special education speech-language tests had not revealed comprehension difficulties, the speech therapist agreed that he had this difficulty and worked with him on it during their weekly meetings.

### The First Fully Integrated Year

#### Summary of Assistance Michael Receives

In addition to the therapy from related service providers and on-going funding activities of his special education teacher, Michael receives the following assistance that facilitates his integration on a day to day basis. In

143

general this is assistance that his non-handicapped classmates do not require. In many instances this assistance is provided on a daily basis.

### Fourth Grade Teacher

His fourth grade teacher is generally responsible for Michael and if the paraprofessional is not present. She assists personally or requests others to assist Michael in the tasks listed below under "Special Education Paraprofessional." If this is not possible, she uses the intercom to request that John or another paraprofessional come to the class. In her daily planning, she plans as needed for ways Michael can participate (or be assisted) in hands-on activities as well as roles he can assume in group activities. She communicates regularly with the paraprofessional and supervises the way the paraprofessional assists him especially in testing situations. She mediates the types of assistance he receives from peers and sometimes has to explain that he needs less assistance or wants to attempt something by himself. She also communicates with his speech language-pathologist about special language instruction needs.

Other assistance that she may provide as needed are: turn off his powered wheelchair in an emergency, plan for how he is to be transported to special events, arrange for

144

how he will get assignments or notes from work missed when
he is with related service providers, communicate with John
when technology devices are disruptive or non-working,
arrange classroom space and game activities taking into
account the physical space that Michael and his chair
require, and interpret his speech for others when necessary.

## Special Education Paraprofessional

The paraprofessional is with Michael about two thirds
of his day. In the fourth grade class these are some of the
ways she assists him: writes on paper what Michael dictates,
accompanies him at the board and writes what he dictates
onto the board, when necessary interprets his speech for
others, and sets up book in holder and turns pages for him
to read. With technology she assists with computer and
various device usage. Generally she knows how to set things
up and get him started using the Unicorn Board and Touch
Talker.

At lunch she feeds him food that he cannot finger feed
himself. She or a peer places finger food and drinking cup
with straw where he can reach it. She often participates in
or helps teach various small groups that Michael is in.
Occasionally she provides hands-on fine motor assistance by
guiding Michael's hand to bat back ball to allow him to
participate in group games. When necessary she takes him to

145

the toilet by returning to the special education area since
she doesn't want to go in the general education boys
bathroom.

She pushes him to places when his motorized chair is
broken, assists when needed with control of the motorized
chair, watches as he climbs ramps in hall, moves furniture
and articles when necessary to make space for his chair, and
picks up what he drops or knocks over with the wheelchair.
At the beginning and end of the school day she puts on and
takes off his coat, hat, or sweater. At dismissal she
transfers him from the power chair to his manual chair,
straps him into the chair and pushes it onto the bus ramp
for departure. She accompanies him on all field trips and
lifts him into bus or car if there is no wheelchair ramp.
Recently she took him and his mother shopping for shoes that
a philanthropic group paid for.

## Peers

Michael's peers assist him when an adult requests it.
When they are nearby and see what he needs, they generally
assist without being requested. Things they do for him
include interpreting his speech for others, turning pages,
setting up his book in a holder, taking out the next books
or things he needs for the next subject, providing hands-on
fine motor assistance for him to bat a ball, and picking up

things he drops or knocks over with the motorized
wheelchair. When his motorized chair is broken, many
especially enjoy pushing him about in the non-motorized
chair. At lunch they may fill the cup on his chair with
drink and position the straw so he can reach it, move finger
food so he can reach it on his wheelchair tray, ask him what
else he wants and supply it.

## Special Education Teacher

The special education teacher regularly communicates
with the fourth grade teacher about how Michael is doing.
He plans his daily schedule so that the paraprofessional can
be in the fourth grade classroom as needed. He is on call
at anytime the fourth grade teacher needs him to come to the
room to assist with anything. Since the paraprofessional is
there regularly, he generally gets called when the power
chair is not functioning. When Michael is sick or needs
toilet assistance, the paraprofessional may request his
assistance with lifting. If the mother picks him up at
school, he folds the wheelchair and assists her with travel
storage of it in her car trunk. At all times, when he is in
the hall with Michael, he keeps a watchful eye on how the
power chair is moving and negotiating ramps.

John keeps Michael's chair and other assistive
technology devices in his multihandicapped classroom. He

charges the batteries of these devices and generally is responsible for their up-keep. He is also responsible for planning which devices will be used in which way. For a more indepth discussion of what John does see the earlier discussion of "Assistive Technology and Teacher's Roles."

## The School Environment

Michael's school is generally considered a good environment for special education students. The preschool handicapped class Michael attended was there. Many parents of special education students try to get their children into this school. As a result, there is a long waiting list for children who don't live in the area.

The principal is supportive and knowledgeable about special education students. He mentions that "we have more children in motorized wheelchairs at this school than all the schools combined in the county." Next year he says, "we'll have a child on oxygen for the first time. I've never known a child to go breathing oxygen carrying his own tank around." It's important, he says, "to be flexible" and to be "ready for the unexpected." He also speaks with pride of the various types of support he provides to teachers when he can.

In many ways this principal seems the embodiment of what proponents of the Regular Education Initiative (Will,

1986; Stainback, Stainback, & Forest, 1989) might prescribe. His philosophy is that his school is for everyone and that all adults should cooperate to better serve all students.

> When John's class was brought to this school, I
> told the faculty what to expect.  The lessons that
> we as adults learn from these children that have
> special needs as well as the regular children in
> this school, are probably just as important as
> anything they will learn in books at this school.
> . . .  I let them know that this is one school and
> whether a child is gifted with no physical
> handicaps or whether they need remediation and
> they have multiple handicaps, it doesn't matter,
> we are going to put together a team approach

The principal views Michael as "clearing a path for more students like himself."  "We're learning a lot by [his] being here about the needs of special education."

> But putting together a program for Michael
> wasn't that difficult.  Organizing the program is
> probably the hardest thing because of all the
> services he receives.  To coordinate all the
> therapies, the speech and the physical therapy and
> the adaptive PE, along with making arrangements
> for him to get to the gymnasium and participate in
> other things, is the biggest problem we have.

149

He speaks of the value of motorized wheelchairs that allow students like Michael to move around independently. He has also learned to be wary of the chairs.

> With those motorized chairs, you have to be
> careful. They'll knock you over and run you over.
> They are real powerful. You can't physically stop
> one. You have to reach for the button and turn
> them off. It's almost like stopping a moving car.
> . . . It's just like a new student driver, you
> know, putting a few dents in the car. . . . My
> custodian follows the children around at the end
> of the day with a paint brush because of all the
> wood that they are knocking off the doors going in
> and out, but that's okay. See he's part of the
> team too.

Because of the technology, teachers like John require extra support, especially when the technology breaks down or the service people arrive. "It's just unfortunate in the technology area, when something breaks, whether it's the wheelchair or the computer, that he has to pretty much stop and get that under control before any more learning can take place." The "biggest challenge" for him personally, the principal says is "making sure [John] has paraprofessionals in there when . . . things happen."

Meeting the needs of parents of students with severe disabilities also keeps him "busy because the parents are super sensitive to anything that happens because of the hard times they've had bringing this child up."

> It's not like where you've sent your child off and
> they have gone outside to play. And you know, you
> have more space and free time away from them. You
> know, these parents have spent twenty-four hours a
> day with these children for the majority of their
> life and now we're trying to tell them to let [the
> children] reach out more and more on their own.
> That's a sensitive subject, it really is. They
> want to do it, but yet they don't. They want you
> to try it, but don't let my child get hurt. I
> understand that. If I had a child like that, I'm
> sure I'd probably be just as concerned.

## Social Relationships

According to his teachers and service providers, one of the biggest successes of Michael's integration into general education has been his social relationships with peers. According to John, Michael's closest relationships in the special education facility were with teachers "who were more his cognitive equal." "Flirtatious behavior" with student teachers was not discouraged. "At one point if a pretty

151

young student teacher or teacher would walk along, Michael would almost jump out of his chair to get her attention and try to interact with her." This response to teachers has disappeared at Southwest since his social life his been directed "toward non-handicapped peers in his classroom. It's much more appropriate, we're getting around to the kind of adaptive behavior that is appropriate and it's wonderful. It's wonderful to watch."

For the first time Michael relates regularly to peers who are not handicapped. For the first time ever he has had school friends visit him after school. He also talks occasionally on the phone to classmates. His mother "holds the phone for him and he talks over the phone and if they cannot understand, then he'll look at his mother and she will translate for him."

His fourth grade teacher's remarks also reflect my observations of Michael's social relations with his classmates.

You know, sometimes fourth graders have these little cliques, this one, this one, and this one is out, but Michael was always basically in with someone. There was always someone that was his friend and then there was the group of kids that never did that. They were always just friends. But he was really just a typical fourth grader.

Like I said, after awhile, we all knew he was
handicapped, knew he couldn't write, knew he was
in a wheelchair but it didn't matter.  He was just
Michael and they just basically really treated him
the same.

## Difficulties in Fourth Grade

Even though he enjoyed good social relationships, he
also encountered for the first time the give and take of
more equal relationships.  At one point he told his mother
that a classmate called him names.  His mother is still
upset over this incident and thinks Michael should be
protected from such remarks.

### Avoiding Work

Towards the end of fourth grade, his teacher speaks of
Michael's growing efforts to avoid work and "take the easy
way out. . . .  But that's sort of a typical fourth grade
thing sometimes.  They don't want to do the work."

I don't think it was any more hard for him
than it was for any other fourth graders.
Although it may have been at first because he
wasn't used to it.  Other children in the regular
classroom have gone [through] first, second, third
[grade], you know, all the way up that way.

153

He adjusted really quickly.  And actually was
really excited at first to be in fourth grade, but
then, like I said, towards the end of the year, he
just didn't want to do the work on his own.  So
then he would sometimes say I'd rather go back to
third grade and things like that.  Well it's
easier in third grade, we would say to him, but
it's not necessarily better.


## Upset Over Grades and Tests

"Sensitive" and "perfectionist" are words adults use to
describe Michael.  According to his teacher he was
especially sensitive about the grades he got--despite making
the A-B honor role.   According to the paraprofessional, the
reason this year is harder and he is so unhappy is he's not
used to  tests, "pop quizzes or whatever, and he's just not
used to that type of having to study.  Last year, to my
knowledge he probably did not have homework . . .  over ten
times maybe."

According to his fourth grade teacher, after one bad
grade the next test "took him forever and he was real
worried about it."  Tests sometimes upset him so that he
forgot what he knew.

I knew that he knew it because he had just rattled
it off earlier in that day, but when it came down

to putting it down on paper on that test, he
couldn't do it.  So we put it away and I asked him
later that day and he said it again so I wrote it
on the test.

## "Lacks Confidence"

Two service providers tell of explaining to him that a
certain event wasn't as bad or negative as he seemed to
think it was.  His fourth grade teacher refers several times
to his "lack of confidence."

So he really lacks a little bit of confidence in
himself.  I think that's why he would say, I want
to go back to third grade.  He didn't want to go
up to fifth grade because he knew fifth grade was
going to be even harder.  He knew that he could do
the third grade work and feel really successful at
that and here in fourth grade it was a little
tougher and he didn't always get A's and he didn't
have a lot of confidence about that.  But I feel
that he has the ability if he wants to do it.

## Sensitivity to Criticism and Needing Peer's Assistance

The paraprofessional tells of how sensitive he was to
being reprimanded in music class.

He was told to be quiet and that was probably the
first time ever in his life that he was told that
he couldn't do something. . . . Now that is not
behavior that is any different from any other
fourth grader. Occasionally you get called down,
but to him that was the worst thing in the world
that could possibly happen to him.

Both Michael and the paraprofessional agree that he
much prefers her assistance to receiving assistance from
peers during instruction time. According to her, the
classmates look for chances to assist him and gladly take
over when she is not in the classroom. According to him,
they do it "because they have to." Any time he hears
someone mention the possibility of decreased assistance from
the paraprofessional in the future, Michael responds, "I
want to quit school."

## Feeling "Rushed"

When I spoke to Michael about these issues I got the
sense of a child who felt overwhelmed. He frequently used
the words "rushed" and "too much." He wants to do "less
work". He feels "rushed," when he has to read "a whole
chapter in one night." Later when I asked him if there was
anything else he wanted to tell me or teachers working with

student's like him, he responded "you could have asked if they would "r" "u" "s" "h" through a book."

At home his mother's remarks extend the theme of feeling rushed. According to her, Michael get's especially upset about timed tests. "He is just so tense and he gets so upset because he's being timed and he can't get the answer out quick enough like he wants to." This timed test situation in one way parallels his decreasing use of technology; "I'm not fast enough."

John explains, there is also "no time now" for Michael to write a song as he did in third grade. But this is also true of his peers without disabilities.

> Well none of the fourth graders could do that
> unless they do it on their own time. There is no
> individual time for them to write music. This is
> something that, unfortunately, will have to be
> done outside the school. Because Michael is such
> a serious student and so involved with his grade
> of school work, his time at home is limited also.

## Michael's View

When I was around Michael informally in third grade, he seemed pleased with his time spent in general education. He talked about "my friends"--one girl in particular who sat near him in language arts. He made it clear that the video

157

shots he was most interested in taking were of his third grade peers.  By the time I interviewed him the last month of fourth grade, however, he made it clear he was unhappy with school.  "Last year was fun.  But this year was not fit for a dog."  He called his teacher "that mean woman."  His favorite subject, however, was "lunch" because "you get to talk with your friends."  At another time when I asked him to tell me about his friends, he spelled, "They S...T...I...N...K!," but had no further details to add.

Being in general education was Michael's first experience of being graded.   When I asked him what sorts of grades he got, he answered, "All of them.  A, B, C, D, and F."   When I tried to get more information on his view of grades, he ended the conversation with, "Grades don't matter."  What does matter is "Going to heaven."

At one point in the discussion of grades and tests Michael asked, "What good is a piece of paper?"  From context I had no clue whether this was because he couldn't hold a pencil, because he wanted a portable computer, because he questioned learning in general or the value of paper products in particular, or what.  Through a process of 20 questions we got down to discovering that he didn't understand the value of classes in science, social studies, music, art, and health.  Translator remarks are in round parentheses:

BN:  What happens when she asks a question and you don't know the answer?

MI:  I don't raise my hand.

BN:  What if it is a test and you don't know the answer and you have to put something down?  Tell me about that.

MI:  I guess at it.

BN:  Are you afraid of getting the wrong answer?

MI:  No.

(You do what?  What about the piece of paper?  Can you spell it?)

MI:  W  h  a  t, what good is a piece of paper?

BN:  Is it not so good because you can't write on it with a pencil?

MI:  No.

(The importance of the paper?)

MI:  (Nods)

BN:  Michael, it sounds to me like you're not understanding why [you should] bother to learn, is that right?

MI:  I understand about Math and Reading but not the others.

BN:  Oh, okay.  So Math and Reading you understand about learning, but Science, the Social Studies,

the Music, the Art and the Health are the ones you
don't, like right?

MI:   And English.

BN:   So tell me why you don't like them.

This time he answers that he doesn't like these classes
because, "They're dumb." Another time he says that "third
grade was okay because it wasn't so much junk." When
pressed about what "junk" was, he responded, "Last year, I
didn't have music and art." The problem with all classes
except math and reading, he says, is  you feel like you have
"to do it or you die." In other words, you don't have any
choice but to do it.

While his overt classroom behavior and relations to
peers seem positive, his expressed views of his situation in
fourth grade were often negative ones. Twice when I tried
to get more details on what was wrong with music class or
why something was "junk," he responded that every one sided
with the teachers and no one believed his version of
anything. From others I learned that he was not just
recently "down on" school or "bending my ear" as a seemingly
sympathetic interviewer. These were views he had been
expressing to anyone who would listen since at least
February of the fourth grade year.

## Tense Home/School Relationship

Without being asked their view of his mother, all but
one adult interviewed had negative things to say about
Michael's mother.  The one adult who was not critical
explained that she felt the mother was doing the best she
could and that it was bad luck for Michael that his mother
didn't have more resources.  "If he has some support, the
sky would be the limit.

When specifically asked if she thinks Michael has
benefitted from being in general education, his mother says
that "he enjoys being with his class instead of" in special
education. She thinks he has learned more "being around
children who [are] of his intelligence."  However, when
asked to describe how things have gone since he left the
special education facility, she has nothing good to say.
She spoke at length of her anger at not being allowed on the
field trip and made it very clear that if she didn't go, he
didn't go.

She has many questions and complaints about what she
sees happening at school--not the least of which is that the
school doesn't listen to her or believe what she and Michael
say happened.

I was trying to tell [his teacher] about some

things the kids had said to him.  She didn't

believe me.  She just made the remark like, "Well

161

even if the children were saying anything", like

you know, I'm a little liar..."even if."

Many of her dissatisfactions can be traced to her view

that his physical needs are even more important than his

academic needs.  Like many parents of children with severe

disabilities, she thinks his physical needs are more

important this his academic needs (Coleman, Koppenhaver, &

Yoder, in press; Koppenhaver, Coleman, Kalman & Yoder,

1991). "All I hear anymore is academic, academic, academic

and to me, Michael's physical needs are even more important

than his academic needs."

She also makes it clear that she tries to support his

study needs at home, but is feeling overwhelmed.  According

to her, Michael has too much to read and too many tests, and

it's more than he or she can handle.  As it is, they do

nothing but eat, finish homework, and go to bed and that

still is not enough to get it all done.  On top of this the

teachers and service providers are continually asking that

she let him do independent reading and she wants to know how

he can manage this considering that he can't turn his pages.

Though not as frequently as Michael, she uses the word

"rush" to describe their time at home.  She also blames his

comprehension difficulties on his "being rushed through

stories."

At one point I asked her if she thought Michael would be better off in John's class again. She replied, "No, he don't want to go back there." When I pressed her on this, trying to determine if she still preferred that he be in the special education center, her response indicated that she didn't have a particular placement or degree of integration in mind. She simply wanted more paraprofessional support for him at school and less homework demands on him and her. But she also admitted that he would be aware of what his peers were required to do and would feel bad if he couldn't keep up.

She is very concerned that his physical and occupational therapy are no longer provided each week. She is also concerned that his paraprofessional support will be cut back. "I think an aide should be with Michael all the time except when he says he don't need an aide."

> It seems like to me since Michael was mainstreamed
> and went to a regular classroom, that everybody
> just thinks, poof, he turned normal. Like now, he
> don't need special help any more. The physical
> therapist and occupational therapist are not going
> to see him anymore except every three months [on a
> consultative basis].

She is proud of his use of technology and wishes he had a computer at home. She views technology as something he

enjoys rather than a way for him to become more independent
or potentially employable. She worries that in the general
education environment people may think that a computer can
replace or be a reason for decreasing his paraprofessional
support.

> [They] just want to get him a computer and let
> that be that. Even if he did have the computer in
> his room and like the teacher is lecturing or
> something and you're supposed to write notes, how
> in the world would Michael be able to do that fast
> enough to get the notes or fast enough to get if
> off the board or stuff like that.

She feels that Michael has no one to depend on but her
for the rest of his life. When I asked her if she had
thought about what she was going to do when he got too heavy
to lift. She answered, "No. All I can do is take it one
day at a time right now." She also mentioned that she hopes
he can just make it until he is old enough to "drop out of
school."

### What's Going On: A Point of View Issues
#### Two Views of Disability

I had not expected to feel as sympathetic to the
mother's point of view as I did. Earlier when I had heard
John and the fourth grade teacher explain that since no

other parents were going on the field trip, and Michael "should be treated like everybody else," I had felt badly that Michael had missed the trip, but I was sort of chalking it up as a new learning experience he had to have on his road to being integrated in general education and learning how to live in a wider world. Some families hold a "crippled" view (Phillips, 1992) of disability. This view contrasts with John's view that emphasizes Michael's potential. People holding this more paternalistic or welfare view emphasize that the person with a disability needs to be protected from any criticism--even the age-appropriate name calling and verbal play between peers. In general the welfare view emphasizes what a person cannot do, whereas the work view emphasizes a person's abilities and need to work and be connected rather than protected.

As I perused and thought more about my data, I began to feel that the view of Michael's family might always be at odds with John's and the school's more "work-oriented" view (Hahn, 1983; Ferguson, Ferguson, & Taylor, 1992). Continually, the mother emphasizes that Michael's physical needs are paramount and John emphasizes Michael's abilities (thus cognitive/social development is paramount). Increasingly Michael's statements about his life, interests, and goals reflect the influence of his mother.

## Technology Issues

One of the important questions about technology use in an integrated environment that Michael's circumstance dramatizes is what to do when the student can't physically keep up with the written output required of the regular education students. When fully integrated for the first time into general education, Michael rather quickly decided that he preferred paraprofessional assistance to using technology. In the case of page turning there was no technology available to accomplish the task. But in the matter of written output should Michael even have the choice of paraprofessional assistance instead of technology use if this means he's jeopardizing past skills acquired and future skills for more independent functioning? Is his current situation, to use John's words, just a hiatus where he is "fighting hard to learn to do all the things the other students do without [technology]" or is it the result of other factors? Will John be able "to get . . . Michael mature enough to realize that he is going to have to work harder utilizing technology to be independent?"

No one doubts Michael's cognitive ability to do grade level work or his ability to use technology for writing and to gain skills that could make him more independent and potentially employable. What people express doubts about is whether he has the support at home, whether he will choose

to use technology for purposes that lead to independence. Given his home situation and his mother's view of his future, how much future independence is possible for him? At home?  At school?  At work?

What is the effect of his not having a computer to use at home?  If the school does not have to supply technology for use at home and he does not obtain a computer for home use, can he ever gain the skills needed to become more independent by learning to use the technology faster and with the increasing expertise needed to complete middle and high school level work?  What effect would reducing the written output requirements have on his self image and relations with his class mates?  Would an ecological assessment including his mother and all people who work with him help with long range planning and ultimately make a difference?  One question future planners might consider is can he do with less paraprofessional assistance if he doesn't have access to technology.  Will his current way of getting homework completed be possible in upper grades?

Is there any route out of or around the current impasse between the family's and the school's view of Michael and his future possibilities?  Is the mother's  view exacerbated by assistance she has to provide for Michael to do homework?

At this point I realize the data do more to dramatize the questions than the answers.  I am surprised to discover

that my study of technology use should have also included the question, "Why did technology use cease?" It does not surprise me, however, to discover that technology use may be powerfully related to affective issues such as how one feels about being handicapped, how one feels about being graded for the first time, how one feels about asking peers for assistance, or how a mother feels about homework.

What the relation is between his current lack of technology use and his current view of himself I can't be sure. Scherer and Mckee (1991) studied personality traits and perceptions of the disability experience in adult users and non-users of technology. Some of their distinctions between users and non-users of technology reflect the same welfare-work distinctions made above.

> Users and non-users reported differences in their
> motivation for increased independent functioning,
> their focus on opportunity vs. limitation, their
> view of the attainability and desirability of
> societal integration . . . . ATDs [assistive
> technology devices] were seen by users as valuable
> enablers for their activities and independence
> whereas non-users tended to perceive ATDs as
> unnecessary, unhelpful, and as inferior
> replacements for their own premorbid functioning.
> (p. 10)

## Affective Issues

Although this study considers affective issues peripherally, it may be instructive to look briefly at some of these issues as they came up for Michael.

Fourth grade is often considered a difficult year for elementary school students. In this school, for example, it's the first time that students encounter a lot of homework. Michael, no doubt, was not the only student to feel rushed and worried about how he could keep up. And, as his teacher pointed out, he was not the only one "trying to get out of doing the work" or looking "for the easy way out."

In comparison to his peers what was different about Michael's circumstances, in addition to his disability, was that this was the first time he was encountering grading and homework at all. Most students who have been in general education from kindergarten have four years to get used to handing in assignments as requested, getting back papers with grades, happy face stickers, or other responses, and gradually learning what it means to be evaluated. They also have ample opportunities to learn that a teacher may speak sharply to them in front of the entire group if they are being disruptive.

