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Identification of issues encountered by deaf educators working with multiply involved children and the related emotional affects that go along with intervention

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IDENTIFICATION OF ISSUES ENCOUNTERED BY DEAF EDUCATORS
WORKING WITH MULTIPLY INVOLVED CHILDREN AND THE RELATED
EMOTIONAL AFFECTS THAT GO ALONG WITH INTERVENTION

by

Kelly M. Herron

An independent study submitted in partial
fulfillment of the requirements for the degree of:

Master of Science in Speech and Hearing
Emphasis in Education of the Hearing Impaired

Washington University
Department of Speech and Hearing

May 21, 2004

Approved by:
Christine Clark M.A. CED

INTRODUCTION

Due to new technology, more and more premature babies with multiple impairments are being born and surviving. Early interventionists are, therefore, faced with more and more issues not related to their area of expertise. "Any pediatric audiologist working with children who have multiple impairments cannot help being struck by the complexity of the assessment, intervention, and management process. It is our good fortune that in this modern time, enhanced technology allows not only for the survival of infants born with severe mental and physical challenges, but also for securing their healthy and productive futures. Certainly, the thoughtful application of hearing technology plays a major role in overcoming some of the obstacles posed by these children's multiple impairments." (Tharpe 2001)

The purpose of my independent study is to determine the most common issues deaf educators are faced with that are not directly related to a child's hearing impairment. To identify some of these most common issues, written surveys were sent to professionals involved in Early Intervention Programs. Included in my mailing were deaf educators from both rural and urban areas in Missouri. With the information I have received from my surveys, I will develop a resource pamphlet to assist early interventionists while working with multiply involved children. Furthermore, I have attempted to identify and assess the emotional affects professionals experience dealing with children who were born with multiple impairments and how they impact their treatment plans.

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INDEPENDENT STUDY PROPOSAL

TITLE: Identification of Issues Encountered by Deaf Educators Working With Multiply Involved Children and the Related Emotional Affects That Go Along With Intervention

PURPOSE: The purpose of my independent study is to determine the most common issues deaf educators are faced with that are not directly related to a child's hearing impairment. Working with children between birth to three years old, and their families will be the focus. A brief literature review will attempt to identify and assess the emotional affects professionals experience dealing with children who were born with multiple impairments and how they impact their treatment plan.

Written surveys will be sent out to professionals involved in Early Intervention Programs, to determine the most common issues they as professionals deal with that are not related to their area of expertise. Based on information received from these surveys, resources will be developed to address these issues. In addition, interviews will be conducted with professionals about the emotional and psychological affects encountered working with these children.

LITERATURE REVIEW

Early childhood is an important and critical time in any child's life. For children with disabilities, this time is especially critical. There are more than fifty years of research to support the effectiveness of intervention for infants and young children with disabilities (Bruder, 2002). Furthermore, this research proves that early intervention is most effective when it begins in the first months of life, is individualized, specialized, intensive, and targets areas particularly affected by the impairments. A report of the Special Education Review Committee in 1993 stated, "consideration of best practice in the United States and elsewhere leads to the conclusion that early intervention is effective when it provides high quality, intensive, and clearly articulated programs, delivered by highly skilled and carefully trained personnel in contents of small group and individual instruction, and which are planned specifically to address individual identified needs" (*Ready to Learn, Children with special needs*)

<http://www.education.ie/servlet/blobServlet/07Main.html>

The Population of Early Intervention Programs

As if the components of reaching the goals of this statement are not enough, the survival rates of children born prematurely or suffering severe infections are exceptional. This is because we are a nation fortunate enough in the advances in technology and expertise to save these lives. However, many of these infants may sustain one or more impairments. For example, forty percent (40%) of the children with early identified hearing loss have other disabilities or developmental delays (Yoshinaga-Itano). Another common disability associated with premature births and low birth weight is cerebral palsy (Robertson et al., 1992).