At the same time that Michael was learning how to be in this different and more demanding environment, he lost the

personal contact he'd developed with John as well as with two service providers who had earlier often functioned as "sympathetic ears," who consoled and counseled him as friends.  These were the people who more easily than most could understand his speech, for whom he didn't have to reduce all communication to a short phrase or two.  Losing these relationships may be no different from the friends and support that any child loses when they move or change schools.  In Michael's case, because of his communication difficulties, the situation has other dimensions.

Other peers can console, chat and verbally relate quickly and in ways that Michael could not.  Perhaps his slow speech also slowed down the time it took to make connections.  Christy Brown (1954), with a disability that affected his speech so that--like Michael--only certain people could understand him, tells us that "speech has always been one of the biggest obstacles in my endeavour to make ordinary contact with people."

It has been the one aspect of my handicap that has caused me the bitterest pain, for without speech one is practically lost, curtained off from other people, left wishing to say a million things and not able to say one. (p. 161)

For the first time Michael was also in a circumstance that his mother saw as a growing problem.  She regularly

170

expressed her dismay and anger to him and school personnel.
Some of the personnel who were working hard for Michael,
often beyond their job requirements, felt strongly the
criticism and lack of appreciation in many of the mother's
responses.  Despite these difficulties, Michael, however,
makes it clear that he prefers being with his regular
education peers and would not chose to return full time to
John's class.

## Larger Perspectives: In Conclusion

Maybe there is no way to integrate a person in fourth
grade who has missed out on growing up in this environment
without there being misunderstanding, anger, and various
difficulties.  Possibly the pain or anger would be there in
some form as a person with a severe disability learns more
about life and how they are perceived by others (Hahn,
1983).  Christy Brown, with disabilities similar to
Michael's, describes at length in My Left Foot (1954) the
effect on him, when at age 10 (Michael's age when this study
started), he fully realized how others perceived him.  His
brothers who were used to romping outside daily with him
"didn't understand what made me such a stay-at-home."

They went right through me, those looks from
people in the streets.  My brothers didn't think I
took any notice, but I did.  Even in the space of

171

a few weeks, . . . I had become as different in mind as I now knew I was in body. I had become more sensitive, more apprehensive to those I met outside my home. I looked on dumbly at my brothers and pals as they played around me, not even using my grunt now. I found no pleasure in their games. I had become a spectator now instead of one of the participants. (p. 52)

Looking back on the clinics and the people who had helped him and people like him, Christy Brown said the most important things they provided were "an understanding that goes deeper than just mere kind words, and a sympathy that is without pity" (p. 164-165).

We need confidence and friendliness as well as, if not more than medical treatment. It is not only our muscles and limbs which bother us--sometimes it is our minds as well, our inner selves that require more attention than our twisted arms and legs. (p. 156).

In addition to "sympathy without pity," it's possible that access to technology is an equally important way to provide for future needs of "the inner self" by making the person more employable and less isolated. Another lens for viewing Michael is to consider what life is often like for people with severe physical disabilities once they leave

school. Isolation from each other and from the rest of society has been the lot of most people in our culture with severe disabilities (Hahn, 1983). "Millions of disabled persons are condemned to lead lonely and monotonous lives in sheltered workshops, institutions, or isolated residences" (p. 40).

Given our society and current disability policies, it's clear that even with great facility in using assistive technology, Michael would have a difficult time getting a job and living a life of choices and connections. There is chronic unemployment among workers with disabilities less severe than Michael's. Thus, Michael's chances at any future employability are less than nil if he does not tackle the task of becoming a user of assistive technology (Wehman, Wood, Everson, Goodwyn, Conley, 1988).

What I see, when I look at Michael, is a fourth grader ceasing to use technology because of his attitude and circumstances at school in fourth grade and at home where his mother can still lift him. I have no sense that Michael or many of the adults in his life except John have a sense of what this decision could mean about the rest of his life.

*We have the technology to improve the quality of life for people with physical impairments. Having this technology, we are accountable for its use. Who would forgive this generation if we use this technology destructively and selfishly? A hammer can be used to build or to tear down or, even, to kill. The choice is in the hand that holds the hammer. We hold technology. What will we choose to do with it?*

*Rick Creech, <u>Reflections from a Unicorn</u>*

# CHAPTER VI

## DISCUSSION, CONCLUSIONS, IMPLICATIONS

> It does not seem particularly
> revolutionary to say that it is
> important to try to understand how
> teachers and classrooms function before
> handing out recommendations for change.
> Yet so much of what is suggested to
> teachers and school administrators is
> said independent of context and often by
> those ignorant of the practices they
> wish to improve.
>
> Elliot Eisner

How does one write up conclusions in interpretivist research? Or is the term "conclusions" inappropriate because either they should have been woven more seamlessly into the report or else they connote that now one point of view is to come to the fore and become the "single correct" view. Though he is not discussing conclusions or findings, Eisner (1991) reminds us that "taking various perspectives is a way of examining situations from different angles:"

> It is not so much a matter of ultimately achieving
>
> a coherent integration among the many perspectives
>
> as one of being intellectually versatile . . . It
>
> is a matter of being able to handle several ways
>
> of seeing as a series of differing views rather
>
> than reducing all views to a single correct one.
>
> (p. 49)

Even though I tried to present others' perspectives as accurately as possible, the perspectives presented in this

report are of necessity filtered both through my points of view and my abilities as a writer. Remembering this, I would like now to speak more about what I understood as I gathered the data, wrote the report, and read research by others. I would not like to take the stance of reducing the many perspectives presented in this study to "a single correct one." My goal in this chapter is to share more of what I have learned from this and others' research on the use of assistive technology in the schools. Topics discussed in this section are (a) use and non-use of assistive technology in an integrated classroom, (c) teacher's roles and larger support issues, and (d) research barriers and possibilities.

## Assistive Technology: Use and Non-Use

A recent study, "Barriers to the Use of Assistive Technology with Children: A Survey" (Parker et al., 1990), reported on the responses of 120 teachers and others working with special education students in Massachusetts. Interestingly (but not surprisingly) the top four areas in which respondents considered their knowledge "poor or nonexistent" includes all the technology Michael has used: "electronic mobility aids," "electronic communication devices," "educational computers," and "switch-activated devices for education or recreation" (p. 532). Like

Michael's teachers and service providers, those who did use
assistive technology reported major difficulties with
maintenance, funding, and the availability of devices in
their community. This report concludes with the exhortation
that "as this exciting area" of assistive technology
progresses, "it will be imperative to address these
difficulties so the promise of technology for children with
disabilities can be realized" (p. 533).

I have often made statements like this. I still make
statements like this, but now I better understand how
complex the situation is considering the nature of the
technology, the environment of schools, and the
circumstances of people with disabilities. As the study
progressed, however, I had a hard time not becoming
discouraged as I watched Michael become a non-user of all
his electronic technology except for his wheelchair. I had
not foreseen that my findings would be part of a new trend
in assistive technology, what some call "the abandonment" of
assistive technology (Barnicle, 1991; Blackstone, 1992a;
DeRuyter, 1992; Phillips, 1991; Scherer 1991a). According
to these people, there are "widespread anecdotal reports of
consumer dissatisfaction and the frequent abandonment of
prescribed technological solutions" (DeRuyter, 1992, p. 86).

According to Sara Blackstone (1992a), who is well known
for speaking and writing about assistive technology and

augmentative communication, abandonment of assistive technology is a trend that indicates professionals need to be more aware of the needs and preferences of users of technology. In an article, the "Abandonment of Assistive Technology: What Consumers Know and Professionals Need to Find Out," she insists that the term to use is "consumer" not "client" or "patient" which suggests "a passive role with professionals making most of the decisions."

The term "consumer" acknowledges upfront that the personal needs, preferences, idiosyncrasies, style and resources of people who benefit from assistive technology (i.e., individuals with problems and their families) have a direct and unequivocal impact on whether and how devices are used. To successfully transfer technology into use, it is necessary to recognize and build on the expertise of the consumer as his/her own long-term "technologist."

Blackstone (1992a, 1992b) makes it clear that she considers the major issue not one of the value of assistive technology but rather of the lack of valuing the point of view of the user ("primary consumer") of the technology. Many schools, she says, make this mistake because as "payers" they erroneously "perceive themselves as the primary consumers" (Blackstone, 1992a, p. 2). According to

178

her, users and families need "to educate themselves about devices and services and develop coping strategies to achieve the most benefit from assistive technology and the service delivery system" (p. 3).

From another perspective, Scherer (1988, 1991a, 1991b) and Scherer and McKee (1991) use qualitative methodology to study "abandonment" as well as the general qualities of users and non- users of assistive technology.  Their research tackled questions like "to what factors do users and non-users attribute their utilization or non-utilization of a technology?"  Another question asked was, "Do technology users differ from non-users in their perception of the disabled experience, their present and hoped for quality of life?"  The people interviewed were adults in rehabilitation settings.

One of their major findings was that "users attributed their successful use of devices to inner motivation, desire (to talk for example), and an unwillingness to be held back from self-expression or independence" (Scherer & McKee, 1991, p. 9).

> Non-users, on the other hand, often cited
> characteristics of the devices as the reason for
> non-use (for example, they're too expensive,
> inconvenient for listeners, will cause pressure
> sores.  Additionally, they expressed a distaste

for a mechanical replacement for their functioning, admitted lack of motivation in some cases and indicated family disincentives to aid use. (p. 9)

If Michael could be compared to these adults, the most that could be said is that he shares characteristics of users and non-users as described by Scherer and McKee. One of the instances where he seems to be the opposite of their findings concerns the "desirability of societal integration." According to Scherer and McKee (1991), "while technology users seemed to be striving toward societal integration, non-users presented themselves as withdrawn" (11).

On the other hand, when Scherer and McKee characterize non-users as "more socially isolated" (p. 13), their findings seem to characterize Michael's mother if not Michael himself. Scherer and McKee (1991) say users see the disabled experience as an obstacle to be surmounted in contrast to non-users who "focus on their disability" and withdraw, "attribut[ing] their withdrawal to a non-accepting society" (p. 11). It is probably not wise to compare Michael to adults in a clinical setting (some of whom were only recently disabled). However, studies like these, using qualitative methods, need to be done on students like Michael in school and family settings.

Before I caught up with the recent research on
"abandonment" of assistive technology, I was willing to
attribute Michael's decreasing technology use to the way his
integration at school was done in fourth grade in contrast
to third grade.  But then, as I saw the complexities of his
situation and understood better John's efforts and point of
view, I began to think that John was right.  The key was to
convince Michael that he needed the technology for future
functioning and independence.  As John saw it, Michael was
"fighting hard to learn to do all the things the other
students do without [technology]. . . .  I don't think he's
quite mature enough to understand what it's going to take
for him to be as independent as possible."  In this
situation John saw that his next task as a teacher was to
help Michael understand that his future needs would be
better served using technology.

At some point in the sifting of data and shifting about
among various perspectives, I started looking more closely
at what Michael and his mother were saying.  This was when I
started realizing I had not considered enough the impact on
Michael of his larger family and social context.  As soon as
I widened my view, the truth of Scherer's and McKee's (1991)
insistence on the importance of other  "interactive" and
"dynamic" relationships became clearer.  "There is a dynamic
interactive relationship among technology use, temperament,

personal capacities and quality of life and this relationship can change over time" (pp. 14-15). Once I looked more closely at "quality of life" and read and thought more about what it means to be disabled (Bogdan & Taylor, 1992; Brown, 1954; Creech, 1992; Ferguson, Ferguson, & Taylor, 1992; Hahn, 1983; Kearly, 1988; Phillips, 1992), my context for Michael's situation enlarged so quickly that I started viewing his assistive technology use as a very small part of his circumstances.

Swinging back and forth between the larger perspective of being disabled in our culture and up-close views of how Michael used or ceased using a particular device was disconcerting. The enlarged "wide-angle" view sometimes makes writing about the up-close "zoom lens" topics more difficult. The "inescapable contextuality of our knowledge" (Ferguson, Ferguson, & Taylor, 1992, p. 295) is one thing. Writing about something in a way that reflects this "inescapable contextuality" is something else (and no doubt explains the power of poetry and great literature). Perhaps the novelist Henry James (1948) is right that "The whole of anything cannot be told; we can take only what groups together."

The "dynamic interactive relationship" (Scherer, 1991b; Scherer & McKee, 1991) of assistive technology with much else in a user's life also includes an element of how others

view a person who uses electronic assistive technology. In other words, people's response to a person with disability may be different than their response to a person with a disability who also uses electronic assistive technology (Creech, 1992, Gorenflo, 1989; Gorenflo & Gorenflo, 1991). In a study, "The Effects of Information and Augmentative Communication Technique on Attitudes Toward Nonspeaking Individuals," Gorenflo and Gorenflo (1991) found that "attitudes are significantly more favorable toward an individual using a technological augmentative communication" device (p. 23).

In a similar vein Rick Creech tells a story resembling John's and Michael's about first use of an electronic communication device. Creech wrote <u>Reflections from a Unicorn</u> (1992) by pressing a mouth stick onto computer keys. In these reflections about his life and use of assistive technology because of severe cerebral palsy, Creech tells about the effect of getting a speech output communication (SOC) system. "Getting a SOC system" was, he says, "a catalyst" for a lot that followed.

> Attending college became viable as the result of
> having a SOC system. I discovered that a SOC
> system is not necessary in attending college;
> however, the regard for speech output is such that
> before I had one, no one in authority, including

myself, considered my attending college as an option. (p. 62)

John's recounting of Michael's first attempts to use a "SOC system" reflects Creech's view of "the regard for speech output." Michael was inept in using his Touch Talker and was unable to input fast enough to keep up with the pace of a spoken (by voice) conversation. However, the Touch Talker, augmented with Michael's attempts to vocalize, became a stepping stone to communication that Michael had never experienced before. As John describes it, "people acquired a little different viewpoint of Michael, a little more positive viewpoint." They viewed him as "intelligent" and were "more apt to try to engage him in conversation."

## Assistive Technology and Integration

Lou Brown, a long-time proponent of integration for students with severe disabilities, raises the question which is the title of an article "How Much Time Should Students with Severe Intellectual Disabilities Spend in Regular Education Classrooms and Elsewhere?" (Brown, et al., 1991). They basically reject self-contained special education classes as well as self-contained general education classes "because each extreme disallows important experiences and opportunities." In the following statement Brown paraphrases federal statutory language.

The preference is that students with severe
disabilities be based in the regular education
classroom in which they would be based if they
were not disabled, and that individually
meaningful amounts of time to be spent elsewhere
should be arranged as needed. (p. 40)

Using Brown et al's reasoning, someone like Michael
might be removed from the general education class for
initial training on how to operate a new wheelchair or other
assistive technology device. At an older age, if he were
going to develop vocational or independent living skills, he
might leave school for work and social experience in
community environments. Brown further states:

How much time should be spent in regular classes?
Enough to ensure that the student is a member, not
a visitor. A lot, if the student is engaged in
meaningful activities. Quite a bit, if she is
young, but less as she approaches 21. There is
still a lot we do not know. (p. 46)

On the one hand, Michael, because of his cognitive
abilities, does not always fit integration models that have
evolved for students with severe intellectual disabilities.
Brown et al.'s emphasis on removing a student from the
general education classroom in order to work on functional
skills (e.g., learning to independently use the bathroom or

make lunch, for example) does not currently apply to Michael because of his motor deficits. Without use of assistive technology, there are few functional skills left for Michael to work on.

On the other hand, because of his severe physical disabilities, more and more integration with less related services and access to assistive technology might not be the optimum way to meet his needs either. Some overarching questions are: What are his long range needs, ...in which environments? What is the role of technology in meeting long-range goals? Should the current emphasis on academic curriculum also include a community and family-referenced curriculum content which the best practices suggest for students with severe disabilities (Orelov & Sobsey, 1991)? Ecological assessment and planning would require all who work with Michael to take a longer range view of his functioning and needs in all environments he inhabits (Orelov & Sobsey 1991). Planning such as that required for the Individualized Family Service Plan (IFSP) for infants and toddlers (Part H, IDEA) more closely approximates this proposal than does the IEP process (Part B, IDEA).

Answers to questions posed above are not simple. The more ecological approach to planning for students with severe disabilities does not necessarily insure that students will gain the literacy and academic skills needed

to communicate and operate needed assistive technology devices.  On the other hand, a more academic emphasis on full integration (Simpson & Myles, 1990), often used for students with mild disabilities, could be appropriate or not depending on the flexibility of the integration model and the skills of the educators involved.

Interpretivist research has less to do with causal links and more to do with webs, guides, and a more holistic understanding. Having located Michael in a web of forces affecting his use and non-use of assistive technology--including those "dynamic interactive" factors outlined by Scherer and McKee (1991)--it's not possible to say that full integration is the cause of his ceasing to use educational assistive technology.  Given his mother's views, situation, and relationship with Michael and the school, it seems likely to me now that in the long run Michael might have ceased to value the functions of technology, especially those that might make him potentially employable.  However, I do think that if Michael had remained in the partial integration circumstances he had in third grade, he would have used assistive technology (especially word processing) for a longer period of time.

So what can be learned from Michael's situation that could be of value to others interested in integrating students with severe disabilities who use assistive

technology? According to Schofield (1990), one useful goal of qualitative inquiry is to study "what may be."

> Techniques suggested for studying what may be include seeking out sites in which one can study situations likely to become more common with the passage of time and paying close attention to how such present instances of future practices are likely to differ from their future realizations. (p. 210)

Assistive technology users in general education are very likely to "become more common with the passage of time." Ultimately, however, it is the reader's job to decide whether or not the circumstances I have described resemble theirs enough to provide insights or assistance in future planning (Ferguson, 1992; Patton, 1990). One of the functions of "thick description" (Geertz, 1973), is to provide enough background and details for readers to be able to make more informed decisions about how the circumstances reported in a study might apply to their own situation. From this study we learn we should not assume that because a student has used assistive technology in a special education environment, (s)he will therefore be able to or will want to use technology in a general education environment. Aside from issues of the general education classroom being different from the special education classroom, the

technology the student is using may be different.  If the
technology was "downsized" or made more portable for the
general education environment, the student may not be able
to access it with the same speed as (s)he could larger and
differently positioned equipment in the special education
environment.

Michael's circumstances indicate that a parent can have
significant influence on a student's assistive technology
use--even if that technology use is limited to school hours.
His circumstances at school show that a student who is being
integrated for the first time, may be very sensitive to
grading, homework requirements, public reprimands, taking
trips without parents, the usual social give-and-take among
peers, as well as perceptions about how his technology use
affects the classroom.

His classroom experiences show that assistive
technology users can be involved in classroom activities
such as writing on the board, answering questions aloud,
etc.  Many of these activities required assistance or
adaptations such as rolling his chair to the blackboard with
other students and dictating or indicating his answer to
someone else who then did the writing for him.  On the
playground when other motor adaptations were not possible,
he often participated by being the umpire or score keeper.

## Teacher's Roles and Larger Support Issues

In a discussion of barriers to general technology implementation in the schools,

Blackhurst, Copel, Mittler, Robinson, and White (1989a) first discuss the barriers which among others include the teaching profession and the classroom environment. For special education, however, they consider the outlook "optimistic" because there is "a parallel list of special education technology promoters for using the technology with disabled individuals" (p.5-6). They conclude that "special educators may be more open to the use of technology than regular educators simply because of their training and the nature of their teaching" (p. 6) According to Blackhurst, Copel, Mittler, Robinson, and White (1989a), special educators may be more open to using technology than regular educators for the following reasons:

1. Special educators are less afraid of technological devices--they work with many devices already, such as wheelchairs and hearing aids.

2. Special educators appreciate good behavioral instruction as is often exhibited in good software.

3. Special educators use a variety of approaches to instruction--if that means technology, then so be it.

4. Special educators bring less baggage with them to the classroom--they are younger, and the field is newer so they carry less tradition with them, allowing them to challenge old ideas.

5. Special educators are used to modifying the educational setting and individualizing instruction.

6. Special educators are used to using unique, modified, or different materials.

7. Special educators think about efficiency, effectiveness, and attention to detail--many have been trained to collect data to make instructional decisions, and they may value the assistance technology can provide in that area.

8. Special educators can get support from a number of existing information networks, user groups, and professional organizations that already focus on special education technology. (p. 6)

All of the above descriptions of special educators characterize  John, Michael's special education teacher. The only one that might not apply is item 2 since I am not certain of it's meaning.  As mentioned above in number 8,

John has received help from existing information networks but one of the keys to his accomplishing so much is that he has established his own assistive technology network of people and information sources as discussed in Chapter IV. This networking is essential to assistive technology teachers. Not all can solder or repair devices, but many build the networks it takes (often including the school custodian) to get an unusually diverse array of tasks accomplished for their students (Orelove & Sobsey, 1991; Scherer, 1991d; Wehman, Wood, Everson, Goodwyn, & Conley, 1988).

To general education teachers, John's role as teacher and facilitator of integration may seem very different from their own teaching role. To many special education teachers in preschool, severe, and multihandicapped classrooms, John's role from repairman to fundraiser may not seem that different from what they do or attempt to do for their students. One new task, for example, that a preschool handicapped teacher in the class next to John's this year had to learn was how to fill and monitor a portable oxygen tank for one of her students. She was also responsible for daily and weekly monitoring of the supply tank which included calling the medical supply company for refills. These different and unique relations to students and service providers are examples of what Blackhurst  Copel, Mittler,

Robinson, and White (1989a) might consider "special education technology promoters" (p. 5).

Blackhurst and others in states like Kentucky are developing lists of technology competencies for special education teachers. Their hope is to "translate the guidelines into certification and licensure standards" (Blackhurst, 1989, p. 9). I think this is the first step. Ultimately a better system of keeping teachers up-to-date and of providing support is needed. Regardless of how technology is integrated into teacher education and initial certification requirements, the changing technology as well as changing needs of students will require continuous training and support of teachers and other special education personnel if they are to meet the needs of assistive technology users.

In his efforts to provide assistive technology for Michael and his other students, John's initial role often resembled what Philip Ferguson (1992) describes as one of two ways to solve a jigsaw puzzle.

> There are two ways to solve a jigsaw puzzle. In
> the first, one goes from piece to piece, noting
> the shapes, finding two that fit, then finding a
> third and so on. Little reference is made to what
> the final result will look like. If you put

enough pieces together, the final product will

emerge. (p. 165)

When he applies this analogy to a particular class in a

school, Ferguson says, "One step has led to the next.

Events seemed to coincide nicely.  People were not looking

for a final picture to guide them.  Or, if they looked, they

seldom told each other what they saw" (p. 165).

After working in this way--getting the computer,

getting Michael positioned, getting software, starting the

literacy instruction and all the other next steps--John

began to articulate a need for what he called a "larger" or

a "longer view" as well as top-down support from the school

system for technology use as well as funding support.  To

use Ferguson's analogy, John is asking that the puzzle be

solved the second way.

The second way to solve a puzzle is by constantly

keeping in mind the picture that is to be

reproduced.  Pieces are sought that match a

particular detail of content and color in the

desired image.  The pieces gain their meaning only

as part of the goal pursued, not as individual

shapes.  (Ferguson, 1992, pp. 165-166)

When applied to a particular school, Ferguson says meeting

the future needs of the special education students "requires

a shift to this latter approach.  An agreement will have to

be reached at some point soon on just what the final goal is" (p. 166).

This statement also applies to Michael's and John's situation. However this way of solving the puzzle is less within the teacher's hands (a bottom up approach) and requires organizational and administrative support and vision (a top down approach). Getting this type of support or approach to solving the puzzle for technology use is problematic in education generally. Blackhurst, Copel, Mittler, Robinson, and White (1989a) discuss some of the reasons for this in general education. In a discussion of technology implementation barriers, the barriers they list that might also apply to special education and assistive technology use are:

    1.  Schools lack both short and long term-planning for technology integration.

    2.  There is no financial support for teacher time and effort. A recent survey showed that 95% of the teachers using technology spend up to 10 hours each week beyond their regular responsibilities to learn the technology but only 20% of them get any extra pay for their efforts.

    3.  There is a lack of human resources to assist in the use of technology . . . few teachers have technical assistance available when it is needed.