Other disorders include learning disability, chronic lung disease, attention deficit disorder, epilepsy, ophthalmologic impairment and mental retardation (Bergman et al., 1985).

Ventura (1996) labels low birth weight as a major public health problem in the United States comprising approximately seven percent (7%) of all live births and contributing substantially both to infant mortality and to children's disabilities (p. 11).

In addition to these disabilities, autism continues to be a major perplexing problem to childhood educators and other professionals. Autism rates are soaring worldwide, for reasons that remain elusive. There are no clear-cut answers to what causes autism—genetics, vaccines, prematurity, birth trauma, diet and environmental factors are all noted as possible triggers (Hill 2000). According to Gross (2003), federal education officials in 1992 reported fewer than 20,000 of the nation's nearly five million special education students, ages 6 to 21, were considered autistic. Ten years later, nearly 120,000 of the six million special education students had autism. That does not count the 19,000 children 3 to 5 years of age receiving autism services under federal law, or those younger whose numbers have not been tallied.

Consequently, deaf educators and other professionals working in early intervention programs will be dealing with an ever-increasing population of children with multiple impairments. With new technology, medicine and research, these challenges will continue and will cause different and new challenges for professionals. For example, universal newborn hearing screening (UNHS) will bring earlier clinical diagnosis of deafness and earlier prescription of hearing aids. It will also bring an increased demand for the professional support services required by families following identification of deafness. A higher proportion of the target population for services will be identified within the first two months of life and families will require support for a

longer period of time. It is vital that effective, family-friendly, multi-agency service delivery and a plan for the professional development of personnel working directly with the families be developed (Alsop et al., 2000).

Challenges for Early Intervention

There is an increased demand for early interventionists trained in specialized fields. In order to meet this growing need, Bruder (2002) suggests that early intervention programs collaborate with childcare programs and deliver services within those settings. In particular, training resources are needed to increase availability and access to childcare programs with children with disabilities. Current practices in early child care are dictated to a large extent by federal and state regulations. Part C of IDEA contains a listing of services which can be made available and eligible to infants and toddlers and B of IDEA dictates the services available to eligible pre-school-aged children.

On-going professional development is, therefore, still a need for early interventionists. Many of the professionals, especially in school districts, have credentials in special education. However, not many have pre-service or comprehensive training working with infants with severe and multiple disabilities. This is also true in educating professionals in the counseling of parents who are still grief ridden about their children's disabilities. Naseof (2002) states that a lot of mistakes (in counseling) occur when people do not understand where parents are in the emotions they are experiencing. Dr. Naseef, who is the father of a son with autism, notes that these emotions can range from anger to sadness to confusion to shock. He cautions professionals to remember each person and family is different.

The need for further investigation of how best to focus intervention on multiple disabilities is still stressed by researchers (Murdoch, 2002). Because children with multiple impairments may need several specialists, it is essential professionals work together and coordinate services. Often, the more professionals involved, the greater potential for confusion and conflict as individuals address needs related to different disabilities. Expertise must be shared. Great strides, however, have been made toward this problem through family-centered practices. Family-centered practices include: treating families with dignity and respect; being culturally and socio-economically sensitive to family diversity; providing choices to families in relation to their priorities and concerns; disclosing all information to families so they can make decisions; coordinating services of all specialists, and implementing community resources to assist family and friends so they do not feel isolated (Bruder, 2002). However, there is still a need for a more efficient and effective use of service providers and funding streams across agencies in many states. This is because the delivery system is composed of independent agencies, institutions and organizations and each may provide a specific service or function.

Hence, most professionals agree that infants with multiple impairments have learning needs which demand a team approach. Service professionals need to meet with each other and with families to plan how best to meet the infant's needs and family's concerns. Families receiving services through home visits need regular contacts with other families and a variety of service providers. Often, in rural communities and in areas with a limited number of service providers, this continues to be a challenge. In addition, the infant's medical needs, hospitalization, family situations and other factors such as early interventionists' schedules and priorities, weather issues (making travel difficult) all play a part in challenges to professionals.

Complicated medical issues of the child with multiple impairments continue to be of concern to early interventionists. Some of these infants or toddlers may use medical assistive devices such as gastrostomy tubes, respirators, tracheostomies, hearing aids, cochlear implants, intravenous therapy, glasses or kidney dialysis. Some may have seizures or feeding issues (Rivera et al., 2001). Early intervention services providers must have some knowledge of these medical assistive devices and should aid families in obtaining answers to their questions about their children's needs. The field of early childhood intervention must be prepared to use any technology necessary to enhance a child's development.

Assistive technology is also a growing field for curriculum use. Paintbrushes with extended handles, velcro strips, CD-ROM's, graphic tablets and output devices such as speech synthesizers are a just a few (Bruder, 2002). Early intervention service providers are also using video recording as "family movies" for observation of specific child behaviors, assessment and team evaluation, demonstrational therapy techniques, caregiver self-evaluation, and professional self evaluation.

New innovative techniques discovered in my literature review such as the Play Project created by Richard Solomon in the treatment of autism (Hill, 2000), the use of Yoga for the Special Child (Sumar, 2004) and the use of photo books for parent home training and reducing skill regression during absences from school are just a few being implemented in helping multiply involved children.

Summary of Literature Review

Providing early intervention to infants and toddlers who have multiple impairments and their families continues to be complicated. Not only do age, abilities, and the needs of each child

require an individualized approach, but also family priorities, home culture and language, location, program sources and state and federal policies influence the nature of intervention services.

These complexities emphasize the need for state technical assistance projects and other agencies to work together to develop activities for service providers and educational networking opportunities for families of infants who are multiply impaired.

METHODOLOGY

Population and sample

The population being studied is deaf educators working in early intervention. I have attempted to study the population by analyzing responses from a random sample of professionals from Missouri First Steps. Missouri First Steps is an early intervention program that offers coordinated services and assistance to young children with special needs and their families. The program is designed for children, birth to age 3, who have delayed development or diagnosed conditions that are associated with developmental disabilities. Areas of service and assistance provided are speech, hearing, and occupational and physical therapy. These services are provided by appropriately certificated professionals. The sampling frame is defined to be deaf education service providers identified on Missouri's First Steps' website, www.eikids.com/mo/matrix. A random sample of 50 deaf educators was selected from the frame. The sample size was chosen based upon available time and economic resources. This sample is an acceptable representation of the population.

Design and rationale

I was interested in getting information about the most common issues early intervention providers experience while working with multiply involved children. Additionally, I wanted to know how these issues affect their intervention with the child and family and what emotional responses they experience while working with these children. Several factors influenced the type of questions, open or closed, used on the survey. The nature of the research was exploratory with the expected range of possible responses not generally known. I did not want to limit or

bias responses by providing fixed, alternative responses. These objectives, supporting the choice of open ended questions, took precedent over the disadvantages such as higher non-response rate and difficulty of analysis. Consequently, a survey instrument comprised of open ended questions was selected.

Several considerations lead to the decision to solicit written survey responses. The respondents are geographically dispersed throughout the state of Missouri. The logistics and expense associated with personal interviews eliminated this option. Telephone interviews, help with the expense and time of the researcher, but from the perspective of the respondents, suffer from logistical issues similar to personal interviews. Written survey responses, distributed via United States Postal Service, provided a method that was logistically and economically feasible for the respondents and the researcher. Further, the written survey afforded the respondent the flexibility to complete the survey at a time convenient to their schedules. It was hoped this would improve the response rate and provide more richness of detail in the responses. Expenses associated with the selected method were controllable to the researcher's budget constraints through wise material selection and a limited sample size.