4. Administrators declare, "I bought it, you use it." creating a problematic situation.

(Blackhurst, Copel, Mittler, Robinson, & White, 1989a, pp. 3-4)

This situation of lack of long range vision and planning, lack of top-down support for technology from general education administrators is often true of special education administrators. Without this longer vision, administrators may think that merely buying the equipment means they are supporting technology. This happened in the special education facility where John first used assistive technology. In the very year that the school made a large purchase of computers and assistive devices, the school system (because of budget problems) would not give teachers professional time off to attend conferences. As a result, John did most of the inservice training in assistive technology. In addition technology was often viewed as something the teachers and parents wanted; it was something that got done or not in the teacher's spare time.

According to Ferguson (1992) the lack of use of the second approach to solving a jigsaw puzzle in the school he studied was an indicator of "organizational ambivalence" toward disabled students. I do not think this particular type of "organizational ambivalence" is the main issue in John's and Michael's current situation. The main issues

196

seem to revolve around money. This ever-present issue of course reflects larger social conditions and values, including attitudes and response to change.

A technology directory in Exceptional Parent, addressed to parents who "are now advocating for the rights of their children to technology" advises that "focusing on funds for a specific piece of technology for a specific child will not change the pool of money available very rapidly ("Securing Technology," 1990, p.6). According to the funding overview provided in this directory, "increasing knowledge about the role and potential applications of technology" can change "attitudes and practices that will facilitate the development of . . . financial support" (p. 6). Parents, however, are reminded about the effects of change.

> ...the process of developing and accepting new technology requires change. The use of technology challenges everyone's desire for stability, because technology provides rapid change. As a result, many of the groups that parents and their children must use respond to such change by resisting it. (p.6)

As a teacher of students who used assistive technology, I was continually aware of all the larger social, funding, and change issues as well as the daily stresses in my classroom. Like John I was good at using the first method

of solving the jigsaw puzzle. I also understood the budget
problems and did not simplify the world with an
"administrators are the enemy" response. Like John I did
make a difference in my student's lives at the same I was
learning about the limits to how much system change can come
from teacher-promoted bottom-up pressures. These bottom-up
pressures for change need top-down leadership and support
beyond the principal level if real changes are to occur in
student's lives and teacher's activities. The need is for
longer range plans and larger visions, for efforts to use
the second method of solving the jigsaw puzzle. In the
meantime, however, it is important for assistive technology
users that teachers keep on with their bottom-up pressures
and unique special education puzzle solving activities.
Who's to say when or how grassroots efforts become
mainstream policies?

### Research: Barriers and Possibilities

Blackstone et al. in a report on "Technology with Low
Incidence Populations: Promoting Access to Education and
Learning" (1989) discuss the many "challenges in the study
and implementation of technology in the service of education
needs" (p. 31). They discuss potentially formidable
barriers to the implementation of technology research into
practice: (a) researchers and practitioners do not often use

the same hardware, (b) change is slower in the schools than in research settings, (c) research and practitioner communities are isolated from each other, (d) they often do not speak the same language, and (e) the academic incentive system does not often reward researchers for answering questions that are important to practitioners.

Each of these attributes runs counter to what is required to advance the application of technology with low incidence disabilities: a team of collaborators that includes both researchers and practitioners who study issues useful to practitioners, who conduct the studies in school settings, and who communicate their findings in the journals, magazines, and conferences geared to the practitioner community. (Blackstone et al., 1989, p. 33)

Blackhurst Copel, Mittler, Robinson, and White (1989b) reach similar conclusions about barriers. They agree that "research conducted in the practical setting translates more easily into practice, but it presents numerous research methodological problems" (p. 19). As they continue their analysis, mentioning difficulties such as "variables are easily contaminated in uncontrolled settings" (p. 19), it's clear they are considering only quantitative inquiry not qualitative, interpretivist inquiry.

"Qualitative research is still new to special education," says Diane Ferguson (in press, p.2). Coleman (1992) agrees. "A major reason for this" is that the quantitative approach better fits "typical assumptions" which are implicit in most special education research to date (Coleman, 1992, p. 50). In an article, "Something a Little Out of the Ordinary: Reflections on Becoming an Interpretivist Researcher in Special Education" (in press), Diane Ferguson maintains that "interpretivist approaches to inquiry, done, well, have much to offer a field perhaps long overdue for some new and different perspectives" (p. 21). She invites young researchers to "assist special education to overcome its historical tendencies . . . that tend to limit the practical utility of our collective research efforts" (21).

For me this dissertation hasn't been just an academic exercise or an "interesting topic". Part of my purpose has been to tell an untold story. When I look at the method I have tried to use, I realize the larger question is can this new way of studying and reporting help us better understand people with disabilities? Can it make a difference in their lives in school or anywhere? So far most of the differences I have actively tried to make in the lives of people with disabilities have usually ended up making the most difference in my life.

Ferguson, Ferguson, and Taylor (1992) maintain that the ultimate goal of their interpretivist research is to improve people's lives. I hope this is so. I hope our society is (or is in the process of becoming) a place where this is possible. "Once free of the continual burden of justifying themselves to others, interpretivist scholars in disability studies can concentrate on fulfilling the promise of their paradigm to improve people's lives" (Ferguson, Ferguson, & Taylor, 1992, pp. 295-296).

In a discussion of "Disability, Interpretivism and the Pursuit of Social Justice," Ferguson, Ferguson and Taylor (1992) ask, "What is the value of telling stories?" (p. 300). Their answer is twofold--"the reformative effect" and the "empowering effect." An example of the reformative effect is that "the telling of their experience by people who lived for years in the large segregated institutions has been one of the most powerful arguments for deinstitutionalization" (p. 300). The reformative effect "is related to a second, empowering effect of simply getting to tell one's stories. Interpretivism empowers devalued groups within our society by giving them a voice" (p. 301).

*So, let us tell our stories and recognize them as legitimate. Let us listen to the stories of others, and appreciate them as additions, not as contradictions. Most important, as we interpret the future and reflect on the past, let us proclaim the value of those whose stories have so often gone untold.*

*Ferguson, Ferguson, & Taylor*

## REFERENCES

Barnicle, K. (1991). Evaluating assistive devices: What you need to know. Proceedings of the 6th annual conference: Technology and persons with disabilities (pp. 43-52). Los Angeles, CA.

Batavia, A., Dillard, D., Phillips, B. (1990). How to avoid technology abandonment. Proceedings of the 5th annual conference: Technology and persons with disabilities (p. 55). Los Angeles, CA.

Behrmann, M. (Ed.). (1988). Integrating computers into the curriculum: A handbook for special educators. Boston, MA: Little, Brown and Company.

Behrmann, M., & Lahm, L. (1984a). Critical learning: Multiply handicapped babies get on-line. In M. Behrmann & L. Lahm (Eds.), Proceedings of the National Conference on the Use of Microcomputers in Special Education (pp. 181-193). Reston, VA: Council for Exceptional Children.

Behrmann, M., & Lahm, L. (1984b). Using computers with children with sensory and physical impairments. In M. Behrmann (Ed.), Handbook of microcomputers in special education (pp.103-137). San Diego, CA: College Hill Press.

Beringer, V., & Gans, B. (1986). Language profiles in nonspeaking individuals of normal intelligence with severe cerebral palsy. Augmentative and Alternative Communication, 2, 45-50.

Berlin, B. (1985). The assessment of an integrated program for severely multiply impaired and severely mentally impaired students (Doctoral dissertation, Wayne State University, 1984). Dissertation Abstracts International, 45, 806A.

Beukelman, D., & Mirenda, P. (1992). Augmentative and alternative communication: Management of severe communication disorders in children and adults. Baltimore, MD: Paul H. Brooks.

Blackhurst, E. (1989). Implementing technology in special education: Barriers and promoters. In L. Lahm (Ed), Advancing technology use: Barriers to research utilization (pp. 8-18). Reston, VA: Council for

Exceptional Children, Center for Special Education
Technology.

Blackhurst, A., Copel, H., Mittler, J., Robinson, S. &
    White, O.  (1989a).  Barriers and potential solutions
    for moving technology research into a practice setting.
    In L. Lahm (Ed), <u>Advancing technology use: Barriers to
    research utilization</u> (pp. 1-7).  Reston, VA: Council
    for Exceptional Children, Center for Special Education
    Technology.

Blackhurst, A., Copel, H., Mittler, J., Robinson, S. &
    White, O.  (1989b).  Barriers to technology
    implementation.  In L. Lahm (Ed), <u>Advancing technology
    use: Barriers to research utilization</u> (pp. 19-20).
    Reston, VA: Council for Exceptional Children, Center
    for Special Education Technology.

Blackstone, S.  (1992a).  Abandonment of assistive
    technology: What consumers know and professionals need
    to find out.  <u>Augmentative Communication News</u>, <u>5</u>(3), 1-
    3.

Blackstone, S.  (1992b).  Assistive technology selection:
    Making it a consumer responsive process.  <u>Augmentative
    Communication News</u>, <u>5</u>(3), 4-6.

Blackstone, S., Brown, C., Cavalier A., Cress, C., Mineo,
    B., Wilson, M., & VanBiervliet, A.  (1989).  <u>Technology
    with low incidence populations: Promoting access to
    education and learning</u>.  Reston, VA: Council for
    Exceptional Children, Center for Special Education
    Technology.

Bogdan, R., & Biklen, S.  (1982).  <u>Qualitative research for
    education: An introduction to theory and methods</u>.
    Boston: Allyn & Bacon.

Bogdan, R. & Taylor, S.  (1992).  The social construction of
    humanness: Relationships with severely disabled people.
    In Ferguson, P., Ferguson, D., & Taylor, S. (Eds.),
    <u>Interpreting disability: A qualitative reader</u> (pp. 275-
    294).  New York City: Teachers College Press.

Brown, C.  (1954).  <u>My left foot</u>.  London: Mandarin.

Brown, L., Schwarz, P. Udvari-Solner, U, Kampschoroer, E.,
    Johnson, F., Jorgensen, J. & Gruenewald, L.  (1991).
    How much time should students with severe intellectual
    disabilities spend in regular education classrooms and

elsewhere? <u>The Journal of the Association for Persons with Severe Handicaps</u>, <u>16</u>(1), 39-47.

Campbell, P., Bricker, W., & Esposito, L. (1980). Technology in the education of the severely handicapped. In B. Wilcox & B. York (Eds.), <u>Quality Education for the Severely Handicapped</u> (pp. 223-246) Washington, DC: US Dept. of Education.

Cassirer, E. (1960). <u>The logic of the humanities</u>. London: Yale University Press.

Cavalier, A., & Mineo B. (1987). The application of technology in the home, the classroom, and the workplace: Unvoiced premises and ethical issues. In A. Gartner & T. Joe (Eds.), <u>Images of the disabled/ disabling images</u>. New York: Praeger.

Cavalier, A., van der Walt, C., & Mineo, B. (1990). Stimulus and listener factors affecting the intelligibility of synthesized speech. <u>Proceedings of the thirteenth annual conference of the association for the advancement of rehabilitation and assistive technologies</u>. Washington, DC: RESNA.

Cobb, H., & Horn, C., Jr. (1986). Planned changes in special education technology. <u>Journal of Special Education Technology</u>, <u>8</u>(2), 18-27.

Coleman, P. P., Koppenhaver, D. A. & Yoder, D. E. (in press). <u>Emerging literacy activities for preschool augmentative communicators</u>.

Coleman, L. (1992). Reflections on "The Cognitive Map of a Master Teacher Conducting Discussions with Gifted Students." <u>Exceptionality</u>, 3, 49-53.

Cosden, M., Gerber, M., Semmel, D., Goldman. S, & Semmel, M. (1987). Microcomputer use within micro-educational environments. <u>Exceptional Children</u>, <u>53</u>, 399-409.

Creech, R. (1988, October). Paravocal communicators speak out. <u>Aug-communique: North Carolina Augmentative Communication Association Newsletter</u>, <u>6</u>(3), 12.

Creech, R. (1992). <u>Reflections from a unicorn</u>. Greenville, NC: R C Publishing.

Crowner, T. (1984, January). <u>Exceptional children and microcomputers: A survey of public school applications</u>.

Paper presented at the National Conference and Training Workshops on Technology in Special Education, Reno, NV.

DeRuyter, F. (March, 1992). The importance of outcomes and cost benefit analysis in AAC. Consensus Validation Conference Resource Papers. A report from National Institute on Disability and Rehabilitation Research (pp. 86-92). Washington, DC.

Division of Special Education. (1986). A new future for children with substantial handicaps: The second wave of least restrictive environment. Indianapolis: Indiana Department of Education.

Dutton, D. (October, 1986). Strategies to promote integration and acceptance of students with disabilities among their non-disabled peers, using microcomputers. In J. Murph & J. Dunnigan (Eds.), Proceedings of the conference on computer technology and persons with disabilities (pp. 45-53). Northridge, CA.

Eisner, E. (1984). Can educational research inform educational practice? Phi Delta Kappan, 65(7).

Eisner, E. (1991). The enlightened eye: Qualitative inquiry and the enhancement of educational practice. New York: Macmillan.

El-Khatib, L. (1989). Factors influencing the instructional use of computers with handicapped students in public schools (Doctoral dissertation, Southern Illinois University at Carbondale, 1988). Dissertation Abstracts International, 49, 1682A.

Ferguson, D. (1987). Curriculum decision making for students with severe handicaps: Policy and Practice. New York City: Teachers College Press.

Ferguson, D. (in press). Something a little out of the ordinary: Reflections on becoming an interpretivist researcher in special education. Specialized Training Program, University of Oregon.

Ferguson, P. (1992). The puzzle of inclusion. In Ferguson, P., Ferguson, D., & Taylor, S. (Eds.), Interpreting disability: A qualitative reader (pp. 145-167). New York City: Teachers College Press.

Ferguson, P., Ferguson, D., & Taylor, S. (1992). The future of interpretivism in disability studies. In Ferguson, P., Ferguson, D., & Taylor, S. (Eds.), Interpreting disability: A qualitative reader (pp. 295-302). New York City: Teachers College Press.

Ferguson, P., Ferguson, D., & Taylor, S. (1992). Interpretivism and disability studies. In Ferguson, P., Ferguson, D., & Taylor, S. (Eds.), Interpreting disability: A qualitative reader. New York City: Teachers College Press.

Foulds, R. Application of microcomputers in the evaluation of the physically disabled child. Exceptional Child, 49, 155-162.

Gartner, A. & Lipsky, D. (1989, June). Equity and excellence for all students. Presentation before the National Council on Disability. National Study on the Education of students with Disabilities. Washington, DC.

Geertz, C. (1973). The interpretation of cultures. New York: Basic Books.

Glicksman, H. (1989, Winter). AAC: A parent's perspective. Communication Outlook, 10(3), 14-15.

Goldenberg, P. (1979). Special technology for special children. Baltimore: University Park Press.

Gorenflo, W., & Gorenflo, D. (1991). The effects of information and augmentative communication technique on attitudes toward nonspeaking individuals. Journal of Speech and Hearing Research, 34, 19-26.

Guess, D., Benson, H., & Siegel-Causey, E. (1985). Concepts and issues related to choice-making and autonomy among persons with severe disabilities. The Journal of the Association for Persons with Severe Handicaps, 10(2), 79-96.

Guba, E. (1978). Toward a methodology of naturalistic inquiry in educational evaluation (CSE Monograph Series in Evaluation No. 8). Los Angeles: University of California, Los Angeles, Center for the Study of Evaluation.

Hahn, H. (1983). Paternalism and public policy. Society, 20(3), 36-46.

Hamre-Nietupski, S. & Nietupski, J. (1992). Functional
    life skills, academic skills, and friendship/social
    relationship development: What do parents of students
    with moderate/severe/profound disabilities value? The
    Journal of the Association for Persons with Severe
    Handicaps, 17(1) 53-58.

Hansen, C., & Perlman, L. (1989). Technology: A vital tool
    for persons with disabilities. Journal of
    Rehabilitation, 55, 18-21.

Harris, D. (1982). Communication interaction processes
    involving nonvocal physically handicapped children.
    Topics in Language Disorders, 2(2), 21-37.

Hofmeister, A. & Friedman, A. (1986). The application of
    technology to the education of persons with severe
    handicaps. In R. Horner, L. Meyer, & B. Fredericks
    (Eds.), Education of learners with severe handicaps:
    Exemplary service strategies (pp. 351-368). Baltimore:
    Paul H. Brooks.

Horstmann, H. & Levine, S. (1990). Modeling of user
    performance with computer access and augmentative
    communication systems for handicapped people. AAC
    Augmentative and Alternative Communication, 6, 231-241.

James, H. (1948). The art of fiction and other essays.
    New York: Oxford University Press.

Kearly, P. (1988). Historical and philosophical issues in
    normalization of handicapped individuals. Child and
    Youth Services, 10(2), 3-33.

Kelford Smith, A., Thurston, S., Light, J., Parnes, P., &
    O'Keefe, B. (1989). The form and use of written
    communication produced by physically disabled
    individuals using microcomputers. Augmentative and
    Alternative Communication, 5, 115-124.

Kissick, Jr., L. (1984). Communication devices and an
    enriched life: An autobiography. The Exceptional
    Parent, 14(4), 9-14.

Koppenhaver, D. (1990). Assessing developmental spelling.
    Aug-Communique: N. C. Augmentative Communication
    Association Newsletter, 8(2), 4-5.

Koppenhaver, D., Coleman, P., Kalman, S., & Yoder, D.
    (1991). The implications of emergent literacy research

for children with developmental disabilities. <u>American Journal of Speech-Language Pathology</u>, <u>1</u>(1), 38-44.

Koppenhaver, D., Coleman, P., Steelman, J., & Yoder, D. (in press). Enhancing, literacy, learning in children and adults. In D. E. Pressman (Ed.), <u>Handbook of Augmentative Communication</u>. Andover Medical Publishers.

Koppenhaver, D., Evans, D., & Yoder, D. (1991). Childhood reading and writing experiences of literate adults with severe speech and physical impairments. <u>Augmentative and Alternative Communication</u>, <u>7</u>(1), 20-33.

Koppenhaver, D., & Yoder, D. (1988). Independent reading practice. <u>Aug-Communique: N.C. Augmentative Communication Association Newsletter</u>, <u>6</u>(3), 9-11.

Koppenhaver, D. & Yoder, D. (1990a, July). <u>A descriptive analysis of classroom reading and writing instruction for adolescents with severe speech and physical impairments</u>. Paper presented at the annual meeting of the International Special Education Congress, Cardiff, Wales.

Koppenhaver, D. & Yoder, D. (1990b, August). <u>Classroom interaction, literacy acquisition, and nonspeaking children with physical impairments</u>. Paper presented at the biennial meeting of ISAAC, Stockholm, Sweden.

Koppenhaver, D., & Yoder, D. (in press). Literacy issues in persons with severe speech and physical impairments. In R. Gaylord-Ross (Ed.), <u>Research and Issues in Special Education</u> (Vol. 2). New York: Columbia University, Teachers College Press.

Kraat, A. (1985). <u>Communication interaction between aided and natural speakers: A state of the art report</u>. Toronto: Canadian.

Lewis, R. (1990). Noncommercial instructional software for students with severe, multiple handicaps. <u>Journal of Special Education Technology</u>, <u>10</u>, 157-168.

Light, J., Lindsay, P., & Parnes, P. (1988). <u>Information processing demands of message retrieval techniques</u>. Paper presented at ISAAC Conference, Anaheim, CA.

Lincoln, Y., & Guba, E. (1985). <u>Naturalistic Inquiry</u>. Beverly Hills, CA: Sage.

Lindsey, J. (1987). <u>Computers and exceptional individuals</u>. Columbus, OH: Merrill.

Lloyd, J., Singh, N., & Repp, A. (Eds.). (1991). <u>The regular education initiative: Alternative perspectives on concepts, issues, and models</u>. Sycamore, IL: Sycamore.

Lofland, J., & Lofland, L. (1984). <u>Analyzing social settings: A guide to qualitative observation and analysis</u> (2nd ed.). Belmont, CA: Wadsworth.

Malouf, D., Weingerber, Rieth, H., & Semmel, M. (1987). Technology effectiveness research (part two): Future directions in microcomputer research. In <u>Invitational Research Symposium on Special Education Technology: Proceedings</u> (Session 6). Reston, VA: The Council for Exceptional Children, Center for Special Education Technology.

Messinger, M. (1983). CP = computer proficient. <u>The Exceptional Parent</u>, <u>13</u>(4), 57-60.

Meyers, L. (1990). Technology: A powerful tool for children learning language. <u>OSERS News in Print</u>, <u>3</u>(2), 2-7.

Michalowski, S., Roulds, R., Leslie, & J. Semmel, D., Charles, M. (1987). Research in the field of rehabilitation technology. In <u>Invitational Research Symposium on Special Education Technology: Proceedings</u> (Session 5). Reston, VA: The Council for Exceptional Children, Center for Special Education Technology.

Mineo, B. & Cavalier, A. (1990). Speech output technology in education and rehabilitation: Implications from behavioral research. <u>Speech-Tech</u>, <u>2</u>(3), 68-75.

Mirenda, P., & Beukelman, D. (1987). A comparison of speech synthesis intelligibility with listeners from three age groups. <u>Augmentative and Alternative Communication</u>, <u>3</u>, 120-128.

Office of Special Education and Rehabilitative Services. (1989). <u>Eleventh annual report to Congress on the implementation of Public Law 94.142: The Education for All Handicapped children Act</u>. Washington DC: Department of Education.

Office of Technology Assessment. (1988). <u>Power on! New tools for teaching and learning</u> (OTA Publication No. 052-003-01125). Washington DC: US Government Printing Office.

Orelove, F. & Sobsey, D. (1991). <u>Educating children with multiple disabilities: A transdisciplinary approach</u> (2nd ed.). Baltimore: Paul H. Brooks.

Panyan, M. , Hummel, J., & Jackson, L. (1988). The integration of technology in the curriculum. <u>Journal of Special Education Technology</u>, <u>9</u>, 109-119.

Papert, S. (1980). <u>Mindstorms: Children, computers and powerful ideas</u>. New York: Basic Books.

Parette, H. (1991, April). <u>Professionals working with people with disabilities: Technology training implications for teacher educators</u>. Paper presented at the Conference of the Arkansas Association of Colleges for Teacher Education, Little Rock, AR.

Parker, S., Buckley, W., Truesdell, A., Riggio, M., Collins, M., & Boardman, B. (1990). Barriers to the use of assistive technology with children: A survey. <u>Journal of Visual Impairment and Blindness</u>, <u>84</u>, 532-533.

Patton, M. (1990). <u>Qualitative evaluation and research methods</u> (2nd ed.). Newbury Park, CA: Sage

Phillips, B. (1991). <u>Technology abandonment: From the consumer point of view</u>. Washington, DC: Request publication.

Phillips, M. (1992). "Try harder" The experience of disability and the dilemma of normalization. In Ferguson, P., Ferguson, D., & Taylor, S. (Eds.), <u>Interpreting disability: A qualitative reader</u> (pp. 213-227). New York City: Teachers College Press.

Provenzano, S. (1988). A study of the use of technology in programs for physically handicapped students in New York State (Doctoral dissertation, Columbia University Teachers College, 1987). <u>Dissertation Abstracts International</u>, <u>48</u>, 1745A.

Research and Training Center on Independent Living. (1987). <u>Guidelines for reporting and writing about people with disabilities</u>. Lawrence, KS: University of Kansas.

Royeen, C. (1988). Investigations into technology integration for the education of handicapped students. Journal of Special Education Technology, 9, 87.

Roth, W. (1983). Handicap as a social construct. Society, 20(3), 56-61.

Scarlato, M. (1989). Teaching concepts to severe physically disabled students through systematic instruction and microswitch technology (Doctoral Dissertation, University of Oregon, 1988). Dissertation Abstracts International, 50, 664A.

Scherer, M. (1988). Assistive device utilization and quality of life in adults with spinal cord injuries or cerebral palsy. Journal of Applied Rehabilitation Counseling, 19(2), 21-30.

Scherer, M. (1991a). Assistive technology use, avoidance and abandonment: What we know so far. Proceedings of the 6th annual conference: Technology and persons with disabilities (pp. 815-826). Los Angeles, CA.

Scherer, M. (1991b). The Scherer MPT model. Matching people with technologies. Webster, NY: Scherer Associates.

Scherer, M. (1991c). Technology and mainstreamed students with physical disabilities: Perspectives toward the end of the 20th century. In S. Goldberg & M. Foster (Eds.), Readings on Equal Education Vol.11 (pp. 95-112). NY: AMS Press.

Scherer, M., & McKee. B. (1991, April). The development of two instruments assessing the predispositions people have toward technology use: The value of integrating quantitative and qualitative methods. Paper presented at the Annual Meeting of the American Educational Research Association, Chicago, IL. (ERIC Document Reproduction Service No. ED 149 514).

Schofield, J. (1990). Increasing the generalizability of qualitative research. In E. Eisner & A. Peshkin (Eds.), Qualitative inquiry in education: The continuing debate (201-232). New York: Teachers College Press.

Schrag, J. (August 10, 1990). Education of the Handicapped Law Report, 16, 1317-1318.

Schwartz, H., & Jacobs, J.  (1979).  Qualitative sociology: A method to the madness.  New York: The Free Press.

Securing technology funding: Empowering parents.  (Nov/Dec 1990).  Exceptional Parent, spec sec 20(8), 1, 6-8.

Semmel, D., Charles, M., & Kinzer, C.  (1987).  Technology effectiveness research--four years and beyond (part one): Teacher issues in the use of microcomputers.  In Invitational Research Symposium on Special Education Technology: Proceedings (Session 6).  Reston, VA: The Council for Exceptional Children, Center for Special Education Technology.

Shell, D., Horn, C., & Severs, M.  (1989).  Computer-based compensatory augmentative communications technology for physically disabled, visually impaired, and speech impaired students.  Journal of Special Education Technology, 10, 29-43.

Simpson, R., & Myles B.  (1990).  The general education collaboration model: A Model for successful mainstreaming.  Focus on Exceptional Children, 23(4), 1-11.

Singer, J., & Butler, J.  (1987).  The Education for All Handicapped Children Act: Schools as agents of social reform.  Harvard Educational Review, 57, 125-152.

Smith, J., & Heshusius.  (1986).  Closing down the conversation: The end of the quantitative-qualitative debate among educational inquirers.  Educational Researcher, 15(1), 4-12.

Smith, R.  (1989).  Technological applications for enhancing human performance.  In C. Baum & C. Christiansen (Eds.), Human performance deficits (pp. 1-80).  Madison, WI: Trace Research and Development Center, University of Wisconsin.

Snell, M.  (1991).  Schools are for all kids: The importance of integration for students with severe disabilities and their peers.  In J. Lloyd, N. Singh, & A. Repp (Eds.), The regular education initiative: Alternative perspectives on concepts, issues, and models (pp. 133-148).  Sycamore, IL: Sycamore.

Stainback, S., Stainback, W., & Forest, M.  (Eds.).  (1989).  Educating all students in the mainstream of regular education.  Baltimore: Paul H. Brooks.

Stainback, S., & Stainback, W. (1988). <u>Understanding and conducting qualitative research</u>. Reston, VA: The Council for Exceptional Children.

Thorman, J., Gersten, R., Moore, L., & Morvant, M. (1986). Microcomputers in special education classrooms: Themes from research and implications for practice. <u>Computers in the Schools</u>, <u>3</u>(3-4), 97-109.

U.S. Congress. (1988). <u>Technology-related assistance for individuals with disabilities act of 1988</u>. PL 100-407. 100th Congress, 102 Statute, August 19, 1988, pp. 1044-1065.

van Kleeck, A. (1990). Emergent literacy: Learning about print before learning to read. <u>Topics in Language Disorders</u>, <u>10</u>(2), 25-45.

Vanderheiden, G. & Yoder, D. (1986). Overview. In S. Blackstone (Ed.), <u>Augmentative communication: An introduction</u>. Rockville, MD: American Speech-Language-Hearing Association.

Wasson, P., Tynan, T., & Gardiner, P. (1982). <u>Test adaptations for the handicapped</u>. San Antonio, TX: Education Service Center.

Wehman, P.,Wood, W., Everson, J., Goodwyn,R., & Conley S. (1988). <u>Vocational education for multihandicapped youth with cerebral palsy</u>. Baltimore, MD: Paul H. Brookes.

White, L. (1987). <u>Administrative guidelines for the implementation of technology in special education</u> (Report No. ISBN 0 86586 173 0). Reston, VA: Council for Exceptional Children. (ERIC Document Reproduction Service No. ED 285 319).

Will, M. (1986). Educating children with learning problems: A shared responsibility. <u>Exceptional Children</u>, <u>52</u>, 411-416.

York, J., & Vandercook T. (1991). Designing an integrated program for learners with severe disabilities. <u>Teaching Exceptional Children</u>, <u>23</u>(2), 22-28.

## One Teacher's Beginning Experiences with

## Assistive Technology in a Public School Setting

Assignment from Jan Nespor    4/15/91:
Write in as great detail as possible <u>everything</u> you know
about Michael, about the school, about John, about assistive
technology (relevant to this).  This should be a <u>narrative</u>.
(Please Note:  This assignment was completed in May 1991
before I started the interviews for the dissertation).


## Summary of My Technology Interests

<u>General Education</u>.  My interest in computer technology

began in 1983 with reading Seymour Papert's (MIT) book,

<u>Mindstorms: Children, Computers and Powerful Ideas</u> (1980).

To use a colloquial expression, this book literally "knocked

my hat in the creek" because it combined  in a computer

language (based on a theory of learning) all I believed

about learning and living.  So in February 1983 I bought a

computer and started learning LOGO.  In March I taught it to

and learned it with ED ("Emotionally Disturbed") students

that I was teaching at a high school in Southwest Virginia.

I love LOGO because it is available and challenging to all

ages (extensible like language is), allows children to

create their own "objects to think with" and has "body

syntonicity," (Papert, 1980, p. 68), e.g., you may first

walk a circle to figure how to program a circle.  At

computer camp I taught children the basic computer commands

215

through dance steps and a song I made up and played on the guitar called, "Let's Play Turtle: FD Move."

Special Education.  My interest in specifically adapting technology--computers and other devices--began when I met Michael, the subject of this study.  I felt he was intelligent and unable to show what he knew.  I also believed that he badly wanted to take part in activities with his classmates (few of whom had severe physical impairments).  First I adapted crayon holders, various utensils, battery toys, and then started figuring out how to make the computer keyboard accessible.  I dropped all attempts to give him computer access when I found out I needed to "prove" his intelligence so that his next school placement would be more appropriate.

At this point I didn't realize I could use the computer for cognitive assessment.  After briefly borrowing a switch controlled lighted scanning board to see if this would help with assessment, I started building one from scratch.  This board (in a later version that someone else completed) was used to assess his cognitive abilities.  Because of this initial project in assessing Michael, I eventually learned how to accomplish on the computer even more than I did on the light board.  This story and others about Michael and assistive technology are told in the following pages.  First

a chronological outline will provide a brief overview by school years.

## Outline Overview (years are by school years)

1983-84    I first met Michael when he was in the preschool teacher's class next to mine at Southwest School. At this time I was teaching Preschool handicapped class at Southwest, taught summer computer camp in LOGO, took my own computer into preschool class and let students play around a bit with LOGO. I didn't know how to adapt computer for accessibility by people with physical disabilities. Also became interested in Logo controlled robots: used Big Trac and Logo turtle robot that drew pictures on large sheets of paper on the floor.

1984-85    Michael was in my class at Southwest (his last year of preschool). This was the year I became interested in adapting devices and computers for assessment. Assessed Michael on light board that I first attempted to make and eventually had made at the Vocational Technical school.

1985-86    Michael spent this kindergarten year at the special education facility. I first met John and first worked with him in the summer (1986), when

217

he bought his computer (knowing Michael would be in his class the next year at the special education facility).

I became part of UVA/IBM Institute project. Telecommunications access (through the University of Michigan--Confer) to special educators working on similar projects in 15 states. Also access to UVA computer for work with Paula Cochran and Glen Bull. With my preschool students I was generally adapting toys and all manner of devices including computers. Became computer consultant and workshop presenter for Preschool Technical Assistance Center at Virginia Tech.

1986-87    Teamed with John on figuring out what to do for <u>Michael</u> and a student in my class. Michael used the powerpad initially and had difficulty accessing it because of his position. John started experimenting with various stands to hold the Unicorn board which Michael was starting to use. John and I started doing inservices for Southwest County on how we were using computers with special students. A wonderful OT, came into our life and made a big difference in our students' life and ability to access technology.

Still part of UVA/IBM project.  Started
attending, with John, <u>Closing the Gap</u>, special
education technology conference.  Did presentation
at technology conferences on how I had used the
board and computer to assess cognitive skills of
multihandicapped students.  <u>Was using Michael as
my main example</u>.

---

<u>A World Condition Note:</u>

It wasn't long ago that the
only floppy disk was a
phonograph record left lying
out in the sun.

Doug Larson

Please note that up until around this year most schools
did not use computers in special education or believe it was
possible for multihandicapped students to benefit from them.
I had the only Apple computer at Southwest school until this
year.  Initially I had the only Apple that any special
education student in Southwest County had access to.  On the
East Coast only Johns Hopkins had a course in which a
teacher could get a degree in special education technology.
Up to this point computers and other assistive technology
were heavily rehabilitation-services oriented and not much
education oriented.

Around this time John and I were being appreciated a bit more and were not considered as crazy/idealistic as we were considered originally. Also places like George Mason University and University of Kentucky (a few years later) in this area started offering degrees in special education technology. And--to our immediate advantage--technology started becoming fashionable to school administrators. They even bought us some equipment and computers and showed us off to visitors.

I attribute this new treatment to their attendance at conferences where they would see videos of the latest technology use or where they were given tours of classrooms that resembled John's or mine. Up to this point I bought all equipment used by my students from my own pocket because I could get few to believe that my nonspeaking, non-pencil holding students could actually benefit from computer use.

Around this time Michael started word processing by copying words he'd "dictated" that were written on the blackboard over his computer. A few people started believing in and supporting John's and my efforts to integrate technology into special education (including LD classes) in Southwest County. At this time Michael was our most visible proof of what we were about. It stopped being such a lonely battle when we made a few inches of progress in a basically hostile and resistant-to-change school

environment.    (From the first the LD teachers were
interested and believing of possibilities--but couldn't get
regular enough access to computers.)

    We took Michael and other students to workshops, school
board meetings, etc. so they could show what they could do.
Others among our students were progressing but weren't as
personable or easy for the general public to identify with
as Michael was.    From the first he had a special charisma
and personality.    At this time we were also beginning to
realize that he was perhaps not at all typical because of
what we were interpreting as high level cognitive abilities.
But as soon as we got confident about what he knew he'd seem
to stop progressing or else we'd discover some big gap in
his knowledge that made us question our assessment of his
abilities.

---

1987-88    Didn't think about Michael at all this year but
           spent most energies on a student in my own class--
           one with somewhat similar physical difficulties as
           Michael but did not catch on cognitively as fast
           as Michael did.    Did presentation at Minnesota
           conference with Christine Appert, Kluge Rehab
           Center in Charlottesville, on assessing young and
           multihandicapped students using the computer. Used
           pictures and stories about Michael.    Final year of

221

UVA/IBM Institute project. In this year John built an "expand a stand" for the Unicorn board that made Michael's access much easier. OT made hand splint with a pointer that functioned as a hand pointer to choose letters below the keyguards on the Unicorn Board and the Touch Talker which Michael acquired this year.

1988-89    Didn't work with Michael but used a lot I'd learned from him in my job as technology specialist at the SPH TAC. Kept up with what he was doing through regular visits to the special education facility. John and I did many workshops and teacher training activities. John started working as part-time consultant to SPH TAC.

With Chris Appert we did a presentation at technology conference in Minnesota where John and I discussed Michael at length-- especially assessment and positioning issues. (See Appendix E.) John showed videos from his class of various stages of Michael's technology use. This was year Michael got his powered wheel chair and Touch Talker. John fund raised for both.

1989-90    Michael wrote a rock song. John called and asked for technical assistance to figure it out and get

it sung in time for Michael to be in the Very
Special Arts Festival. Classroom paraprofessional,
Martha, figured out the tune by using an
electronic keyboard and asking 20 questions. From
tapes of the keyboard tune and Michael's input on
the tune and tempo, my brother sang and recorded
it.  Michael played the recording at the festival.
He also played a synthesized version on the Touch
Talker.

My brother also participated later in making
a video I was planning called "Michael's Song."  I
was hoping to make a video that through the
vehicle of the song would tell the story of what
Michael could do using assistive technology and
through video interviews of all the participants
explain how he had gotten to this point.

1990-91    Was continuing to edit the story of his song.
Observed him at Southwest and saw how far he is
getting on use of the Touch Talker for
communication as well as how little he currently
used technology in his general education class.

Marsha, his paraprofessional, sits beside him
3/4 of the day or more in fourth grade.  She
writes for him and interprets his vocalizing.
Some of his single and two word utterances are

223

understandable. Some of his classmates understand
a few words. Marsha understands a lot. People
not around him much understand almost nothing he
says. John is in process of setting up the Touch
Talker for more portable output--written and
spoken. He fundraised for a Diconix Serial
Portable Printer.


## Background on Michael

Michael was born in 1979 with cerebral palsy (cerebral
palsy). Because Virginia was one of the first states to
provide preschool handicapped services to two year olds, he
was enrolled in a local preschool handicapped program at a
public school. Services provided regularly and free of
charge were educational instruction, occupational therapy
(OT), physical therapy (PT), and speech therapy. Michael's
condition was diagnosed as severe mixed spastic athetoid
cerebral palsy.

In his last year of preschool, Michael could indicate
yes and no with his head and occasionally say a word that
was understandable in context. Functional skills were
depressed by his inability to stand and his generally poor
motor control of all extremities. He could not hold a
crayon, cut with scissors, or reliably point to or pick up
objects. He became toilet trained in his last year of

preschool.  This meant that if asked, he could indicate whether or not he needed to use the toilet.  He could not lift himself from his chair or transfer himself to the toilet.  Because of the lifting and transfer required, he still does not toilet independently.

His alertness, determination, and general good humor were often interpreted by people who worked closely with him to indicate average intelligence.  The speech pathologist who worked with him at this time, in his final year of preschool, adapted test items from tests including the Preschool Language Scale or Peabody Picture Vocabulary .  She would offer him verbal choices and he would indicate the answer to test items by a noise or nod.  With pictured choices, she would point to each in turn and he would nod to indicate yes.  As his preschool teacher, I worked in a similar way adapting preschool activities and test items from the Learning Accomplishment Profile (LAP).  Michael took part in all classroom activities from music, to cooking, to language games but usually with many adaptations and the assistance of a paraprofessional.

## Michael in Preschool

1983-84: Three to Four Years Old.  When I first met Michael, he was four years old and in another teacher's preschool handicapped class.  Our classes often had playtime

and physical education together, so I got to know him initially through attempts to help him participate in individual and group gross motor activities. I placed him on a tricycle and held him on so he could scoot around the track. Keeping his feet out of the spokes and his hips on the tricycle seat required a lot of physical effort because of his involuntary muscle spasms where his head and neck would stiffen and extend in one direction, while his hand and legs would extend in an opposing direction.

My first memories of Michael are of feeling physically exhausted and thinking how better to let him be a part of activities in ways that did not require so much physical lifting and control from me. (I have chronic back pain from an injury in childhood.)

Puddle Duck Story. He obviously appreciated my efforts, and we became good friends. One day I remember in particular. He was visiting my preschool handicapped class and listening to the story of Puddle Duck, a duck who loved to splash in puddles. I asked the class who knew what a puddle was. Michael didn't seem to know, so we went out on the patio, took off our shoes and jumped up and down in puddles. It started to rain a bit. Since it was hot, we stayed there jumping and discussing and acting out various Puddle Duck routines from the story. I unstrapped Michael from his chair and held him upright against me as we jumped

and splashed. I had seldom heard him laugh so heartily or look so enthusiastic about being a part of things. Because I was holding him upright the way he might be if he could stand, children were holding his hand and relating with eye-to-eye contact at a level he was not used to from his chair.

When we came inside to change into dry clothes, Michael started howling which shocked me. At this point he vocalized little. I thought he could not get the wind in his lungs to make more than moderately loud noises or occasional laughs. He kept looking at the tumbling mat and back at me and making noises louder than I'd ever heard him make. I alternated between fear that something was wrong and my hunch that he wanted so badly to communicate something important. (I almost sent a child to tell his teacher to come and check the situation out.) After looking back and forth between him and the mats, I guessed what was going on. He wanted to act out the rest of Puddle Duck where all the baby ducks go to bed in the same bed at the end of the day. So I asked, "Do you still want to be Puddle Duck and go to bed?" He nodded and howled in a different way.

So I continued as if we were still part of the story--admonishing the class as if I were mother duck, I herded them all onto the mat and put a big beach towel over them all. I kissed them all good night, and we ended the story the same way the book did.

<u>1984-85: Four to Five Years Old</u>.  I was very glad to have Michael in my class the next year.  By now he was just enough heavier that I simply could not do the lifting and carrying of him that I had the year before.  My class consisted of nine very active children (1 blind, 1 deaf) plus two in wheelchairs (Michael, and another child who could walk with a walker, but used a wheel chair to go distances).  The classroom paraprofessional and I did all lifting of Michael together.  He was able to bear weight for awhile and this made it possible to use the kindergarten's toilet.

<u>General Adaptations for Michael in Preschool</u>.  In the morning when he first arrived he was strapped into a prone stander and held in place with wide straps of velcro.  Getting him in and out of this was not easy.  But the real problem with the prone stander, which held him in an upright position, was that there was little he could do in it, and he was bored stiff as well as physically uncomfortable.  In addition he towered way above his classmates who were working on tables and mats below him.  Adaptations I made to make this 40 minutes of his life more fruitful and tolerable were:

1.  Placed a low stool nearby that another child could stand on and be lifted up to his height to work

with him or color on his table top, or just hang out at
eye level.

2.  Made him a wooden dowel and velcro crayon
holder that allowed him to make some attempt to mark up
a sheet of paper with colors. (Paper was anchored with
a dycem mat.)  Making this kind of device is actually
an OT's (occupational therapist's) job, but the
preschool OT at the time did not look at his fine motor
goals in ways that led to his participating in the kind
of classroom activity.

3.  Got another tray to attach to the prone
stander, a tray with a recessed bowl that could
hold all manner of things he could tactually
explore.  I even once cracked a raw egg in there
and let him stir it up with his hand.  (He never
did know that we didn't actually include that
particular "beaten" egg in our recipe.)

4.  Talked to the PT regularly about ways to make
him physically more comfortable while upright--
eventually we developed two knee pads that seemed to
stabilize him better, but as he kept growing it became
harder to stabilize his upper body for better fine
motor control in the prone stander.  It often seemed
that just as we got him comfortable and able to control

his arms and hands a bit better, he'd grow an inch or so and the whole process would start over.

I feel like I could write a book on the adaptations I made for Michael this year, especially for art and drama. Always the overriding goals were autonomy, choice (when possible), and inclusion in on-going classroom activities. For example, in a school talent show we sang and danced to a guitar song I wrote called "Up on the Mountain." As each child's name was called, they would choose a partner to skip around with in the circle; at one point in the dance they'd have to hold very still as if they were making a statue. The first time Michael had a turn with this dance, I gave him a choice of a man or a paraprofessional who could still lift him from which to choose his partner. At statue time his dance partner almost up-ended him and held him just off the floor. He made such an effort to hold still to make a "statue" that it was touching. Later his PT (physical therapist) said that she did not know he was physically capable of holding so still in such unsupported positions. It obviously took great concentration on his part. His efforts to make a "statue" had the effect of quieting and gathering the attention of the group. At preschool graduation his statue earned him a rousing round of applause.

Types of adaptations made were:

1.  Classroom schedule and social adaptations (see dance above)

2.  Fine motor/gross motor adaptations (crayon holder, knee pads in prone stander)

3.  Communication Adaptations (eye gaze, waiting for response)

4.  Assessment Adaptations (eye gaze, various physical changes in way LAP was administered, manual scan for test item choices, switch operated scanning board--see technology adaptations)

5.  Technology Adaptations (plate switch and other contact switches to operate toys, play music, and operate blender during cooking activities, switch operated scanning board with test items from the Columbia Mental Maturities Scale. A bristle block attached to the open apple key of the computer keyboard.

Technology Adaptations. I began to realize that I could adapt till doomsday, but his fine motor skills were so poor he'd never be able to write or really indicate what he knew unless he had access to a computer. The only way he was accessing the computer I had put in the classroom was by banging at the keyboard or having his hand held to press a particular key with his finger, or hit the bristle block attached to the open apple key.

I'd read about and seen TV clips of people operating computers with their head.  I called the education department at  Va. Tech and at UVA for advice or courses to take.  Tech said they were teaching LOGO, but did not know about access methods other than through the keyboard.  UVA told me to call Children's Rehabilitation Center (CRC);  CRC (now K-CRC for Kluge Children's Rehabilitation Center) told me about an upcoming workshop by Bud and Delores Hagen from "Closing the Gap" (CTG).  From the CTG people I learned that with the purchase of about $200  of equipment I could make my Apple computer talk and provide switch access using a variety of public domain disks they gave me.  At first I pondered how to get the money from the school or other people, but I figured that they might not want to buy equipment for my computer.  There wasn't another Apple in the school, and so I couldn't argue that the equipment could be used elsewhere if I moved away.  I was also insecure about asking for stuff I couldn't prove he could use.  At that point I wasn't questioning my expertise to adapt the computer and handle all the new technology. (This insecurity would come later after I had already gained a minimum expertise and had enough of a network of technology buddies to help me out at strategic points.)

Placement Considerations--After Preschool.  As I was considering these purchases I found out that his placement

the next year was likely to be a special education facility
for people with severe handicaps. One class that one of the
related service providers described sounded like a living
nightmare to me. Basically in her scenario, he'd be in a
class with people who were very retarded, and he'd not hear
much language--except from the adults. I kept thinking,
"It's bad enough to be trapped in your body the way he is.
The next living hell would be to be trapped in a class where
you wouldn't even hear language and see how your peers
related." This idea of his being isolated from hearing
normal language and seeing normal peer interactions was what
seemed so horrible to me.

## Assessing Michael for Placement after Preschool

_Assessment Issues_. I couldn't get this "nightmare" out
of my mind. I kept going around to various people saying,
"But he's not retarded." One administrator asked, "Can you
prove it?" So I talked to the psychologist responsible for
preschool testing and explained all these neat ways I
thought test items could be adapted. He explained to me
that all those "neat" adaptations negated the test results
because the test wasn't standardized to be administered that
way. In addition the tests were often timed, and what I was
describing would sometimes take days instead of hours to
administer.

233

This psychologist was sympathetic though and later told me he'd dug up the Columbia Mental Maturities Scale (CMMS). From what I'd told him earlier, he wondered if I could adapt for that. It was an untimed test and the score still would not be really valid, but it could possibly give us a ballpark figure of Michael's cognitive level. He also explained that the score would be more accurate the quicker we administered the test. While it was generally considered "untimed", he seriously doubted this meant 30 minutes a day for a week.

At this point I realized I'd better drop attempts for further computer access for now and spend my energies on figuring out how to get Michael tested so I could prove his intelligence. It had never occurred to me that only an IQ type test would be accepted. This I now realize was the dark ages of testing students with severe disabilities. Later I learned that I was right in my gut level anger at the need for an IQ test. However, at this point in time most schools were requiring this type of assessment. Other types of functional assessment and adapted testing would get into the schools later after more years of experience serving students with severe disabilities.

So I had my goal--get Michael access to something that would allow the psychologist and me to jointly administer the CMMS and come up with an IQ equivalent score--all to get

Michael an appropriate placement upon leaving preschool. While eye gaze and some rudimentary pointing could be used for a few choices or simple test items, it would never do for a long item test requiring both accuracy and administration in two sessions on two consecutive days. The CMMS was designed for people to indicate their answers by pointing to one of five pictured items presented with each question.