Procedure and timetable

First, I developed the survey which was reviewed by three practicing professionals. Adjustments were made to make sure the survey was clear and appropriate. Accompanying the survey was a letter of introduction and explanation of the goals of the research. Provisions were made and offers extended to the respondent to receive a copy of the findings. This offer was made in order to encourage survey participation. Otherwise the respondents were anonymous.

A pre-addressed, stamped envelope for return of the completed questionnaire was also included.

The study was conducted according to the following timetable:

<u>Date</u>	<u>Task</u>
Jan. 1-15	Develop survey instrument, review and modify
Jan. 20-23	Submit survey to independent study advisor for approval
Jan. 26-30	Mail surveys to 50 early interventionists
Feb. 15-27	Analyze survey responses
Mar. 1- Apr. 30	Literature Review
	Design pamphlets;
	Complete manuscript describing project

Plan for analyzing the data

To analyze the open-ended questions, responses were summarized in a chart.

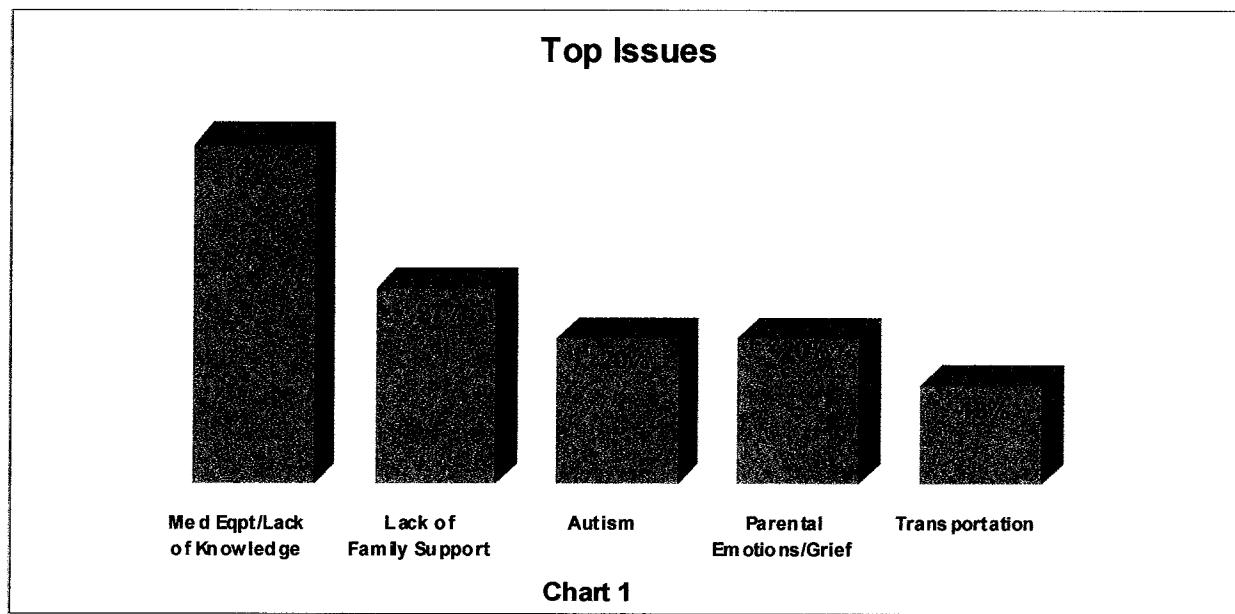
RESULTS

Fifty questionnaires were mailed on January 30, 2004. Fifteen were returned, for a return rate of 30 percent. The questions were as follows:

Question #1: List the 4 or 5 most common issues you face unrelated to your area of expertise.

The responses to question 1 have been summarized in chart 1. There were 15 respondents to the question. The chart depicts the most common issues these professionals face unrelated to their area of expertise.