At this point I was vaguely picturing some kind of switch operated scanning device that he could use to indicate which of the five pictured choices was his answer. What ever system I developed would also have to take into account the "exhaustion factor." Currently Michael was accessing radios and toys using a plate switch on his wheel chair. However, his hand flailed about and often missed the switch. I couldn't imagine his consecutively hitting that switch to indicate his answer to 30 or more test questions.

Getting Support--Technically and Emotionally. My first decision was to enlist the aid of someone else--to have a cohort to share the joys and sorrows. At this point I was beginning to realize I wanted cohorts and a network not just for problem solving but for emotional support.

I was feeling shaken by people's view that I was kidding myself about Michael's abilities or potential. One administrator had patted me on the back and assured me,

"These children were born limited.  It's just sad, but it doesn't do to get over involved."  Another administrator, in a less sympathetic manner, admonished me that I was just going to feed the parents's unrealistic view of what these students were capable of.  A general education teacher I was talking to, responded, "I've heard of some teachers who actually think they can tell what their students are saying by where their eyes look."  Many of the special education teachers and service providers were willing to grant that Michael wasn't retarded, but they couldn't see how that would make much difference in where he was placed given his severe physical disabilities.

No one I talked to except his speech-language pathologist (SLP), had any vision of his possibly fitting anywhere except a special education facility serving students considered "Severe" (SPH) or "Trainable" (TMH).  This speech-language pathologist was not a full time employee but was providing contractual speech services to County.  She agreed to help me, and we decided to get started by trying to borrow a switch scanning board from some clinic she had connections with.

Attempts to Build a Switch Operated Scanning Board.  The scanning board we borrowed showed Michael could possibly be tested using such a device if we solved two problems: making hand access to the switch easier and getting lights

more visible to him.  As he hit the switch a different compartment on this box would light up--moving left to right and top to bottom.  The answer that he chose would be the picture beneath the light.  However, the lights were very small.  At times Michael didn't seem to know where he had stopped the light or which answer he had chosen.

Our next step was to call the Virginia Department of Education.  I talked at length to the director of services to SPH students, who assured me that he was doing a technology workshop in the Southwest area in the last week of November and this would solve our problems.  In fact we could even build our own lighted scanning board using one of his diagrams.

The speech-language pathologist and I made plans to get off from school to attend this all day workshop in Southwest City.  We came away a bit disappointed that the workshop was mainly oriented to building simple switches which we already knew how to do, but the presenter had given us a diagram of a board to build.  He had assured us that if we ran into glitches, he'd be a phone call away and would see us through this.

To make a very long story short we spent three weeks cutting, sawing, wiring, rewiring and buying adapters from radio shack and electronics supply houses and nothing we did could make that board work.  So we called the state

department man, who couldn't seem to understand why our system didn't work. He said he was coming to Southwest in January. and would either have the answer or bring us something he'd built.

When he came to Southwest, he admitted he couldn't get the board working from the diagram he had given us. He had, however, built us a large clock communicator "that Michael could use." This clock communicator was designed so that Michael would hold down the switch as a large clock hand rotated. Test item pictures would be placed, for example, at 12 o'clock, 3 o'clock, 6 o'clock etc. positions. Wherever the clock hand stopped, when Michael released the switch, was to be the answer. This board, alas, did not work for two reasons: 1) the clock broke constantly because it was a mass of not very sturdily put together wires, and 2) Michael couldn't hold down the switch long enough. A hold and release switch would never fit his fine motor skills at this time.

At this point we were feeling pressured because there was so little time left. She started looking into the possibilities of renting a scanning board from some organization somewhere. At this time these boards were both very scarce and very expensive. I was still hoping that with the right expertise, we could get the scanning box running. I told the tale of our efforts to the psychologist

who was starting to inquire about when he thought we might begin testing Michael. He suggested I talk to the principal at the vocational technical school.

To make another long story short, a teacher and students at the vocational technical school built a scanning box for us. The electronics teacher had a degree in psychology and was instantly interested in this project. After looking over the diagram from the man at the state department, he declared that it would never work because such a model required integrated circuits. He ordered the particular circuits needed from California. The carpentry shop made the board, the electrical shop wired it, and the autobody shop painted it.

Getting in the Newspaper--the Final Scanning Board. The week we went over to pick the board up and let them watch Michael use it was "Vocational Technical Week. While we were at the vo tech school a reporter looking for a story discovered us. It was also good luck that Michael's mother was along and could give immediate permission for him to be photographed. This article appeared on the front page of the Southwest Times and World News. I was a bit astonished to wake up the next morning and see our faces in a very large format on the front page of the newspaper. I had expected some back page blurb with a small picture.

239

<u>Choosing the Right Switch</u>.  I now realize that we never did get the best switch, but we did make a modified type of leaf switch which he could activate by moving his hand slightly up and over.  We anchored his arm from just below the wrist to near the elbow so his arm wouldn't flail around. When this arm restriction became tiring  because of his involuntary motion against it, we switched to a plate switch accessed by a backwards and forwards motion of the hand.  An up and down lifting motion was much less controlled and seemed to tire him quicker.  Our back-up plan was that if all arm motions got out of control and he was tiring too much to finish the test in the prescribed time, we'd hold the plate switch at his head or any place he chose that at that time he had more control over.

The PT and OT helped us with these switch placement issues.  The major problem was that once he had activated the switch in the same position over 10 times he started flailing wildly and losing his ability to control arm movements.  (Working with John later I realized that this problem was greatly exacerbated by the lack of proper positioning of his hips in his wheel chair, which he was already outgrowing.)  At this time I did not realize the crucial role of the shape of the wheel chair seat for access to switches by hand.

What made our beginning attempts work was our willingness to give him access with different styles of switches placed in different positions depending on his control and exhaustion. He had such strong reflexes that at times he would break a switch we had just made. This was when I discovered the various brands and types of soldering material and used a stronger bond to hold the switch.

Preparing for Assessment with the Scanning Board. These were the things we did to prepare for the test session with the school psychologist:

1. Made sure Michael was very familiar with the board and understood that the light was the means of indicating choices. We began by setting 6 small books on the shelf below the lights. We asked him to choose the book he wanted us to read to him. When he stopped the light, we asked, is this the book you wanted? He would nod. Later we put test items from The Peabody Picture Vocabulary on the board so he would have practice choosing from black and white line drawings like the CMMS would present. Michael had no trouble with any of this and caught on quickly.

2. Taught Michael to look over choices before he touched the switch to move the light. His initial method was to move the light and look at each picture for the first time as it was lighted. This was

functional for non testing situations, but we explained that looking first would save energy and make him less tired when he had many questions to answer.

3. Put black construction paper around each light on the board. Most of the time Michael had no trouble seeing the light, but some days the sunlight in our room was so bright that he did have trouble unless we surrounded the board light with a contrasting dark color.

4. Made back-up switches, assuming he'd break some in the testing session

5. Progressively increased his time on the board and had the PT and OT observe and give further advice. The PT suggested just letting him stop awhile and get a short break when he started losing control. I tried massaging his arms. He liked this, but it didn't seem to increase his control, so I just held his hand and described how well I thought he was doing.

6. Put pictures on the board and asked, "Which one doesn't belong?" This was to give him practice with the format of CMMS questions.

7. Explained to Michael what would happen the day of the testing. Explained that this was something all the preschoolers were going through, but we thought it would be easier for him to use the board and switch

since it was tiring to answer so many questions at one time.  Several times when the psychologist was picking up other students to test, we explained to Michael that it would soon be his turn.

8.    Invited the psychologist to hang out a bit with Michael and watch how he used the board to indicate choices.

9.    Consulted with Michael on what would motivate him to keep going a little longer when he tired.  The best motivators were going outside, holding hands, and brief "conversations."  I have never been one of these "GOOD JOB" teachers.  I will use the phrase occasionally, but I generally assume people want specific praise and that it shouldn't be over done.  To Michael I would say things like, "When we asked you that last question about playing ball, I figured that you might miss it since you aren't on a baseball team. How in the world did you know that?"  Or else I'd hold his hand and say, "I realize how hard you're working."

Since puffy stickers with moveable eyes were the rage in preschool that year, I expected he'd choose that as a motivator.  He indicated that he'd gladly accept them, but I think he basically wasn't working for them.  My interpretation is that Michael was very motivated to do the best he could on this test and

243

puffy stickers didn't have a lot to do with it.  Motor
control and exhaustion were the major factors.

10.   Xeroxed pictured item choices from the CMMS,
and cut them to be taped on the scanning board.
Pictures of five (occasionally six) answer choices for
each test item were put in envelopes and marked by test
item and the order in which they were to appear on the
board.  To speed up matters in the testing situation,
small loops of tape were put on the back of each
picture so that Michael wasn't waiting for us to
constantly break tape for each picture.

Assessing Michael with the Switch-controlled Board.
The actual assessment with the switch-controlled lighted
scanning board went more smoothly than we'd anticipated.  No
switches were broken.  We had to force him to take breaks
several times because we saw his hand control going.  After
an hour on the first day, we asked him if he wanted to stop
and finish the next day, and we were surprised when he very
vigorously indicated "yes."  We knew he was tiring but
hadn't realized how anxious he was to stop.

During the testing the psychologist sat on Michael's
right, I sat on Michael's left, and he was in the middle
with the plate switch on his wheelchair table.  We all faced
a long table containing the test items and the scanning
board which was placed directly in front of Michael's

wheelchair.  It was positioned so that the middle of the board was slightly below eye level.  This allowed him to see the board and rest his head against the head rest of his wheelchair.

This was our procedure for all test items.  The psychologist and I taped on the light board the picture choices from the first test item.  They were arranged in the same order they appeared on the test card.  I would then ask, "Show me which one doesn't belong."  Michael would look over the five choices, then hit the switch until the light stopped at his choice.  Occasionally his hand would activate the switch before he'd looked over all the choices.  In these instances he'd run the light through all the choices first and then make his choice on the second time through. While the psychologist recorded Michael's answer, I would take down the pictures from the first question and put them in the  envelope.

This sort of precise, two-person routine was developed to keep us organized with all these pieces of paper.  We also had to be concerned that our board layout was as similar as we could make to the flat picture layout of the test boards.  This way if the psychologist recorded that Michael chose item 3 it had to be in the same position as item three on the test layout. I had earlier numbered each picture by its position.  After another person had double

checked my numbering, we placed the pictures in an envelope in the order they were to go on the board. As I handed each envelope to the psychologist, I double checked that pictures were positioned correctly.

We had only one or two glitches when we had to stop or double check our test item positioning. One of the unforeseen results of our organized routine was to limit the amount of "downtime" during the testing. Because Michael wasn't getting as much "down time" between each choice as he had got in non-testing circumstances, I became concerned that things were moving too fast for him. "Downtime" here means the student is waiting for the next event, and this usually means nothing of recreational or instructional value is happening.

As I sensed how more demanding the timing of this test was than the timing of our practice tests had been, I started worrying about his fatigue and his choosing any answer to get it over with. However, this didn't seem to be happening since his answers were generally correct. He didn't actually ask to quit for breaks during this first test session. I just arbitrarily declared after 15 or twenty minutes that now was a time for a break. His activity choices for a break were to be pushed around in the hall once and to sit and "chat" twice.

The second and last session of the test the next day
lasted about two hours, including a half hour of break time
which he requested at various intervals.  On this day he
didn't seem as determined to keep trying despite fatigue.
When he reached the ceiling of the test (missed 5 items in a
row), he started looking at me in a way I interpreted to
mean he didn't know the answer.  I had earlier told him that
some of the questions he wouldn't know the answer to and
when that happened he was just to look at the choices and
make a guess.  He actually stopped making choices and looked
at me before he'd reached the ceiling of the test.  I asked
if he wanted a break.  After he shook his head, I said,
"Remember you're not supposed to know it all.  Take a look
and choose what you think might be the answer."  Several
times he'd almost hit the ceiling and would then get another
one correct.  This meant the test kept being administered
because it wasn't over until he missed 5 in succession.

Later after the psychologist scored the test, he
reported that Michael had done quite well.  The CMMS has an
IQ equivalent score.  If this score could be taken for fact,
Michael had actually scored in what his school system
considered gifted.  However, the psychologist cautioned me
that this test was too limited in design and scope to be
taken as a substitute for cognitive abilities in the way
such tests as the Kaufman  or Stanford Binet could be.

Also, we'd made the results suspect because of our cut and paste and switch adaptations.  However, since we knew all this before Michael took the test, he did think the test indicated that Michael was not mentally retarded and had at least average cognitive abilities.

The Eligibility Meeting.  I felt like a battle had been won.  Since I was new to special education and to this school system, I had not sat through many eligibility meetings.  So I talked to people and tried to think what I would recommend as a placement for Michael the next year.  There really was nothing currently in place to suit the needs of a multihandicapped non-retarded student.  I was also a bit innocent in understanding my role in the proceedings.  I really thought my role was to speak for Michael and not just look at what was currently available and say how he could fit that.

I kept trying to think of a mixture of special and general education.  I believed he needed to be with kindergartners and hear language, but I also didn't want to remove him from his special education network of PT's, OT's, and paraprofessionals trained to toilet him.  I also figured he might be uncomfortable being fed in public in front of general education classmates. Just the occasional upkeep and repair, for example, that kept his wheelchair going was something I figured general educators might not be as

willing or able to do.  So my recommendation was that he start the morning in a general kindergarten in a school 1/3 of a mile from the special education facility.  Buses were always coming and going from the separate education facility, so I figured it was no big deal for one to pick him up and bring him to the separate education facility before lunch.  This way he could get his various therapies after lunch and also be in place for the special bus to go home.

The eligibility meeting and its aftermath were very discouraging to me.  Michael got placed in almost the identical class at the self-contained facility that he would have been placed in if I had not "proved" his intelligence. His mother, who liked me and was supportive of my testing efforts, started talking at the eligibility meeting about how she was happy with a placement at the separate education facility.  "I don't want other students making fun of Michael.  Her basic point became that the world of the self-contained facility is safe and nurturing for him and general education is unsafe and unnurturing.  Later she told me, "I don't want to be the only parent in a school with a child in a wheelchair."

I also learned I had not endeared myself to the special education administration with my half-day-here and half-day-

there recommendation. I was told that such a bus schedule was not possible to work out.

The next day I took my computer home from the school. The sight of it and all the plans I'd made to give Michael access was more than I could bear. When people asked me about it, I said, "Oh I don't think I have the time to set up the things they need, so I'm just taking it home." I went through all the other eligibilities that spring writing very honest reports emphasizing the strengths of my students and recommending very specific instructional and non-instructional things they needed. But not once did I suggest what the actual placement might be.

A Period of Mourning. I was so aware of how discouraged I was that I forcibly decided not to let it affect my relationships with the students or Michael. I told the classroom assistant in mid April that since the testing was over we were going to have fun. No more technology, no more tests, no more worrying about cognitive IEP goals. We sang, danced, conducted science experiments, cooked, did all kinds of messy art projects,and wrote and acted our own plays. We socialized with kindergarten, took tours of the school at odd times to see how people baked bread, stapled brochures, emptied the dumpsters, fixed the plumbing, etc. The librarian even remarked on how many books we were checking out.

250

In all my years of teaching, I think I did the least planning I'd ever done. Many days I didn't know what we were going to do until I saw what the weather was and how many children were present. Sometimes "show-and-tell" items took all morning to explore properly. I found myself enjoying just listening to the students and being in present time with them in a different way.

I wasn't really mourning the loss of special education technology because I didn't at this point see myself as into special education technology. I just saw the switches, the computer, and the scanning board as symbols of my failure with Michael after such high hopes, so I wanted a break from even looking at them. I felt discouraged on many levels including my relation to Michael's mother.

## 1985-86--The Year Michael was in Kindergarten

Michael at the separate education facility. At the end of the school year, I went over to the separate education facility to introduce myself to the woman who was to be Michael's kindergarten teacher (a primary Trainable Mentally Handicapped class). I told her the story of my efforts to get Michael placed. I also made it clear that I wasn't expecting her to work on a better placement situation since his mother wouldn't consider general education.

This was the beginning of what came to be an ongoing friendship with her and later her husband, John. She assured me she wouldn't treat Michael as if he were retarded. She said she also suspected that some of the other students in wheelchairs at the separate education facility weren't as low functioning as everybody thought. We talked about technology and how maybe someday it wouldn't be so hard to get the computers and devices these children needed. Before leaving, I went around the building scouting for a computer, and there were none anywhere, not even on the secretary's desk.

During his kindergarten year, I made no effort to keep up with Michael. His kindergarten teacher gave me reports when we'd meet at school functions. Basically she had a class of non-speaking students in wheelchairs that she'd convinced the school principal to give her. She considered them all potentially higher functioning than others thought. She was making many non-technology adaptations. She also said that Michael was beginning to say a few words more reliably and she had hope that maybe he could improve even more.

Adapting the Computer for Preschoolers. In my next preschool handicapped class at Southwest I had only one child in a wheelchair, so the computer software and Logo programs I already owned were accessible to a more able-

bodied population. After Thanksgiving I brought the computer back into the class and gave my attention to how able-bodied preschoolers did and could use a computer. One of my first insights was to understand how developmentally inappropriate the standard keyboard was.

So this year I was off adapting and making appropriate alternate access for students who could speak and use their fingers to make choices (e.g. switch software operated through the Open-Apple key, Koala Pad, Muppet Keyboard, PowerPad, and the regular keyboard adapted with puffy stickers and small blocks glued onto certain keys). I really didn't spend a lot of time on this. It seemed an easy and natural thing to include the computer sometimes into speech therapy, sometimes into art activities, sometimes into individual and group lessons, and always it was available during free play. I feel like the students taught me what was needed or what they could do. I did spend a lot of time observing them and getting feedback on what they were trying to do or how they viewed a particular computer activity. I was also aware that the computer was being used more than I had expected it would be.

Technology and Literacy Learning. Now that research is coming out on how students with severe speech and physical impairments gain or fail to gain literacy skills, I realize that my early use of talking word processing was supportive

253

of my students emerging literacy skills.  In this and
subsequent years, I used the software <u>Keytalk</u> (Apple) or
<u>Listen to Learn</u> (IBM --a later Apple version was <u>Talking</u>
<u>Textwriter</u>) to type in their morning news or type what they
indicated they wanted on a page which later they
illustrated.  When left to their own devices, however, they
basically used the software to "babble" and explore sounds.
They loved this and would fill screen after screen with the
likes of this:

rrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrr

eeeeeeeeeeeeeeeeeeeeee

jjjjjjjj    jjjOhhuuuu

bbbbbbbbbbbbbbbbbbbbbb    kkkkklllllllll

The look of this is not imposing.  THE SOUND OF THIS IS
SOMETHING ELSE.  Eventually we moved onto putting stickers
on the keyboard vowels so that the noises would resemble
words--nonsense words that is.  Without the vowels the
computer (Echo speech synthesizer) just said each letter
individually.  After weeks of listening, the students got
the difference and one even asked, "How do I make it 'aaack'
or 'eeeep' instead of just going 'J J J J' ?"  A few
students even got to more traditional looking literacy
activities such as using word cards I made for them to type
in "I love you." or "Happy Birthday, Mom."  Sometimes when a
nonsense word resembled a real word, they would get excited

254

and gather around the computer and make it repeat the sound
over and over. There were regular and informal discussions
on such topics as "how to make it say a bathroom word," or
"moan like Jamie did."

I was amazed at how much time they spent with this.
But I also got very tired of hearing those nonsense sounds
fill my ears day after day. At the time I could not have
clearly articulated the learning goals or cognitive
processes of this. If I had not also had Montessori
training, I would have put this software away and retreated
into a less noisy classroom. But I was acting on the
probable truth that children do not attend so avidly to
something they are not learning from. Also, I liked that
they were motivated to explore so much on their own. In
other more traditional learning activities they were often
passive and less responsive.

Adult Response to Computer Use in Preschool. The main
surprise for me this year was how much adult attention I got
for what I was doing. This was at a time when most adults
did not know how to word process, and there still was no
Apple computer in the school except a very recently
purchased one in the library. The speech therapist was the
first to mention my computer use. I showed her how to use
the voice printing software and the microphone I'd rigged
for my student (also her student) who seldom spoke above a

whisper. Into the microphone he and I would bark, laugh, growl and make all kinds of noises. The louder he sounded, the more interesting the soundwave patterns on the computer screen were. He and I had started a contest on who could make the "strongest" patterns.

Next the parents started bringing in people to watch what their children could do. The OT's were using some programs to motivate older children they were working with to reach and activate buttons on the computer. They generally scheduled this therapy while we were at lunch. The preschool coordinator from the Technical Assistance Center (TAC) at Virginia Tech visited my classroom and assured me I should do some workshops for other preschool teachers. I kept saying, "But I really don't know that much about computers. I barely keep two steps ahead of my students." She insisted that it wasn't my knowledge of computers that she needed as much as my knowledge of how to integrate them into a preschool classroom.

The School Board Visits. On the day when the School Board members came to observe, there were more dark-suited adults in the class than there were children. But this class was very social and liked to show off. One child amazed them with his response to a computer glitch. Something stopped working, and I was preparing to restart the software when he announced. "Now let's trouble shoot:

one, is the caps lock key down, two, is the monitor on,
three is the powerport off?"  I responded "OK" to each item.
He looked at me a bit perturbed and said, "Well, it's
probably that old 16-pin connector again."

I still remember the silence and the look on those
School Board members' faces.  At this point I decided to let
this four-year-old show off a bit more.  So I took off the
top of the computer and invited him to see if any of the
chips were loose.  He very dramatically grounded his hands
and went about carefully checking some chips.  At this point
school board members were peering over into the computer
saying things that indicated they'd never seen the inside of
a computer.

With this group and all people I could talk to, I
emphasized the importance of the school's purchasing and
supporting this kind of technology use.  I always made it
clear that I owned this  computer and all equipment and
software the children were using.

Modeling How to Get Help with Technology.  The story
above illustrates something I feel very strongly about and
try to be consistent about in technology use with all of my
students.  When teachers respond to technology problems and
the inevitable computer glitches, they should always be
aware that they are powerful models of how to respond to
technology problems.  I've seen teachers all but wring their

257

hands and curse the computer, thereby modeling a very powerless and negative way to respond to what is probably going to be a growing issue in everyone's life. It's possible that this hassled and powerless response is the most powerful thing being taught to the students --far more likely to remain in their experience than any cognitive goal of the software being used (a medium-is-the-message issue).

To fight the very human urge to complain and inadvertently model a negative mindset, I try to:

1) Articulate a simple list of troubleshooting activities to undertake. This list is written and illustrated on a chart by the computer for all to use.

2) Try to keep a matter-of-fact manner throughout the trouble shooting process, as if to say, "Well, this computer is acting up again. That's to be expected of course."

3) Trouble shoot out loud and encourage the students to suggest what comes next. Use the technical vocabulary; some children will remember it and enjoy the "different" words.

4) Admit it when I don't know what is wrong and either cheerfully decide to use other software or calmly declare, "Well, I'll think about this again at a later time."

258

5) With students with very severe disabilities for whom the computer is their "interface to the world" (Goldenberg, 1979, p. 150). I apologize that the "downtime" is going to prevent their communicating or doing something they counted on. I admit that it is maddening to depend on machines that are often so unreliable. Then I sign off with some request like, "Now if I don't get this fixed soon enough, you remind me, OK." Even though many do not speak, they have very creative ways of reminding me from eye gaze to running their walkers over to the device and batting at it with a difficult to control fist.

Money Problems. Despite this attention and "show-off" year, I became discouraged again because the school would not pay for any equipment or software. At this point my own family expenses were mounting with college costs and unexpected medical bills. I saw no way I could continue to purchase what was needed or make a repair that I had known was imminent when I first took the computer to school. So when the disk drive "died," I took the computer home and explained that it wasn't the school's computer. Always, I encouraged people to encourage special education administrators and others to supply funds.