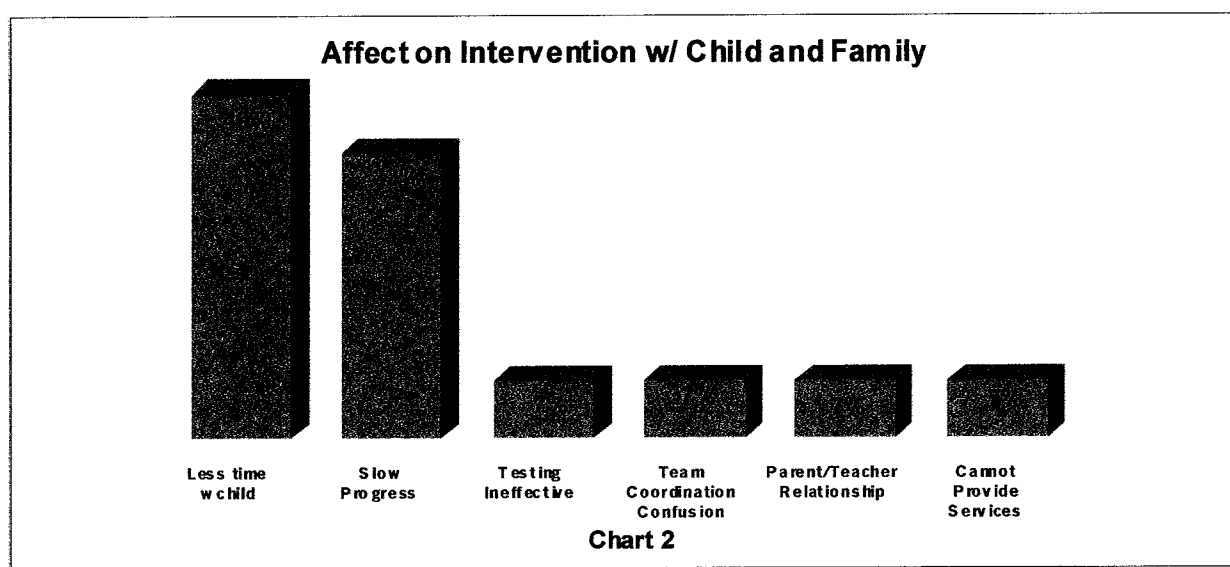
The most common single issue mentioned was lack of knowledge about medical equipment. Within this category, feeding tubes, oxygen equipment, and tracheostomies were mentioned. It is evident that dealing with parental and family related issues are significant. When combined parental support issues and parental emotions was mentioned by 47% of the respondents. It is natural to assume some relationship between these complex parental issues.



Question # 2: How do these issues affect your intervention with the child and family?

The responses to question 2 have been summarized in chart 2. There were 15 respondents to the question. The chart depicts how the issues affect the intervention with the child and the family.

Less time with the child was the most prevalent effect on intervention. Extra time was consumed by paperwork, medical equipment issues, and additional research to learn about the child's disabilities. The multitude of disabilities and inconsistent therapy sessions lead to slow progress. In some instances, the issues prevented the professionals from working with the child at all because there were too many factors involved in the situation.