Since my computer was much used, purchased second hand, and had little memory, I wasn't sure that I would even repair it. In these years Apple computers were much more expensive than they are now. Because they didn't come with a color monitor, I had earlier purchased ($175) a VHS monitor to function as a color monitor which I consider essential for computer use in preschool. I was also aware that we badly needed a printer. At this point though, I was beginning to question whether I could afford to get into special education technology. I think when I was forced to retire that computer, I might never have gotten much further into special education computer technology except for the good luck of being included in the UVA/IBM Institute.

## UVA/IBM Institute on Learner-Based Tools for Special Education

_Being Selected_. Months before, when trying to build the scanning board for Michael, I had called UVA in search of courses on special education technology. A secretary had put my name on a list to receive a manuscript and disk being developed by Professor Glen Bull and doctoral candidate Paula Cochran. I'd volunteered to field test this item for use with preschool students with speech impairments. In the meantime Bull and Cochran had received a large grant from IBM to develop and test learner-based computer tools for use

in special education.  For at least two years each of 20
participants in the Institute was to gather at UVA in the
summer, plan projects, and leave with computers, adaptive
equipment and telecommunications access to each other--all
paid for by IBM and co-sponsored by IBM and the Department
of Education at UVA.

Participants had been selected from all over the U.S.
including Alaska.  Most were more knowledgeable about
technology than I was, but few used computers with
preschoolers. I was invited, one, because I did know LOGO
and had interest in the field and, two, because one
candidate had a family emergency and dropped out the week
before the Institute was to begin.  Because of my name on
the secretary's list, I got a late night quasi-interview and
invitation from Glen Bull to join them.  My initial response
was "They wouldn't include me if they really knew how little
I know."  However, when I realized that I was guaranteed a
computer, a printer, and adaptive equipment and several
thousand dollars worth of software, I accepted the
invitation.

Becoming Part of the Group.  At first I was a bit in
awe and overwhelmed.  But after getting at ease with the
machinery and the people, I found myself feeling like I
belonged, like I shared values and ways of thinking with
these people.  It was energizing to hear their stories and

begin to get a view of what was possible for students like Michael. Hearing their stories of what went on in their school systems made me realize I wasn't so "impractical" after all.

It was also very exhilarating to see such good looking women being just as adept at fixing and programming as the men were. The men also were a unique breed for me. They were competent and knowledgeable in ways that might have earned them more money if they had not purposefully chosen to work with special education students. Watching one man work so patiently with a student who drooled all over him had me close to tears one day. But the best part of all was not being alone trying to figure it out all by myself.

Response to Story of Michael's Assessment. One day in an off-hand manner I brought in my scanning board and told my story of Michael. I remember getting in the middle of the story and taking note of how interested they seemed. Afterwards we discussed Michael for a long time, and I was so pleased at their appreciation for what I had done as well as their practical advice on what he needed next in technology. Paula Cochran, however, impressed me with her view that what the schools were requiring of students like Michael in the way of a score was barbaric. She assured me that if he had failed the CMMS miserably, we could not have taken that to mean retardation.

262

## 1986/87--John /Computer Access for Michael

**The First Meeting**.  In April Michael's kindergarten teacher was telling her principal that her entire class needed access to computers and other devices.  In May her husband, John, was saying that he was interested in getting into computer use with special education students.  In June the principal started the process of requesting computer funds for John's class--consisting of all of the kindergarten teacher's former students including Michael. (Eventually the PTA donated $3500 which the school matched.)

In July--the week I returned from the UVA/IBM Institute-- John called, introduced himself over the phone, and said his wife had told him to call me.  He explained that he realized if he didn't buy his own computer, he wouldn't be able to learn fast enough or get things started before school if he had computer access only on the computer at school which hadn't been purchased yet.  He said he was buying his own computer the next day and wondered if he could bring it over to my house for me to get him started.

I had never met John, but I will never forget that day he drove up in his pick-up truck with his Apple IIe in unopened boxes in the back.  We talked, laughed, and worked for hours.  It was as if a buddy from the UVA/IBM Institute had moved to Southwest.  Instantly we started plotting for Michael.  I showed John how my IBM equipment gave me (and

now "us") telecommunications access through the University of Michigan to other people like us all over the U.S. I used this telecommunications access (Confer) at least twice a week for the next two years. I introduced John to the group over the modem and would ask for information he requested. When he met many of these people later in Minneapolis, they already knew who he was and what our projects were.

First Closing the Gap Conference. Within a year John and I were Southwest County schools' special education technology "experts." We did three two-day inservices (two hours each day) for special educators interested in technology. We even convinced a non-special-education administrator to pay for our attendance at Closing the Gap (CTG), an expensive, international special education technology conference in Minneapolis, Minnesota.

At this conference John met many of my UVA/IBM Institute buddies and became an adopted member. This conference was an important source of motivation and information for us. We met Lake Kissick, an adult with cerebral palsy whose disabilities resembled Michael's. Lake attended and participated in conference discussions using a Prentke Romich Light Talker. After telling him about Michael, we jokingly said, "We wish you'd come to Southwest, Va. and do a workshop for us." To our surprise he responded

that he had a consulting business and would travel to
Southwest if we would pay a workshop fee as well as the
lodging/travel costs for him and his attendant.  Once we
figured out the cost of two airline tickets, and all the
other costs multiplied by two, we didn't discuss this with
him any more.

Our Favorite T-Shirt Message.  We both bought T-Shirts
to wear during workshop presentations.  This was the message
printed on the back: "Our first belief is that disability is
a relational concept.  It does not reside within an
individual.  Our second belief is that electronic technology
can alter environments in such a manner as to allow people
who have various functional deficits to operate without any
disability whatsoever.  John Read, CCD Newsletter, Fall
1988, vI (2)."

The Unicorn Board: Scanning and Direct Access
Issues.  John attended a pre-conference session at CTG on
using the unicorn board.  He was hoping this board would
give Michael direct access to the computer.  The following
brief discussion of  the importance of achieving direct
computer access when possible will hopefully explain some of
the technology issues we were learning about and dealing
with at this time for Michael and all our students.  With
direct computer access, for example, the user chooses the
letter to type from a standard or adapted keyboard. The

method of choosing is usually by hand, with a head stick (an actual stick attached to the head), or with an optical light pointer that directs a beam at the letter to be typed. Switch access is indirect because the user has to access the computer through a visual or spoken scanning method--either direct scanning or automatic scanning.

Scanning Methods Generally and Michael Specifically. Scanning generally requires specially adapted software and is usually a much slower method of access. With direct scanning (for a person with functional vision), the user activates the switch and moves a curser among keyboard choices displayed on the monitor, stopping the cursor at the letter to type. With automatic scanning, the user watches the cursor or pointer move among the keyboard choices displayed on the monitor and chooses the letter to type by activating the switch when the cursor is on the letter to be typed. This automatic scanning is more difficult than direct scanning because of the timing and waiting element added. A user does not hit the switch four times and move the cursor over four spaces. Instead the user waits for the cursor to move, and when it gets to the targeted letter four spaces over, the user activates the switch to choose the letter.

During his assessment using the CMMS, Michael had accessed the scanning board using the direct scanning

method. Each time he hit the switch, the light moved over one more space on the board. At that time all of us, including the PT and OT, thought Michael would never have direct access to technology. His head control was not reliable and his hands could only reliably choose in a gross manner such as hitting a switch with a surface of at least 10 square inches. Reaching over and choosing one particular letter on even an enlarged and adapted keyboard did not seem to be a motor skill that Michael would ever develop, at least that's how I felt in 1985. John's success in giving Michael direct access through the unicorn board is (a) a story of improved positioning of Michael's entire body (b) a story of the adaptability of special boards like the unicorn board and (c) a story of John's ingenuity in building a plexiglass stand that held the unicorn board at the precise angle Michael needed.

Scanning and Communication Issues.

Always the goal is to enable the technology user to have direct access if at all possible. Convenience, speed, and more accessible software are important issues for computer use. Where direct access is even more critical is when the technology is used for communication. Bruce Baker at Prentke Romich has done research indicating that people simply will not wait very long for a device user to respond.

They either give up waiting for the response or else they start answering for the person.

## Other Topics

Below are remarks and further discussions of technology topics not integrated into the preceding chronological narrative.

Change Agent Issues.  I see very clearly now that a single teacher can make a difference in her class and perhaps in her school, but this kind of change that does not get system-wide support has limited effect.  I also see that even change that supposedly gets system-wide support, as John finally got for the computers and technology use at the separate education facility, has limited effect if it's just "a good idea" or "something we have to do" because of legal mandates or parental pressure.

There was no administrator with vision and power who knew how to support the push for technology use in special education.  Without this vision, the administrators think that merely buying the equipment means they are supporting technology.  In the very year they put all the money in computers they refused to supply the teachers time off to attend a conference or get training in how to use the devices purchased.  Also, technology was basically viewed as something the teachers and parents wanted; it was something

that got done or not in the teacher's spare time.  This
bottom-up pressure for change needs top-down leadership and
support if real changes are to occur in students' lives and
teachers' activities.

Being at Closing the Gap and knowing the UVA/IBM group
gave me a sense of the various levels of support technology
was getting in different school systems.  I had the sense
that without the support of John and my telecommunications
group, I would not have been able to accomplish as much as
I'd done without more system support.

> There is a limit at which forbearance
> ceases to be a virtue.
>
> Edmund Burke

> If you want truly to understand
> something, try to change it.
>
> Kurt Lewin

One very important source of system support I had were
my building principals.  This was crucial, not only because
of having one less battle to engage in, but because both
principals at various times supported me against the
responses of those who didn't welcome, for example, my

proving that a non-speaking, non-mobile person was intelligent. The school system had no real placement for such a student. Some administrators worried that parents would start pressing for computers and create budget problems.

Any system change is slow and has resistors, supporters, initial resistors who become supporters, and the whole dramatic cast. What was hardest for me was that technology of the kind I was using was so new that people -- even supporters-- simply didn't have a clue to what its potential was. I often got praised for the wrong thing or had parents thinking the computer would make up for or somehow "cure" their child's learning disability. I was often in the position of speaking for or defending something I wasn't yet sure of myself.

Importance of Telecommunications Access. A doctoral student at UVA studied how we used the Confer system at the University of Michigan. According to her rating we used it 40 % of the time for actual instructions and technology information help and 60% for an emotional, buddy type of cheering each other on with "keep-trying, you-can-do-it" types of messages.

Assessment Issues. There are problems of cuing while using technology--especially scanning methods. One service provider was getting very inaccurate scores. The student

had learned that if he waited, she'd cue him. She didn't realize she was cuing him or waiting longer for another response when she got an inaccurate response

I started using scanning boxes developed on the computer two years after Michael left my class. This takes place of a scanning board for test items like the CMMS.

Positioning Issues. Positioning that was earlier acceptable becomes unacceptable when the student needs to access technology. More precise support and attention is needed. One of John's students came back from a rehab center bouncing in her chair and unable to use the computer. He showed the doctor and had him order a new wheel chair and seat insert. With this support she was able to use the computer. Before the "technology era," poor positioning was perhaps less noticeable because people didn't expect as much from the client. Also, earlier there was less reason to provide support to reach and make choices (such as those needed to access the Unicorn Board) when the person had poor fine motor skills and couldn't hold things.

Positioning is still a problem when the service providers don't have a vision of what is possible or understand the requirements of being able to activate a switch or use a unicorn board. Support from a good PT and OT is crucial.

Technology Breakdowns.  Working on technology projects
sometimes feels like trying to hike through mud in lead
boots.  Every deadline seems to get passed. Four more things
than you'd foreseen need to be done and everything seems to
take three times longer (if not 10 times longer) than
planned.  Then just when you're all ready, the student has
learned how to use the device, and things seem to be
smoothing out, a battery goes dead at a crucial time--just
when the student was to do a presentation to the school
board as part of your PR for more funds.  And so on and so
on and so on.

Then when things seem to be on track again, the student
grows two inches.  Now the switch has to be replaced and you
become part of a process to get a different wheel chair
which will change everything yet again.  Sometimes the
students get so discouraged at the mishaps and breakdowns
that they lose their enthusiasm to keep trying.  At the time
I worked with Michael, I didn't fully realize how patient he
was or how hard it was to discourage him.  He was
disappointed at breakdowns but he seemed to understand the
effort being put into the activity.

The better the technology, the less
aware of it we are.  In fact, we tend to

be most conscious of workplace systems

when they don't work.

C. Begole <u>Working Woman</u>, May 1991, p.47

<u>Downtime and Other Learning Issues</u>. I was very
relieved when Michael started spelling and indicating he
could read. Students with his disabilities often have a
hard time gaining literacy skills. Often you think they know
a lot more than they do. Just as often you think they can't
do something that they eventually can. It's hard to know
what is lack of interest, lack of ability, lack of
functional sight or hearing, or lack of experiences that
other children just pick up with out needing expensive
technology or direct instruction.

Downtime is often a big problem. Downtime is when the
student is waiting for the next event. This usually means
nothing of recreational or instructional value is happening.
Technology adjustments, glitches, and outright breakdowns
cause a lot of downtime. Another student might talk to a
peer, pop rubber bands in the air, or make an unnecessary
trip to the hall. Even though this may be "off task," it is
not downtime as it is with students like Michael. Michael
cannot pop rubber bands, chat casually, or check out a
buddy's science contraption. He must sit waiting while the
teacher scrambles around trying to get the device working
again. While he's waiting there may be nothing of interest

to look at and no way to continue self-instruction
especially if all the lesson content is on a computer that
is down.

Because of the time it takes to get into position to
use devices and because of the space wheel chairs take up,
it's not always easy to arrange other things for the student
to benefit from when downtime occurs unexpectedly.  This may
be why one teacher I know has devised "velcro walls."  On it
she puts objects students can eye gaze for communication,
alphabet letters, enlarged pages from books, game pieces,
posters, and simple technology that can be accessed with
less fuss, e.g., crayon holders with velcro straps or a head
band with a light beam that allows the student to indicate
choices on a chart.  When downtime occurs she reaches for
one of the velcro items to give the student something to do
or a way to communicate in the meantime.

Teacher Relationships to Students with Severe Physical
Disabilities.  My relationship to students with severe
physical disabilities is different.  Initially I was turned
off by being drooled upon.  Even the computer keyboard
needed a membrane cover to keep the drool from getting down
inside.  But after a while the "severeness" of their
disability was not my major focus.  It became a matter of
the disabilities forcing us to go a different path to meet
human needs.

It was only after I left the classroom that I started missing the multisensory contact.  Lifting, holding, wiping, watching eyes for meaning, supporting an arm for stability, retrieving my clutched clothing or hair from hands that could grasp but not release, listening closely to a small repertoire of sounds for meaning--all this created a unique closeness, a unique exhaustion, and often just a total immersion in daily needs issues.  I will never forget the velcro--the ripping and unripping sounds of velcro strapped all over to stabilize feet or shoulders from sagging.  Often the technology devices were covered with velcro to stabilize or position some part more reliably on a chair or holder. Today when I visit classrooms for multihandicapped students, the long, high sound of a thin velcro strip will remind me of one of my students while the more muffled sound of a short, wide velcro strap will remind me of another.

A few special education teachers remarked on my formal, reserved manner at times during instruction.  I think they meant I did not tousle hair, rub noses and proclaim "good job."  Somehow it seemed to me that when students weren't being lifted or having velcro attached to some body part, they'd prefer a more normal way of being related to.  I also felt this was a way of teaching them how people without disabilities related.  Perhaps, I also needed another more separate relationship to them.

For students who also had speech disabilities, unique ways of relating to them were often determined by their methods of communication and degree of discomfort or pain. Sometimes I found myself encouraging them to keep trying when it was physically uncomfortable or painful for them to move. I often asked myself how long should I keep making this request of someone who may be exerting more energy or toleration of discomfort than I can realize.

Often I found myself explaining to them that I didn't know yet what I was doing with this new technology device, but hopefully, if they would keep trying, we could figure out how they could use it to order their own lunch or whatever. Realizing that most students don't have to have another adult send notes home to explain what their school day was like, I developed a regular activity of helping them write diary pages (with and without technology) that were a story of what they had done that day. These pages went back and forth in their wheel chair packs and could function as a vehicle of communication between home and school.

## Appendix B

## Additional Study Questions

1) The history of how Michael became an assistive technology user.

(a) What technology has he used since entering public school?  For what purpose?
(b) What is his current level of expertise?
  --use story of how he wrote "Michael's Song as an example of his interests and expertise
(c) How is he currently using technology in a general education setting.
(d) How does his technology use in a general education class (school) compare or contrast with his technology use in a special education self-contained class (school)?
(e) What are plans for future technology use?

2) The support and decisions that got Michael to his current level of technology expertise.

a) What role did technology play in the assessment of Michael's cognitive abilities?
b) How were decisions made about what devices to use?
c) How was funding for devices obtained?
d) How was curriculum adapted for him?
e) What organizational and related service support did Michael receive (role of principal, OT, PT, SLP paraprofessional)?
  --type of planning (transdisciplinary or whatever)
  --use "Michael's Song" as example of amount of additional help needed to assist Michael with projects
f) How did teachers and related service providers learn to use the technology?  How has technology use affected their roles?

3)  What happened to Michael in this process (socially and academically)?  In the questions below emphasis will be on the influence of technology.  However, more general questions are also needed to round out Michael's story and indicate his current situation in a general education fourth grade class.

a) How is Michael doing now in fourth grade--socially and academically (special emphasis on literacy skills).
b) Has his use of technology influenced peer and adult relationships at school?
   --use "Michael's song as one example of effect of technology on peer relations and source of additional information on people's view of him
c) What was the transition from self-contained special education to general education classes like for him?
d) How does Michael communicate generally? How much is he understood? How does technology influence his communication?
e) What is Michael's view of his current situation in general education, of the process of learning to use technology, of his future?
f) What is his parent's view of his current situation and the process of his learning to use technology?

# Appendix C

## Data Log

INTERVIEWS:

Video Tape # (if number is not given, only an audio tape was
              made)
Place of Interview (second item below person's name)


#13   6/05/91           Michael
                        Student--fourth grade
                        Southwest School              17 pages

#14   6/07/91           Michael
                        Student--fourth grade
                        Southwest School              18 pages

#15   6/10/91           Michael
                        Student--fourth grade
                        Southwest School              14 pages

#16   6/13/91           John
                        Teacher--Multihandicapped
                        Southwest School              36 pages

#17   6/18/91           John
                        Teacher--Multihandicapped
                        Southwest School              33 pages

      7/17/91           Principal
                        Southwest Elementary          18 pages

#18   7/25/91           Marsha
                        Paraprofessional
                        Her home in Salem             34 pages

      7/31/91           Occupational Therapist (OT)
                        Rehabilitation Services       20 pages

#19   8/20/91           Speech/Language Pathologist (SLP)
                        Southwest County School Offices
                                                      29 pages

      8/21/92           Teacher--Third Grade
                        Southwest School              16 pages

#20   8/22/91           Teacher--Fourth Grade
                        Southwest School              16 pages

279

```
#21  8/22/91          Physical Therapist, PT
                      Rehabilitation Services       28 pages

     9/11/91          Mother
                      Ground Round                  42 pages
```

OBSERVATIONS:

April 17, 1991       Southwest School; Michael's fourth grade
                         teacher

April 17, 1991       Southwest School; Michael in OT therapy
                         with occupational therapist (OT)


DOCUMENTS:

Teacher Memoir       Description of Michael in preschool, the
                     first years of his technology usage, and
                     this teacher's memories of first using
                     assistive technology in a public school
                     (63 pages); (See Appendix A)

Conference           Computers and Assessment of Students
Presentation         with Severe Disabilities: (unpublished)
                     Presentation at Closing the Gap
                     Conference, Minneapolis, MN, October 28,
                     1989 (See Appendix E)

School Records
Psychological Assessment on 4-30-85 (age 5-4) by School
     Psychologist

Psychological Assessment on 6-08-87 (age 7-6) by School
     Psychologist

Psychological Assessment on 5-16 23 30-91 (age 11-5) by
     School Psychologist

Educational Evaluation on 4-16-85 (age 5-4) and 6-6-85 (age
     5-6) Preschool Handicapped Teacher at Southwest
     Elementary

Educational Evaluation on 6-4-86 (age 6-6) by
     Multihandicapped teacher at the special education
     facility

Educational Evaluation on 6-03-87 (age 7-6) by John,
     Multihandicapped Teacher at the special education
     facility

Educational Evaluation on 6-13-88 (age 8-6) by John,
     Multihandicapped Teacher at the special education
     facility

Educational Evaluation on 6-13-89 (age 9-6) by John,
     Multihandicapped Teacher at the special education
     facility

Educational Evaluation on 6-06-90 (age 10-6) by John,
     Multihandicapped Teacher at Southwest School

Educational Evaluation on 6-14-91 (age 11-6) by John,
     Multihandicapped Teacher at Southwest Elementary

Speech/Communication Therapy Report on 5-28-86 by
     Speech/Language Pathologist

Speech/Communication Therapy Report on 9-22-86
     Speech/Language Pathologist

Speech/Communication Therapy Report on 5-23-88 by
     Speech/Language Pathologist

Speech/Communication Therapy Report on 4-13-90 by
     Speech/Language Pathologist

Speech/Communication Therapy Report on 6-22-90 by
     Speech/Language Pathologist

Occupational Therapy Report on 1-06-86

Occupational Therapy Report on 6-15-86

Occupational Therapy Report on 10-26-86

Occupational Therapy Report on 6-18-87

Occupational Therapy Report on 5-31-88

Occupational Therapy Report on for 1988-1989

Occupational Therapy Report on 6-14-90

Physical Therapy Report on 5-31-85

Physical Therapy Report on 12-15-85

Physical Therapy Report on  5-21-86

Physical Therapy Report on  10-12-86

Physical Therapy Report on  5-12-87

Physical Therapy Report on  10-26-87

Physical Therapy Report on  6-7-88

Physical Therapy Report on 6-11-89

Physical Therapy Report on  10-3-89

Physical Therapy Report on  2-15-90

Medical Report (Orthopedic Clinic) on 11-14-85 from Bureau
     of Crippled Children

Recreational Therapy Report on 7-24-86 by from Children's
     Rehabilitation Center in Charlottesville


OTHER DATA COLLECTED:

DIARY/ NOTES/REFLECTIONS/ETC. These notes are kept on a
                             daily/weekly basis as needed

POST-INTERVIEW COMMENT SHEETS Information (not shared with
                             the informant) on emotional
                             tone, difficulties, insights,
                             reflections

WEEKLY INFORMAL ON-SITE
VISITS TO SOUTHWEST SCHOOL    Information gathered from
                             these visits are included in
                             written diary/field notes

PHONE CALLS                  Weekly phone calls made to
                             gather additional information
                             or as needed in order to
                             follow up on information
                             provided in interviews

STUDENT WORK                 Samples of Michael's writing

VIDEOS                          9 tapes made during the
                                interviews (see first page of
                                this log) and 12 tapes made
                                during class activities or
                                taping for "Michael's Song
                                (See attached log of "Other
                                Videos")