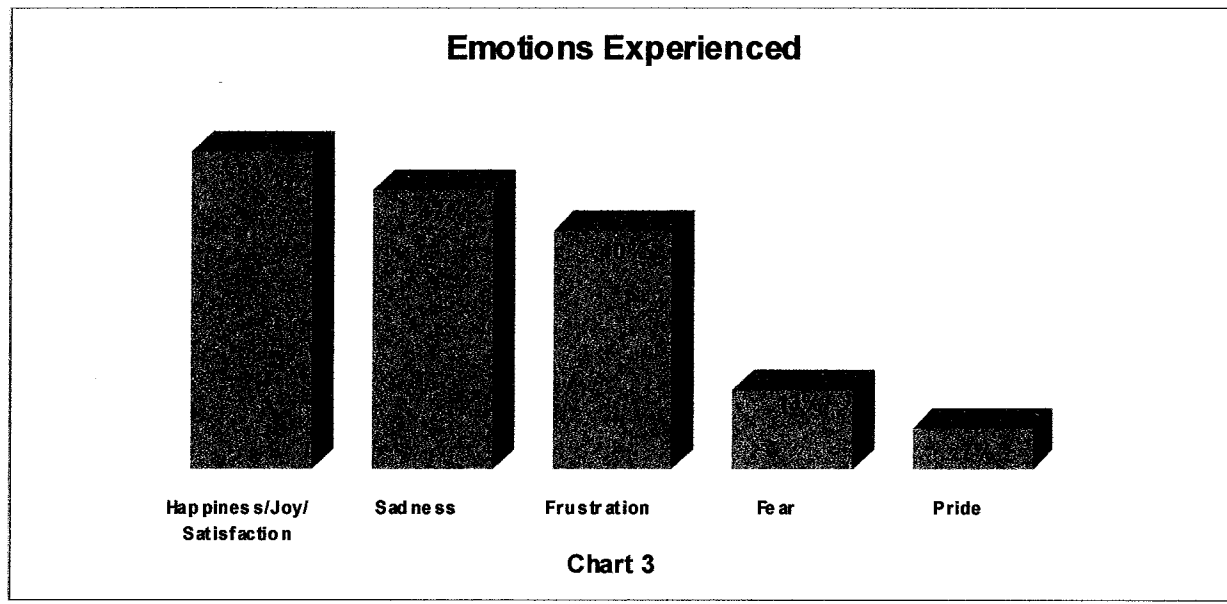


Question # 3: What are some of the emotional responses you experience while working with these children and their families?

The responses to question 3 have been summarized in chart 3. There were 15 respondents to the question. The chart depicts the emotions early interventionists experience

while working with multiply involved children and their families. Respondents typically experienced multiple emotions.

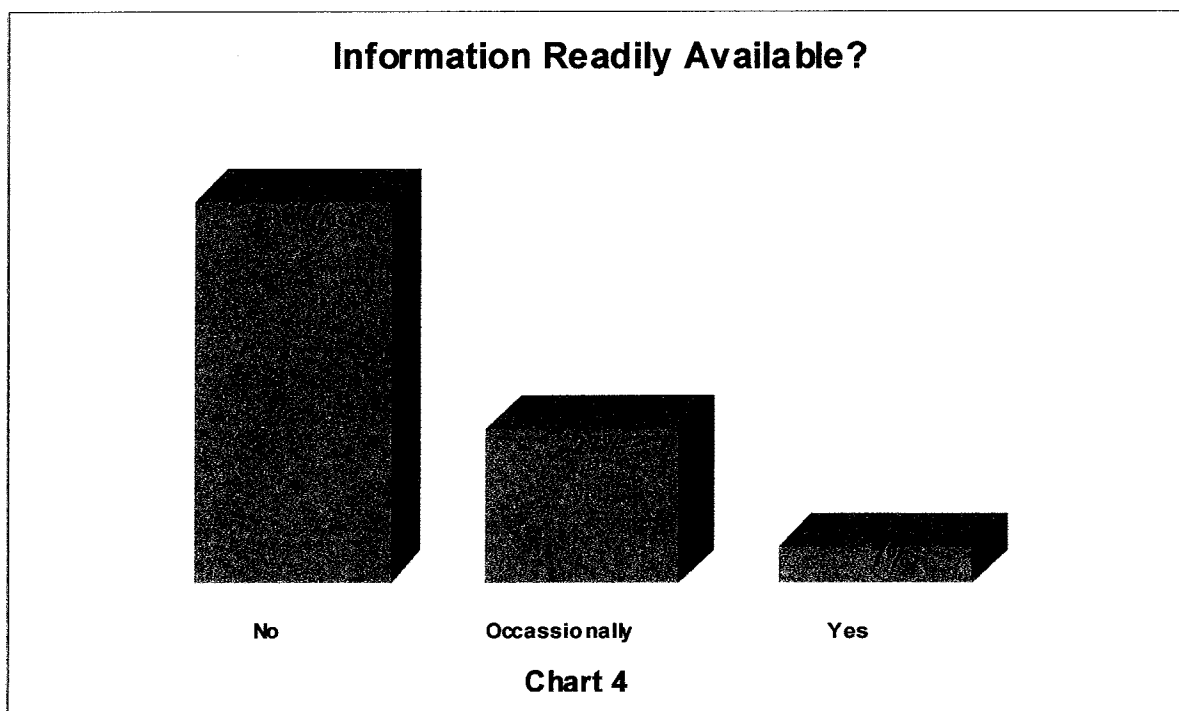
A wide range emotions was reported by the deaf educators. Interestingly, in the face of several issues beyond their area of expertise and their associate affects on intervention, over half of the respondents reported positive emotions, even to the extent of joy and pride. These positive emotions resulted from virtually any kind of gain or progress made by the child or when they were able to assist the family in a constructive way. Unfortunately, these were offset by an almost equal amount of negative emotions. Examples of the triggers for these negative emotions are the death of a child, poor living conditions, lack of family support, and needed services that are not available.



Question # 4: Was information readily available to assist with these issues?

The responses to question 4 have been summarized in chart 4. There were 15 respondents to the question. The chart depicts the percentage of respondents that indicated if information was readily available or not.

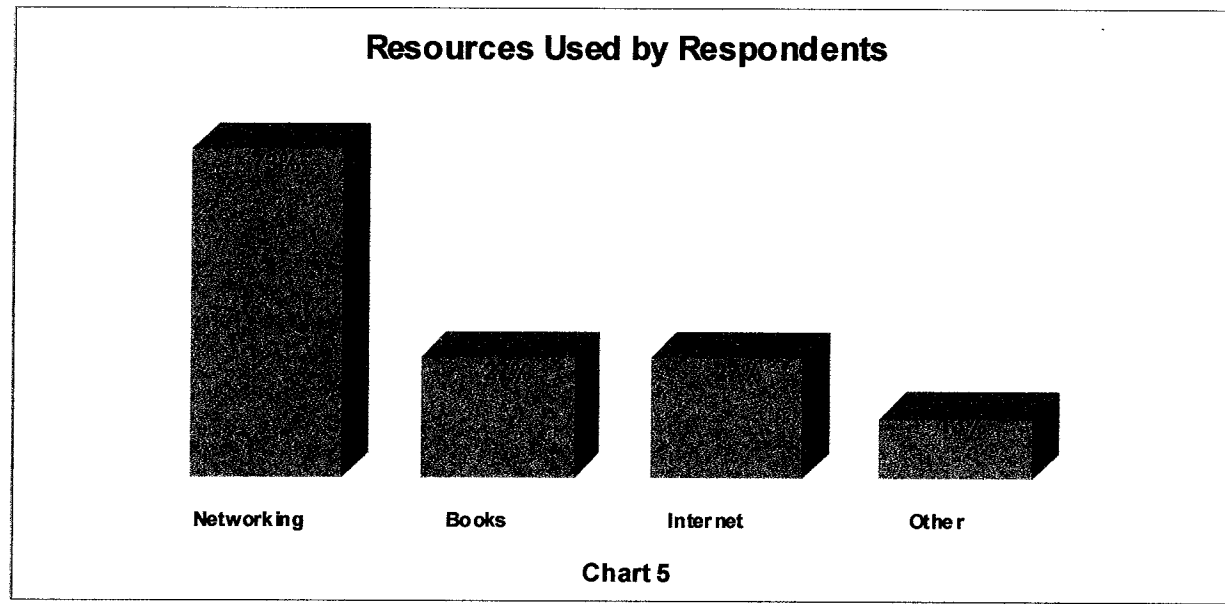
Out of the 15 respondents, a significant majority reported no readily available resources to assist them while working with children who are multiply involved. Only 7% reported that information was readily available.