OTHER VIDEOS

| TAPE # | TITLE | FORMAT | DATE | PERSON TAPING | LOG | LOCATION AND SUBJECT |
|--------|-------|--------|------|---------------|-----|----------------------|
| 1 | Michael's Song | Dubbed to VHS from SVHS | 5/29/90 | Paul Rossi | yes | First day of taping for Michael's Song at Southwest. |
| 2 | Michael's Song | Dubbed to VHS from SVHS | 5/30/90 | Paul Rossi | yes | Second day of taping for Michael's Song at Southwest. |
| 3 | Michael's Song | Dubbed to VHS from SVHS | 5/30/90 | Paul Rossi | yes | Second day of taping for Michael's Song at Southwest. |
| 4 | Michael's Song | Dubbed to VHS from SVHS | 6/1/90 6/7/90 | Bonnie Nelson Paul Rossi | yes | Third day of taping at Southwest and first part of taping at swim party. |
| 5 | Michael's Song | Dubbed to VHS from SVHS | 6/7/90 | Paul Rossi | yes | Last part of taping at swim party. Including Mickey singing (second time) in garage. |
| 6 | Michael | Beta dubbed to VHS | 9/87 to 10/89 | John | yes | Special Education Facility - samples of beginning technology use over 3 years. Taped in SP speed. |

| TAPE # | TITLE | FORMAT | DATE | PERSON TAPING | LOG | LOCATION AND SUBJECT |
|---|---|---|---|---|---|---|
| 7 | Michael | Beta dubbed to VHS | | John | yes | Special Education Facility - samples of beginning technology use over 3 years. Same as #6 but poorer copy. EP speed. |
| 8 | Special Education Facility Classroom 1989 & Ft. Collins Project | Beta dubbed to VHS | 1989 | John | yes | Various scenes including interview of Michael (same as tape #6). |
| 9 | John's '89 Class at Southwest | 8mm dubbed to VHS | 9/89 | John | yes | Southwest: Starts with first day of school, then Halloween, etc. Good scenes of integration. Original is in EP; this copy is SP speed. |
| 10 | Michael's Song Tape of taping at Southwest | VHS | 5/29/90 5/30/90 | Stephanie McLaughlin | yes | Tape of taping for "Michael's Song." |
| 11 | Southwest inservice "Invaders" | 8mm dubbed to VHS | 9/89 to 3/90 | John | yes | Tape John put together for inservice called "INVADERS" (mostly taken from tape #9). Original is in EP speed. This copy is SP speed. |

285

| TAPE # | TITLE | FORMAT | DATE | PERSON TAPING | LOG | LOCATION AND SUBJECT |
|---|---|---|---|---|---|---|
| 12 | Michael's Song: in progress | Dubbed to VHS from SVHS | 8/8/90 | Paul Rossi | yes | First tape to plan for eventual tape at LRC. This is too quick in parts. No dissolves. |
| 13 | Interview of Michael | VHS | 6/5/91 | Bonnie Nelson | yes | Southwest. Michael answers questions about technology and attending regular ed. |
| 14 | Interview of Michael | VHS | 6/7/91 | Bonnie Nelson | yes | Southwest. Michael answers questions about technology and attending regular ed. |
| 15 | Interview of Michael | VHS | 6/10/91 | Bonnie Nelson | yes | Southwest. Michael answers questions about technology and attending regular ed. |
| 16 | Interview of John | VHS | 6/12/91 | Bonnie Nelson | yes | Southwest. John answers questions about Michael's technology use. |

## Appendix D

### Forms Used

INTERVIEW FACESHEET

Person interviewed:

Occupation/position:

Date of interview:

Interview number
(if in a series):

Place of interview:

Sex:

Age (estimate):

Education/work experience:

--no. of years in Southwest Co.
--no. of years working with Michael

Interviewer:  Bonnie Nelson

Method of data collection:

Date of data transcription:

## POST INTERVIEW COMMENT SHEET

Person interviewed: _____

Date interviewed: _____ Video Tape #: _____

Today's date: _____ Location: _____

Comments:
"This is not material that is shared with the informant....
[note] emotional tone, any particular difficulties
(methodological or personal) that were encountered, your own
feelings during and about the experience, insights and
reflections... The jotted notes on such sheets are later
incorporated into the interview write-up and become a
portion of the data log"  (Lofland & Lofland, 1984, p. 58)

# OBSERVATION FACESHEET

**Person/event**
**observed:**


**Date:**


**Observation number**
**(if in a series):**


**Place of observation:**


**Time (from - to):**


**Name and title of people <u>interviewed</u>**


**Observer:**

**Method of data collection:**

**Date of data transcription:**

# POST OBSERVATION COMMENT SHEET

**Person observed:**

**Date observed:**

**Today's date:**

**Comments:**

# DOCUMENT SUMMARY FORM

Site:

Document #:

Date Received:

Name or description of document:




Event or contact, if any, with which document is associated:




Brief summary of contents:

# DATA ACCOUNTING SHEET

\# _____

OBSERVATIONS:

INTERVIEWS:

DOCUMENTS:

OTHER DATA COLLECTED:
DIARY/NOTES/REFLECTIONS/ETC.

CONSENT FORM
SERVICE PROVIDERS AND SCHOOL PERSONNEL


This is to certify that I (please print), _____,
title _____ have read and understand the
procedures outlined below and give permission for this
interview to be included in this study.  I understand that
Michael will be the /focus of a research study being
conducted by Bonnie Nelson, Doctoral Candidate and
Technology Specialist at the SPH Technical Assistance Center
in the College of Education at Virginia Polytechnic
Institute and State University.  I understand that Michael's
mother, has given permission for me to provide information
about Michael for this research and video.

This research will use qualitative methods to examine
Michael's use of technology: the history and effect of his
technology use, the issues involved, as well as the support
required of others.
The procedures to be followed are:
> 1) Video tape (or audio tape) and interview
> Michael, Michael's family, teachers, therapy
> providers, and others who are influential in
> Michael's life.
>
> 2) Analyze and describe information obtained from
> tapes, records, observations, and interviews.
> Present information in written study which will
> fulfill partial requirements for an Ed.D degree in
> Education.
>
> 3) In addition to the written research study, a
> video may eventually be made and may include
> portions of this interview.  The video may be
> shown for general educational purposes to
> illustrate the uses of technology in special
> education.

If you have questions about any aspect of this study, please
contact Dr. Bonnie Billingsley at (703) 231-9715.

Your participation is voluntary and you are free to withdraw
consent at any time for any reason.  Attached is a copy of
this permission form for you to keep.


_____        _____
        date                             Signature

CONSENT FORM (MOTHER OF Michael)


This is to certify that I, _____,
mother of Michael, have read and understand the procedures
outlined below. I give permission for Michael to be the
focus of a research study being conducted by Bonnie Nelson,
Doctoral Candidate and Technology Specialist at the SPH
Technical Assistance Center in the College of Education at
Virginia Polytechnic Institute and State University.

This research will use qualitative methods to examine
Michael's use of technology: the history and effect of his
technology use, the issues involved, as well as the support
required of others.
The procedures to be followed are:
     1) Video tape (or audio tape) and interview
     Michael, Michael's family, teachers, therapy
     providers, and others who are influential in
     Michael's life.

     2) Analyze and describe information obtained from
     tapes, records, observations, and interviews.
     Present information in written study which will
     fulfill partial requirements for an Ed.D degree in
     Education.

     3) In addition to the written research study, a
     video may eventually be made and may include
     portions of this interview.  The video may be
     shown for general educational purposes to
     illustrate the uses of technology in special
     education.

If you have questions about any aspect of this study, please
contact Dr. Bonnie Billingsley at (703) 231-9715.

Your participation is voluntary and you are free to withdraw
consent at any time for any reason.  Attached is a copy of
this permission form for you to keep.


_____
   date

## Appendix E

### Conference Presentation by Bonnie Nelson

Part of presentation, "A Sleuth a Work: Computer Adapted Assessment Environments," by Chris, John, and Bonnie Nelson at Closing the Gap, 1989 Conference on Microcomputer Technology in Special Education and Rehabilitation, Minneapolis, MN, October 28,1989.

### Computers and Assessment of Students with Severe Disabilities

I work in southwest Virginia and currently go into small and medium sized school systems (as well as residential facilities) that do not have many students with cerebral palsy or orthopedic impairments. There is often pressure in these systems to obtain a formal testing score or similar "proof" of cognitive level before considering placing a student with severe physical disabilities with students whose cognitive level is considered normal. As a teacher I have been caught in this predicament of wondering how to show a score that means anything for students who don't speak and have little or no hand control. I think when we are caught in these circumstances, we should try to educate the people asking for such scores.

Generally with these more severely involved students we need to view assessment as an ongoing process by a multi-disciplinary team--not a one shot attempt producing THE SCORE. In a sense all adaptive testing of these students is informal. Certainly comparisons with non-physically disabled students are risky. Some of my early, misguided

attempts to get formal scores led to inventions--such as computer scanning boxes--that later became an important tool in my instruction of these students.

I will share with you a few of my attempts to get more "formal" assessments as long as you understand the limitations I am placing on this term.  In many instances these kinds of assessment adaptations are only appropriate for people who are not severely cognitively impaired.

Earlier when I was caught in the predicament of having to produce a score, I actually cut up "Peabody Picture Vocabulary Test-Revised (PPVT-R)" pictures and put them on a switch controlled communication board to see what kind of score I could get. The "PPVT-R" is an individually administered, untimed test of receptive language.  The student is asked to indicate (pointing or however) which of four pictures matches the word read aloud by an examiner. As you probably know the "PPVT-R" is not intended to be used as a major test of cognitive level function.  Anyway, none of my students (even the higher functioning ones) ever did well on the "PPVT."

Later I used switch-controlled scanning boxes on the computer as one method of assessment.  This method I call the cut-and-tape monitor-method.  Test items/pictures are cut and scotch taped on the monitor.  The student is asked, for example, "Show me the circle."  As (s)he hits the

switch, a box around each picture choice is in turn lighted. The box that remains lighted is the student's choice. Prentke Romich's Light Talker can also be accessed by switch and lights in this way.



COMPUTER MONITOR WITH TEST ITEMS
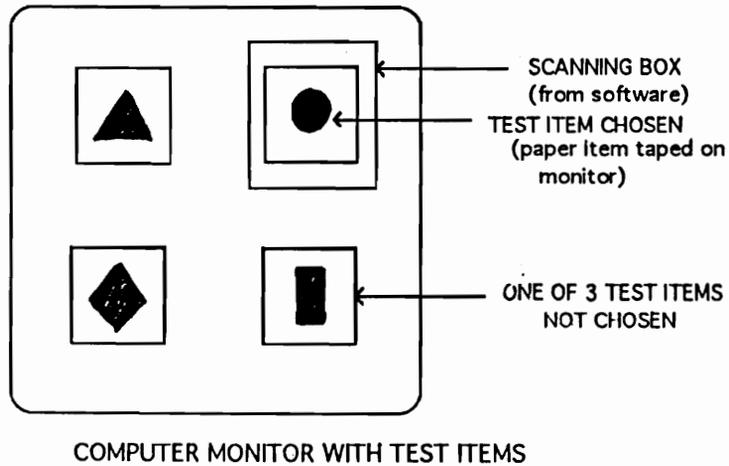
Figure 1.  Computer Monitor with Test Items

I once used the cut-and-tape system with the <u>Columbia Mental Maturities Scale</u> to assess a high functioning student with cerebral palsy.  This scale is a nonverbal measure producing maturity and mental age scores.  The psychologist asked the questions.  While he marked the answers, I took down the paper pictures taped on the monitor.  We both taped up the pictures for the next question.  I have also helped

speech teachers administer the TACL ("Test for Auditory comprehension of Language") using this method.  The TACL, similar to the PPVT-R in administration, assesses auditory comprehension and helps to identify people with receptive language disorders.

This cut-and-paste switch control method of assessment could probably be adapted to any test or instruction where the answer choices can be indicated by pointing or by eye gaze (as with the French Pictorial Test of Intelligence). FOR ME THESE BOXES BECAME MUCH MORE USEFUL AS AN INSTRUCTIONAL TOOL--especially with students who have difficulty indicating choices.  My original scanning boxes were written in LOGO.  Recently I discovered a public domain version, "Step by Step," that can be used in the same way.

I my efforts to assess higher functioning but severely physically involved students, I keep searching the literature for suggestions.  One book that I have found helpful is "Test Adaptations for the Handicapped" by Wasson, Tynan, and Gardiner.

Another assessment tactic that I use to gather information which I integrate into reports is to look at switch software that the student already uses and first assign a ball park cognitive level to the achievement.  For example, "Davy's Digits" from the Apple disk, Motor Training Games, is generally a five and six year old skill.  Same and

different distinctions are generally an earlier cognitive skill for able bodied students. Next I observe how and what my students do with the switch software to learn about their interests, abilities, attention to task, etc.

In one version of "Davy's Digits," for example, a number comes on the screen and the student is asked to activate the switch that number of times. Watching one of my students use this software showed me for the first time that he grasped the concept of one-to-one correspondence. I also began to suspect that this student was a strong visual learner. Over time I have learned a about that student's interest, concept formation, and attention to task from observing his use of the activities on <u>Motor Training Games</u> (public domain) and similar software. For a list of such public domain programs for Apple and IBM, contact Colorado Easter Seals, 5755 W. Alameda, Lakewood, CO 80226.

I think the kind of demand for "scores" that I have been describing is more likely to occur when the student is younger and at a point where special education eligibility committees are making decisions on placement. Once the student is older and has been around awhile, the emphasis--especially for multihandicapped students--should be on functional and vocational assessment and instruction. There are good books by Paul Wehman and others on how to

conduct this kind of assessment which is multi-disciplinary and often uses checklists.

In conclusion I would like to briefly mention one other method of assessment which I think we could integrate at any stage of a student's life. This assessment method might be called the video case study. With videotape and case study tools we can provide both quantitative and qualitative data to support assessment conclusions on a student. The tape would also be helpful when a student changes schools or goes to a teacher who is not familiar with how that student uses adaptive equipment.

**Appendix F**

<u>Interview Questions for Special Education Teacher</u>

<u>General Approach</u>

Gather information on John's technology background, history
of Michael's technology use, on issues of funding, on how
decisions of which technology to use and how were made, on
technology IEP goals, on his view of Michael's future, on
contrasts of working in regular and special ed school
environments, on the types of support most helpful, on what
else is needed for Michael, on how Michael has used the
technology and what interactions have been made possible for
him through the use of technology.  Basically John is a
source for all questions on all topics.  Because he is very
verbal and very opinionated, and often goes off on
tangential explanations, I mainly need a few questions to
get him started.  Since I am interviewing him more than
once, it is important that between each interview I analyze
the transcripts for questions not covered or areas I didn't
probe far enough.  As I listen to him answer I am going to
be less concerned to mentally check off the topic he is
covering than I will be to try to hear what he is saying
from a learner's perspective to see if I need to ask him to
simplify or explain in further detail.  It would be easy for
him to fall into a Bonnie-John chat and the level of the

301

answers would not be detailed enough for non assistive

technology people.


Background information to check out.
--How long a teacher--a special ed teacher---in Southwest
County
--What classes (types of students) have you taught most
-- Medical description of Michael's condition.
-- description of related services he receives?
-- How many years did you teach at the special education
facility--a self-contained special education facility?
--How many years was Michael in your class at the special
education facility?
--Michael's date of birth


Questions about Michael at the separate special education
facility
1) When you first met Michael, what was your background or
experience in using technology with students like him?  How
have you gained your expertise in assistive technology?
2)  Please describe your first experiences using technology
with Michael?
3)  How would you describe the progression of his technology
use
--from the first device on?
--at what point was he able to use word processing
--first sentence Michael wrote
--Direct access issue:  Did you ever consider that he would
have to use scanning and not be able to directly access the
unicorn board?
--what technology other than the Apple computer did he use
at the special education facility?
4) How did you first assess his cognitive abilities?
5)  Curriculum issues
--what program or curriculum did he first use when learning
to read
--what adaptations did you make.
6)  How were decisions made regarding which technology he
would use?  How was it funded?
7) Positioning
-- Please describe the work you did to get Michael
positioned properly in his wheel chair.
--What effects did the positioning have on his use of
technology (the unicorn board in particular)
8) Related Service Providers
-- What is your relation to related service providers in
planning technology for Michael?
     --PT

302

```
        --OT
        --SLP
        --OTHER agencies: K-CRC, etc.
--Is your relationship with the same service provider
different when the student is a technology user?  (Is this
more general question not limited only to Michael OK to
ask?)
9) When did Michael get his powered chair?  Describe how he
learned to use it and the effect that had on his life.
10) What administrative support did you get from the school
and special education administrators while helping Michael
become a technology user.
--CTG funds
--Computer
```

Questions about Michael at Southwest Elementary school--a
general education facility

```
11)  What is Michael's day like at Southwest now? (Split
between special and general education).
--At what times does he use technology?
12)  What technology does he use?
13)  How much is technology used in every day interactions
as compared with instructional tasks?
14) Other technology questions/issues to be covered
--problems of others understanding the speech synthesizer
--do you write technology goals in his IEP?
15)  What training and school support for technology use is
required in this environment?
--How do the support needs differ in this general education
environment as compared to the self-contained class in the
special education facility?
16)  How do you assess his ability or acquired skills now?
--I saw him spelling from cards Karen Cromley gave his and
from memory, "I am 11 years old."  At what level is his
independent language writing/composing abilities?
--I think once you mentioned that he may not be grade level
in comprehension skills?
        --How are his comprehension skills now?
        --What is he doing to develop these skills?
17)  Tell me about his song and how he wrote it.
How has writing Michael's song affected his life, his
relationship with peers.
18) Relationships in School
        --How would you describe Michael's relationships with
            his peers, (their influence on him and his
            influence on them)?
        --How would you describe his relationships with adults?
        other:
        --touch talker communication; how will or does it
            affect social relationships
```

19) Michael's Future
    --Think about Michael three or four years from now.
        What technology might he be using?  Will the
        function of technology be similar to what it is in
        his life now? (Please explain)
    Other
    --Any new device or equipment you're plotting to get.
20) Is there anything else you'd like to tell me about
Michael or his use of technology?

## Appendix G

### Michael: A Brief Chronology

1979        December, Born with cerebral palsy

1982-83     In preschool handicapped class in public school
            (2-3 years old).

1983-84     In preschool handicapped class next to my
            classroom (3-4 years old).
                 This was the year I first met Michael.

1984-85     In my preschool handicapped class (4-5 years old).
                 Technology used were switches, scanning
                 board, and unadapted efforts to use the
                 computer.  This is explained in detail in
                 Appendix A.

1985-86     At Special Education Facility, Kindergarten Year
            in Trainable Mentally Handicapped (TMH) Class (5-6
            years old).

1986-87     At Special Education Facility, John's TMH Class
            (6-7 years old).
                 He's beginning to copy words from the black
                 board onto his computer through the Unicorn
                 Board. Obtained his first motorized wheel
                 chair.

1987-88     At Special Education Facility, Multihandicapped
            Class (7-8 years old).
                 He's using the Unicorn Board and beginning
                 word processing.  Started using Light Talker
                 for augmentative communication.

1988-89     At Special Education Facility,  Multihandicapped
            Class  (8-9 years old).
                 Michael's speech is becoming more
                 understandable to people who are around him a
                 lot.

1989-90     At Southwest School, John's Multihandicapped Class
            until January.  After January Michael is in third
            grade after lunch for language arts (9-10 years
            old).
                 Michael wrote a song in February and
                 presented the song at The Very Special Arts
                 Festival in April.  In June I taped him in
                 his third grade and his multihandicapped

class for a video story of "Michael's Song."
He used adapted camcorder to tape some school
scenes.

1990-91    At Southwest School, full time in fourth grade
Classroom  (10-11 years old).
First formal observation for this study began
in April.

1991-92    At Southwest School, full time in fifth grade
classroom (11-12 years old).
This study does not include this year.

## Appendix H

### A Chronological listing of Technology Michael Has Used

From his first technology use in preschool through his teacher's plans for future purchases, all technology devices discussed in this study are listed below in the order in which Michael used them. The computer used in preschool was my personal computer. Computers, printers, switches and adaptive computer keyboards boards used after preschool were purchased by the schools. The Touch Talker, portable printer, and power chair were obtained from the funding efforts of his special education teacher who worked closely with many local community organizations and the Children's Miracle Network at the Kluge Children's Rehabilitation Center in Charlottesville. Technology listed below is described in text or in Appendix A. See the last section of this appendix for special adaptations made.

### Initial Use in Preschool

1. Wobble switch, plate switch, and assorted hand operated pressure switches to operate toys and devices (2-5 years old).

2. Scanning box made in preschool; he pressed switch and light indicated his choice (5 years old).

3.  Apple Plus computer with keyboard adapted with a flat bristle block attached on top of open apple key to operate switch software (5 years old).

4.  Atari Joy Stick at home to operate Atari video games (5-8 years old).

## First Use at Special Education Facility

1.  Apple IIe computer with Echo (Street) speech synthesizer and internal Adaptive Firmware Card with external plug for switches and the Unicorn Board (6-11 years old).

2.  Wobble switch with public domain switch software (simple graphics, games, shape recognition and cause and effect software) accessed through the Adaptive Firmware Card (6 years old).

3.  Powerpad and software designed for Powerpad (6 years old).

4.  Power wheelchair (Everst-Jennings Marathon Motorized Frame) (7-11 years old).

5.  Unicorn Board (Adaptive Firmware Card) with keyguard.  Initially this board was divided into 32 sections and later into 64 sections.  (7-11 years old).

6.  Touch Talker (Prentke Romich) with keyguard (8-10 years old).

1.  Power Chair (Everst-Jennings Marathon Motorized Frame) with custom molded seating system.

2.  Unicorn Board (keyguard over the board divided into 64 sections) plugged into the Adaptive Firmware Card. Software most often used with this board is Dr. Peet's Talk/Writer (Hartley), a talking word processing with large size text on screen and printouts.  He uses Comic Book Maker (Pelican) for special occasions only because graphics printouts are VERY slow.

3.  Touch Talker (Prentke Romich) with Smooth Talker speech upgraded from earlier Echo speech used at the special education facility) with a purchased keyguard and a Diconix portable printer mounted on back of wheel chair.  Handpointer needed to choose letters. Use not well integrated into the day because of repair problems and broken collar which was added to support hand when choosing letters in the bottom section of the keyboard. Has used in classroom with  headphones, then later with one earphone.

4.  Unadapted Apple IIgs in school's computer lab. For certain software programs he can manage to hit the space bar.  Typed input is done by a paraprofessional. He does this to be with his class when they attend

computer lab where there are no computers with adapted access.

     5.  Switch 100 (Ablenet) on the Universal Mount (Ablenet) was used as a head switch for on/off operation of a camcorder mounted on his wheel chair tray with a second Universal Mount (Ablenet).

     6.  A small battery operated TV--connected to the camcorder on his wheel chair tray--enabled him to see what he was video taping.


Future Plans

Unless otherwise noted these are items that his special education teacher is considering for Michael to use next.

     1.  Page turner.

     2.  Apple IIgs with Adaptive Firmware Card and Echo speech synthesizer on a portable computer table for him to use in the regular education classroom  with an earphone in one ear.  Earlier headphone use in the regular classroom was discontinued because he couldn't hear the teacher with them on.  Without them the speech synthesizer disturbed the class.  Solution seemed to be an earphone in one ear.

     3.  Assessment for voice entry with Dragon Dictate (Dragon Systems) to see if his speech has enough sound

distinctions for him to be able to use his voice as a method of inputting information into the computer.

4. A speaker phone at home is not on the purchase list but has been mentioned as a need so he can have more independent phone conversations with peers.

## Adaptations for Electronic Technology

Some of the technology listed above required further adjustments and adaptations for Michael to be able to use. The following is a list of adaptations made by his teachers and service providers. The only items they did not personally make are the railings for the wheel chair ramp which were initially made for Michael because he was the first student in the school to use a power (motorized) chair.

1. Hand pointer made by OT from poly plast (used with Touch Talker and Unicorn Board).

2. Plexiglass collar to support palm on bottom part of the Touch Talker made first by OT and later his teacher.

3. Shelf behind wheel chair, made by his teacher, to hold Diconix printer for Touch Talker.

3. Keyguard (made of plexiglass) for the Unicorn Board, made by his teacher.

311

4.    Slowing or speeding up the scanning rate of switch accessed software; accomplished by programming the Adaptive Firmware Card.

5.    Railings added to wheel chair ramps when he got his motorized chair.

6.    Expand-a-stand, made by his teacher, to hold Unicorn board on wheel chair tray (designed specifically for use with person with cerebral palsy with severe athetosis).

**Appendix I**

<u>Skills Acquisition and Literacy Issues</u>

Information in this section explores (a) literacy acquisition issues for people with severe speech and physical impairments, (b) literacy instruction given Michael in school, (c) Michael's skills acquisition in other areas, (d) how Michael's circumstances reflect or don't reflect current research findings on literacy acquisition.