Question #5: What resources have you utilized to obtain information on these issues?

The responses to question 5 have been summarized in Chart 5. There were 15 responses to this question. The chart depicts the percentage of respondents that indicated they used a particular resource. Respondents typically used multiple resources.

Overwhelmingly, networking with other professionals, especially coworkers, was the most utilized resource. The number of resources used were limited to 3 major categories. Responses of handouts and resource guides were not clearly understood, hence were grouped together in the category of "Other".



Conclusions

The results of the survey were helpful in many ways. There are issues deaf educators in early intervention programs face unrelated to their area of expertise. The lack of knowledge and unfamiliarity of medical equipment was the greatest issue reported. Other issues mentioned were lack of family involvement, grieving parents, autism, and transportation. Due to these issues there is less time spent working with the children and more time spent on paperwork and learning about the multiple disabilities. It was reported that slow progress is common while working with children who are multiply involved. In the most severe cases, services could not

be provided because there were too many outside factors involved in the situation. I was also able to note a range of emotions early interventionists experienced while working with children who have a multitude of issues. While feelings of happiness and joy were amongst the highest by respondents, feelings of sadness and frustration were highly reported, also.

When asked if information was readily available for the early interventionists to help with these issues, "Yes" was reported by only 7% of the respondents. Networking with co-workers and other professionals is the most utilized resource for the professionals working in early intervention. Books and the internet were the next most popular method for retrieving information.

Limitations

One limitation is that the sampling frame may not have been representative of the population of early interventionists because it was limited to providers from the Missouri First Steps Program.

The low number of respondents is a limitation. Due to resource constraints, the sample size was relatively small. That combined with a low response rate provided a smaller than desired number of responses. The time required for proper response to open ended questions, possibly contributed to the low response rate. Would non responders have different issues?

Recommendations

The preparation of this project stimulated several ideas.

1. I think it would be beneficial to broaden the scope of the survey to include early interventionists both within Missouri and other states.

2. I would recommend that further research be done to identify the reported medical shortcomings in more detail. If specifically identified, it would seem that these type of issues could be dealt with in a straight forward manner as compared to more complex issues.
3. Investigation of alternatives to allow for the timely dissemination of ideas and information among the early interventionists is recommended. Networking is currently the most commonly used method, however, it appears to be chiefly limited to co-workers. An alternative that provides for an expansion beyond coworkers may be quite beneficial.

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APPENDIXES

APPENDIX A
COVER LETTER FOR SURVEY

Herron

January 28, 2004

Dear XXXX:

I am a graduate student at Washington University School of Medicine. I am conducting a research study at Central Institute for the Deaf at Washington University. The purpose of the survey is to determine the most common issues deaf educators involved in Early Intervention Programs face that are unrelated to their area of expertise. Based on information received from these surveys, resources will be developed to address these issues.

As a practicing professional, your input on these issues would be greatly valued. If you are willing, please complete the enclosed questionnaire and return it to me in the addressed stamped envelope. Any responses you may give will be kept confidential.

I hope you will participate in my survey. Should you wish to contact me, you may reach me at (314)-351-4497 or by e-mail at herronk@msnotes.wustl.edu.

Thank you,

Kelly Herron
Program in Audiology and Communication Sciences
Central Institute for the Deaf
Washington University School of Medicine

Enc.

APPENDIX B
SURVEY

SURVEY

1. List the top 4 or 5 most common issues you deal with that are not related to your area of expertise.

2. How do these issues impact your intervention with the child and family?

3. What are some of the emotional affects you experience while working with these children?

4. Was information readily available on these issues?

5. What resources have you used to get information on these issues?

APPENDIX C
RESOURCE PAMHLET