**Literacy Acquisition Issues**

Since collecting data for this study, I have become aware of recent research on how people like Michael gain literacy or, more typically, have difficulty attaining literacy. Most recent research on literacy acquisition and people with severe speech and physical impairments views literacy as a "constructive," "interactive" process that begins in infancy and "develops throughout life" (Coleman, Koppenhaver, & Yoder, in press; Koppenhaver, Coleman, Steelman, & Yoder, in press; Koppenhaver, Evans, and Yoder, 1991; van Kleeck, 1990). In this view "there is no early childhood phase whose conclusion is marked by readiness for conventional literacy."

Literacy is used as an umbrella term referring to both the ability to read and the ability to write. Reading, unless it is otherwise

313

indicated, refers to constructing meaning from
written texts. Writing refers to constructing
meaning in written texts. Both reading and
writing, then, are constructive processes.

Both are also interactive processes. Literacy depends
on a well-orchestrated integration of subskills (e.g.,
spelling, word identification), personal background
knowledge, comprehension or composition strategies, clearly-
understood purposes (whether self-imposed, or provided by
others), and the context in which these are integrated.

Michael, like many students with severe speech and
physical impairments, might never have been ready for
literacy instruction from a "reading readiness" perspective.
In this view biological maturation and "prerequisite
knowledge and skills" are emphasized:

In school-based reading readiness programs, young
children are taught the subskills thought to
underlie the achievement of conventional literacy:
letter names; colors; visual and auditory
discrimination of letters, words, sounds within
words, left-to-right sequencing; and so on. These
activities are typically designated as prereading
and taught to every child in mainstream classes
before reading instruction is introduced. These
readiness skills are often taught to mastery in

314

special education classes and, consequently, many children with severe impairments never experience actual reading and writing because they cannot master the prerequisite skills.

(Koppenhaver, Coleman, Kalman, Yoder, 1991, p. 39)

Until recent developments in the miniaturization of computer technology, people who are unable to speak, write, or sign had no access to communication except in very adapted or limited ways such as eye gaze or otherwise indicating symbol choices from a communication board. Even with access to technology, however, the ability to read or write at a sophisticated level is often crucial for the simplest communication. "Literacy skills unlock the doors to independent communication and offer access to more complete, comprehensible, and self-initiated interactions" (Koppenhaver, Evans, & Yoder, 1991, p. 20). The dilemma for people with severe disabilities is that while their need for literacy can be crucial for the simplest functioning, they often "experience literacy in quantitatively and qualitatively different ways than their nondisabled peers; that is, their activities do not support the emergence of literacy" (Koppenhaver, Coleman, Kalman, & Yoder, 1991, p. 40).

Michael's circumstances illustrate this dilemma. Unlike the average two year old who can say, "See dog,"

Michael at age two could not even reliably point at a large dog.  He was eight years old before he gained enough literacy skills to be able to communicate "See dog" by typing words like this on an adapted computer keyboard. Even this communication could not occur in the context of actually seeing a dog since he had to be strapped into an expensive chair and use the non-mobile computer in his classroom at whatever times nearby technology trained adults decided to position him properly and turn on the computer. If the technology trained adults were absent that day, or the computer was malfunctioning, he would not have even this limited access to these types of literacy activities.

During storytime at school or book reading at home, he could not see the picture of a dog unless the reader made a special effort to position the page in front of his face. Even so he might not be able to see the word "dog" because involuntary head movements or poor positioning can make focusing his eyes on printed words difficult.  For similar reasons, he might not have the opportunity or physical position to pay attention to a hand written grocery list or store sign containing the words "Dog Food."  Not until age seven did he even gain access to a device that would allow him to put the letter "d" on paper.

## Literacy Instruction in School

According to Michael's mother she has never read much to Michael.  He started reading, she says, "with word cards in preschool."   By "word cards" she is referring to environmental labels put on things in the room, a milk carton brought back to the class for a discussion of words printed on it, or a birthday card on which the teacher wrote the student's words.  Since I was Michael's teacher his last year in preschool and used a lot of cards in this way, I was surprised that she considered him to be reading these cards.  At the time I was not aware that he could read any printed word.  I did hold up books and cards for all to see.

According to her, he could read the four or five cards he brought home each week in his wheelchair back pack.  The cards brought home were usually from labels made for show and tell items as well as various art and language activities where the children glued or drew something that I then labeled for them using a word or short phrase like " a horse" or "the horse jumps up and up"--words dictated by the children.  At this stage in his life, Michael's mother was one of the few people who could understand his vocalizations.  I understood very little that he vocalized and had to use his eye gaze and a few sounds that he could make to guess at what he wanted on his word cards.

In general though, all of his preschool years as well as his kindergarten year were language rich environments. In every classroom there were lots of books read, songs dramatized, environmental labels read at eye level, games and plays that encouraged acting out the meaning of words, and teachers who responded in ways that encourage children to expand their vocabularies and explore language as a meaningful enjoyable activity. All of his teachers adapted activities and items like crayon holders so that Michael could take part. (See Appendix A and K for a more indepth discussion of adaptations made for Michael in his last year of preschool.)

More formal, direct instruction in reading and writing started in the same year when he was seven years old, the year in which John became his teacher, the year he started using a computer. The paraprofessional who worked with him that year remembers that he began by "typing words" and later progressed to reading books.

> He started typing words, small words, into the
> computer, names of people--things that pretty much
> he dealt with on a day to day basis. How to spell
> "mom," how to spell this. . . .and they had some
> beginning readers that Michael went through when
> he would work at home and of course using the most
> often used word list, learning to spell them,

learning the sounds of every letter.  I guess
that's where it all began.  Then he just
progressed to more and more difficult types of
reading materials.  We would read to him a page
pointing out every word.  Then we would have him
read it to us.

Both John and the paraprofessional who worked closely
with Michael remember that he was interested in spelling
from the beginning and worked hard at spelling functional
words he wanted to use.  All this was very slow at first
because of the time it took John to get him positioned
properly.  With a keyguard and a special holder for the
unicorn keyboard, he could initially word process on a board
at three or four short words per minute.  According to John,
at this time "word processing [was] primarily what we did
with him."

> The first thing he wanted to do was to write love
> letters to his girl friends.  He started
> correspondence with a number of his girl friends
> and people he had met along the way and he wrote
> nice letters to his mother.  Then we got him to
> write a letter of introduction to himself, to a
> total stranger, that he could pull out if they
> couldn't understand his speech.  Oh, we did a
> bunch of things.  It just grew from there.

John recalls that Michael's initial interest and energy was for writing.

He started off writing letters and in writing letters, he found out he had to learn how to spell some words so he started working on his spelling and when he got a little more sophisticated, we got to be a little stricter about his grammar and he had to learn to punctuate his sentences. We got a little more sophisticated on that, it was like doing it as he needed it. That was very highly motivating for him. He wasn't learning something and not realizing why he was learning it. He realized that he needed to learn it, so he learned very quickly.

Below is one of the letters he wrote home at a time when he still needed a lot of help with his spelling. After determining what he wanted to write, John or the paraprofessional would put the words on the board over the computer.

Dear Mom,

Thank you for all the things you do for me. You feed me, you wash me, you dress me. You love me. I love you.

Michael

320

Another time he wrote, "Dear Mom, I like the way you smell." After typing these letters into the computer, he would print them out. Regularly letters went out from school to home in his back pack. John recalls that when Michael's mother first started getting these letter this "had to be a thrill for her; it was a thrill for us."

The next step as John describes it was using a Holt-Rinehart reading program "because that was the one that was being used at the time in elementary schools in the county."

> We had some difficulty with that because I didn't
> have the experience with Holt . . . didn't have
> the time to really follow his program too closely.
> It was primarily being done by one of the
> paraprofessionals. It wasn't carried through in a
> manner in which it would have been if he had been
> in a regular classroom. It would have been a
> little bit more organized. But he was still
> learning.

After this John and Michael moved from the special education facility to a multihandicapped class in a general elementary school. "In one year, he went through two years, two reading levels of the Holt Rinehart program which got him to the third grade level," says John.

> He missed a lot of peripheral type work that he
> would have gotten in the classroom. What he was

doing was going straight through a reading book
and the reading workbook and he didn't get any of
the added exercises that kind of embellish the
program and make it more understandable.  But we
were just trying to get him through as fast as we
could and if we ran into an area where he was
really having trouble, then we would try extra
activities to catch him up or go a little bit
slower.

For examples of his writing in this year at 10 years
old, see the earlier discussion in Chapter III of how he
wrote "Michael's Song."  Below is a note he wrote
independently without spelling help or words to copy.

I want to go home.  I am sick.  Harry up Lorelei.

Come on now Lorelei.  I hope she called her

work....becouse she might get fired. vxp

"Harry" is a typo for "hurry."  "Becouse" is a misspelling
of "because."  Lorelei is his sister who is driving to pick
him up from school early because he is sick.  "Vxp" are most
likely letters he hit by accident and didn't bother to
delete before printing out the note.

The software Michael used for these samples is Dr.
Peet's Talkwriter (Hartley).  This simple word processing
program displays and prints in forty columns and talks by
letter, word and sentence using the Echo speech synthesizer

for Apple II computers. After using a lot of different software, John declares that Dr. Peet is his favorite software and is generally the best way to start students word processing. Occasionally for special occasions he uses Comic Book Maker (Pelican) which integrates word processing and graphics. Comic Book Maker, however, is not good for general use because the graphics print out "too slowly."

The above writing samples, as well as, "Michael's Song" were written in third grade--the first year Michael was in the general education facility and are the last writing samples John has. A stack of longer writing samples that were to be given me were misplaced in a move. According to John and the occupational therapist (OT) who worked with Michael on some of these longer assignments, he has difficulty writing on an assigned topic. Syntax and grouping of sentences by paragraph are difficult for him. The OT was surprised at how much cuing he needed.

I said well don't you want to thank the man and how would you go about saying that. And he would help me out with a couple of words. Then he got stuck and he would need a couple of more cues to keep on going. Of course he didn't have any idea about the body of a letter and your closing and everything so I had to help him with that part too.

According to the OT "he can tell you what he likes about a person, but it's real difficult [for him] to put it down. . . . Even to think of the words that comprise a sentence, it's hard for him." She speculates that part of his difficulty with the structure of a written sentence is that "he's writing like he's talking" and is not used to the more formal structure requirements of writing. "You know, when we speak we don't have to use big sentences and worry about the subject and verb and proper tense and everything."

In fourth grade he ceased word processing and instead began dictating to a paraprofessional who writes what he says on paper or blackboard. Classroom assignments generally require that he dictate one or two paragraphs a week. The remainder of his answers are a sentence or, more likely, a short phrase to indicate what goes into a worksheet. When questioned about giving up technology use, Michael says the problem is "how slow I am," meaning he cannot use his assistive technology to word process fast enough to keep up with assignments required in fourth grade.

During fourth grade his scores on the Iowa Test of Basic Skills were in the 40th to 60th percentile except for his comprehension skills which were in the 30th percentile. (Math was his highest score.) At the request of his general education teacher, the speech-language pathologist started working on comprehension. She would have him read a

paragraph or two and then answer her questions about it.
She discovered that if she read the paragraph to him or if
he vocalized as he read aloud, he could answer almost all
her content or meaning questions accurately.  If he read to
himself silently, however, he had much more difficulty
answering her questions.  It's not clear to her why
vocalizing assists his comprehension.  The general education
teacher thinks it's possible that during silent reading, he
"was pretending he was reading and he wasn't actually doing
it."  There are times she catches him supposedly "finished
before anyone was finished and I would say, Michael there's
no way."

The paraprofessional is surprised that he has such
noticeable difficulties with comprehension.  Her view is
that "he can comprehend pretty much what he wants to if it's
of interest."

> Something that's really interesting like a Sports
> Illustrated magazine that he pretty often would
> get from the library, he could tell you word for
> word what some of that stuff there is saying.  So
> I really don't think comprehension is something
> that's going to be a real problem for him in the
> future providing he doesn't let it become a
> problem.  He can comprehend pretty much what he
> wants to when it's of interest.

His mother is not surprised at his comprehension difficulties. She says it's because he always has to rush through assignments and can't go at the pace he needs. The speech-language pathologist and general education teacher think his reading comprehension is made worse because his mother reads homework assignments to him instead of allowing him to read to himself. (The tension between the mother and the school over the amount of homework required is discussed in more detail in the following section on "The First Fully Integrated Year.")

John thinks the biggest difficulty is lack of access to recreational reading. For Christmas John made Michael a stand that holds a book open at an angle. This, however, still requires someone else to turn every page. Automatic page turners are very expensive, says John, but he keeps thinking about how to get Michael one because "I so badly want him into recreational reading." John's view is reflected in the speech-language pathologist's assertion that "lack of exposure" not "deficits" may be the main problem.

Michael still works on spelling even though he's not writing. When necessary, he spells words to help the listener discover his meaning. For example, "'W' 'H' 'A' 'T' good is a piece of paper," he asks at one point in a discussion. John says they started the auditory spelling

because at seven years old "sometimes by just giving us the beginning letter we could decipher what he was saying." It was motivating and helped him see the need to read. "As it began to work for him his rate of learning literacy skills increased rapidly."

Now, however, his vocabulary has increased and because of that his speech is sometimes more difficult to understand. Currently the spelling is more helpful than usual to figure out his meaning.

> The range of subject matter in his speech is much more than it used to be. At one time, when we were translating for him, it was very easy to translate because what he would say was predictable. That's very typical with a child with a severe language disorder. They say what they know people will understand because it's very frustrating to try to communicate and not be understood. So they fall back on what they know will be understood. It limits them a great deal in what they can do and how much they can control their environment.

## Other Academic Subjects

Michael's math instruction was initially from some math software John purchased from Marblesoft. Michael remembers

this as a negative experience because "it was too fast." He
did not realize that the wait time for an answer to an
addition or subtraction problem could be adjusted. Instead
of indicating that he needed more time, he tried, often
unsuccessfully, to keep up with the computer's request for
an answer that he could not type in fast enough. By the
time John and the paraprofessional realized what the problem
was, Michael hated the software and would not use it again.
During our interview--two years later--he was still adamant
about how he does not ever want to do math again on the
computer.

John and the paraprofessional used Addison-Wesley
textbooks in the multihandicapped classroom to get him up to
grade level before he entered fourth grade. According to
John, math seems easy for Michael. The only difficulty they
had was when they rushed him too fast through his
multiplication tables and did not give him the time needed
to absorb it.

> Children in a regular classroom get all
> this extended practice and you're
> learning your multiplication for eights,
> over a course of your study. You might
> utilize 8 x 5 or 5 x 8 thirty or forty
> times. Well Michael we were pushing
> through so fast he might be able to do

> it once or twice or three times and then
> we would move on to the next set.

John says that his purpose in "rushing through" was to catch Michael up with other third graders, so that he could be more fully integrated the next year. After slowing down, however, and doing some of the "peripheral type work that he had missed," Michael he caught up and understood it. In fourth grade Michael scored in the 60th percentile (total score)in math on the Iowa Test of Basic Skills.

The one subject that Michael says he "hates" is science. He indicates that he doesn't understand why he needs it. Though he didn't mention it, the paraprofessional says he feels the same way about social studies. She thinks he is "turned off because these subjects [are] particularly hard for him" though his grades are usually good. She feels that he doesn't like these subjects because they're new and because he has not had "hands on experience" with the things being studied. "Because he is handicapped as he is, [he] does not experience a lot of the things that are talked about in these two subjects."

> He had probably never seen Jamestown. He's never
> been to Monticello, not that we didn't try to get
> him to go, but the field trip, his Mom pretty
> much, I think, persuaded him in not going because
> she was not permitted to go. . . .other fourth

graders, are able to experience other things that
Michael is pretty much sheltered from.  Not only
field trips but going to the beach, seeing the
sand, seeing a star fish.  Things you hear about
do not stick in your mind like actual things that
you visit, places you see, things you touch.

During tests the paraprofessional is not allowed to
read the questions or texts to him.  She holds the book or
sheet and writes what he indicates.  I asked him, "How do
you take a science test?"  He replied, "I answer A, B, or
C."  According to the paraprofessional these tests are
"multiple choice except for the essay questions . . .I just
write for him and he tells me the answer."  This is
basically the way Michael is tested by teachers and others.
For more information on how technology was used to assess
Michael when he was younger, see Appendix A, E, and K.


## Michael and Literacy Research

Literacy is especially crucial for individuals who
would not otherwise have access to language.  Researchers
are currently investigating (a) how some people with severe
speech and physical impairments have learned to read and
write, (b) what early home and environmental conditions
support literacy acquisition, and (c) what teachers and
others can do to support literacy acquisition in students

with severe disabilities (Blackstone, et al., 1989; Coleman, Koppenhaver, & Yoder, in press; Koppenhaver, 1990; Koppenhaver, Coleman, Kalman, & Yoder, 1991; Koppenhaver & Yoder, in press). This is a very new field of study, and at present research contains a lot of questions and beginning case studies (Beringer & Gans 1986; Kelford Smith, Thurston, Light, Parnes, & O'Keef, 1989; Koppenhaver & Yoder, 1988; Koppenhaver, Coleman, Kalman, & Yoder, 1991)

In a study, "Childhood Reading and Writing Experiences of Literate Adults with Severe Speech and Motor Impairments," Koppenhaver, Evans, and Yoder (1991) ask what home and "school contexts surrounded the literacy learning of 22 literate individuals with severe physical and speech impairments as they were growing up" (p. 21)? In answer to a question about why they thought they had been successful in learning to read and write when so many others with similar disabilities had not, the respondents emphasized "parental support and expectations" as well as their "own persistence and talents" (p.26). "Persistence and talents" seem to characterize Michael well. Parental expectations however does not seem to fit his circumstances as much as teacher expectations.

In one important way--being read to at home--Michael's circumstances are different from most of the people in this study who attribute an important part of their literacy

acquisition to "being read to aloud as they followed the text with their eyes" (Koppenhaver, Evans, & Yoder, 1991, p. 28). In another way, however, Michael's circumstances may resemble those of adults in this study when they say their dominant memory of literacy activities at school "had to do with frustration or unhappiness (as cited by eight individuals)" (p. 28). While Michael's initial circumstances may not have been frustrating, the later circumstances of not being able to input fast enough into the computer or to keep up with homework requirements were frustrating.

Michael's circumstances reflect recent research on literacy and people with severe speech and physical impairments in three areas: (a) his need for auditory feedback from the speech synthesizer, (b) his beginning with a functional approach to reading and writing, and (c) and his strengths and difficulties in writing. Studies on the value of speech feedback and the use of speech synthesizers with computers and augmentative communication devices have been conducted with individuals whose degree of motor or speech impairments vary widely. Despite this variation, much of the research supports the use of auditory feedback for developing literacy (Koppenhaver, Evans, & Yoder, 1991; Mineo & Cavalier, 1990).

When Michael started word processing and spelling by learning the words he wanted in order to write letters and messages, this was a practical, functional approach that according to Coleman, Koppenhaver and Yoder (in press) is the way to begin. "Most literacy learning occurs as a result of participation in activities whose purpose is a practical one involving print" (p. 11). Even though Michael was older than the students in this study, results support that the way to begin is with functional activities, not formal teaching or mere exposure to print alone.

One case study (Berniger & Gans, 1986) suggests that students like Michael are better at encoding than decoding. This means that they demonstrate a strength in writing relative to reading (Koppenhaver, Evans, & Yoder, 1991). Michael's circumstances may support this finding but it's hard to be sure since he doesn't have access to recreational reading. One study by Koppenhaver & Yoder (1990, July) shows how little access to writing students like Michael have in school. What they describe certainly characterizes Michael's circumstances now. Another study by Koppenhaver and Yoder (1990, August) shows students having difficulty with syntax in ways similar to Michael. They also discuss the difficulty of teachers who seem "to be working from an implicit model that writing is talk written down, rather than thought written down" (p. 5). Thus students, may view

writing as "a written version of face-to-face-interaction"
(p. 5).

# BONNIE ELIZABETH NELSON

| | |
|---|---|
| 2721 Carolina Avenue | Technical Assistance Centers |
| Roanoke, Virginia 24014 | 103 Jackson Street |
| (703) 983-2265 | Blacksburg, VA 24061-0533 |
| | (703) 231-5167/(800) 848-2714 |

## EDUCATION

1985 - 1992   Completed coursework for Supervisor of
              Special Education endorsement.  In last year
              of doctoral program.  Dissertation to be on
              using computer technology with students with
              severe disabilities, Virginia Tech
1983 - 1986   Completed coursework for special education
              endorsement in Pre-school Handicapped,
              Radford University and Virginia Tech
1974 - 1977   Completed coursework for NK-4 certification,
              Richmond College (CUNY, New York)
1975 - 1976   Completed coursework for Montessori
              Certification: Primary, American Montessori
              Society
1965 - 1967   MA in English, Pennsylvania State University
1963 - 1964   Exchange Student to the University of
              Stockholm, Sweden
1961 - 1965   BA, completed coursework for certification in
              English, College of William and Mary

## EMPLOYMENT

TECHNOLOGY COORDINATOR   Technical Assistance Centers at
1988 - 1992              Virginia Tech.  Program
                         development, consultations with
                         teachers and school personnel,
                         technology research, teacher
                         training and workshops on computer
                         use with special populations 0 - 21
                         years old.

TEACHER                  Teacher of Emotionally Disturbed
1983 - 1988              (5/7) at High School.  Third grade
                         teacher.  Transition and Preschool
                         Handicapped Teacher.

MONTESSORI TEACHER &     Taught at Children's House of Park
TEACHER TRAINER          Slope, NY (1980-83).  Montessori
1976 - 1983              School of Mill Basin, NY (1979-80),
                         B.B. Montessori, NY (1976-77).
                         Teacher trainer in 3 accredited

|                    |                                      |
|--------------------|--------------------------------------|
|                    | Montessori teacher training programs. |
| EDITOR-WRITER<br>1969 - 1976 | Simon & Schuster.  Writing, editing, and cover copy work. General Editor for Monarch Press. |
| ADULT EDUCATOR<br>1971 - 1973 | Hofstra University - lecturer in adult education courses. |

## OTHER PROFESSIONAL EXPERIENCE

CONSULTANT AND WORKSHOP PRESENTER
>  Using technology in special education (1984 to present).  Computer use includes talking word processing and special software for students with learning disabilities as well as switches and adaptive equipment (includes environmental control devices) for persons with severe disabilities of any age.  Was a presenter at international conferences in Minneapolis, Minnesota, 1987-1990, on computer use for special populations, as well as at other national and state conferences.

VATS (VIRGINIA ASSISTIVE TECHNOLOGY NETWORK)
>  Am member of consortium that is planning for use of federal funds to be spent in Southwest Virginia.

UVA/IBM INSTITUTE ON LEARNER BASED TOOLS FOR SPECIAL POPULATIONS
>  Helped develop, critique, and use software for all special education populations.  One of 15 special educators chosen for this project with equipment and funding for IBM (1986-88).

TELECOMMUNICATIONS
>  UVA/IBM Institute member of CONFER Telecommunications through the University of Michigan.  Am part of a network of special educators using and adapting technology for people with various handicapping conditions including Deaf/Blind (1986-present).

TV AND RADIO
>  Interview experience (1975-82).  Script writer for WNYC educational TV in New York (1969).

GAMES DESIGNER
>  Designed educational games for children to use on car trips.  Pocketmate Publications (1966).

GRANT WRITER
>  Experience writing State and Federal grants (1985-present).  Helped plan and write proposal for Montessori Teacher Training Program (1982-83) that is currently offered at New York University.

## PUBLICATIONS

Author. "Computers and Special Education: A Peripatetic View." <u>Technicalities</u> (Jan-Feb, 1969) 1-2.

Author. <u>Science and Computer Activities for Children 3 to 9 Years Old</u> (Teacher's Manual). Roanoke, VA: Lintel, 1988.

Author. "Puddles, Pods, and Paper: Science with Young Children." <u>The Constructive Triangle</u> (Winter 1982) 17-20.

Author. <u>Kazantzakis' "Zorba the Greek"</u>. NY: Simon & Schuster (Monarch), 1973).

## OTHER

Member of honor societies, Phi Kappa Phi and Gamma Beta Psi.
Listed in <u>Who's Who in American Education</u>.

_Bonnie E Nelson_
Bonnie E. Nelson