AER Journal Research and Practice in Visual

Impairment and Blindness

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Association for Education and Rehabilitation of the Blind and Visually Impaired

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AER Journal: Research and Practice in Visual Impairment and Blindness

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AER Journal: Research and Practice in Visual Impairment and Blindness

A quarterly journal in the field of education and rehabilitation of persons of all ages with low vision or blindness



AER Journal: Research and Practice in Visual Impairment and Blindness

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on Falls and Falls Prevention



Submit papers reporting on research results and practice outcomes related to falls and falls prevention for people with vision loss. The theme issue will focus on positive practical approaches to rehabilitation that are shown to prevent falls. Authors are invited to include implications for the vision rehabilitation professional.

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Cover Photo: The power of intervention: A student who is deaf-blind and her intervener plant seeds as part of a horticulture activity. Photo courtesy of the W. Ross MacDonald School for the Blind, Ontario, Canada.



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Limited physical activity can lead to many health issues, isolation, and mental health issues. There are many barriers to participation in physical activity, sport, and recreation for people with sensory impairments of all ages. Increasing physical activity can improve all of these areas, increase quality of life, and improve perceptions of abilities of people with visual impairments or blindness in the sighted world. This issue aims to fill this gap and provide cutting edge information related to this important area.

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Special Issue: Current Practices with Children Who Are Deaf-Blind

To begin, I must thank Deborah Gold for the invitation to serve as guest editor of this special theme issue, and express my sincere appreciation to many colleagues for their thoughtful reviews of submissions.

The current emphasis on evidence-based practices requires those of us working with children with disabilities to evaluate and align our professional practices with relevant evidence. Given the low incidence nature of deaf-blindness and the extreme heterogeneity of this population, there is limited research on the education of these children and consequently, scant evidence on which to base practice. However, evidence-based practice may be defined as a decision-making process that draws from the combination of the best available research, professional craft knowledge, and family wisdom and experience (Buysee & Wesley, 2006). The field of deaf-blindness has a rich legacy of professional knowledge and family wisdom.

We must collect data from families and professionals in a systematic manner and promote research efforts to guide our practice. Based on available evidence, families of children who are deafblind and professionals working with them must collaborate to identify the best approach to an individual child's severe communication, developmental, and other educational needs.

About This Issue

I am pleased to introduce this special theme issue of the *AER Journal* as a contribution to the evidence base related to serving children who are deaf-blind. Seven selected articles cover a range of topics derived from research, professional knowledge, and family experience. Content focuses on the challenges of obtaining accurate assessment findings, the complexity of supporting a child's communication and language development, and the many intricacies of providing high quality educational services. This issue leads off with an article by Rowland, Stillman, and Mar about the results of national surveys on most commonly used tools to assess children's social interaction, communication, and cognitive skills. Findings identify the need for adaptations when using standardized tools with children who are deaf-blind and selected assessment tools that have been found to be specifically useful. The second article involves a particular child-guided assessment protocol. Nelson, Janssen, Oster, and Jayaraman examine the reliability and fidelity of the van Dijk framework for assessing students with multiple disabilities and deaf-blindness. Findings indicate that multiple practitioners could implement the assessment protocol with fidelity and reach similar conclusions about targeted skills and learning abilities of a particular child.

Parent experiences are highlighted in the third article on children who are deaf-blind with cochlear implants, Bashinski, Durando, and Stremel Thomas report on parents' perceptions of the overall effects of their children's implants and identify the need for creating effective listening environments and facilitating auditory skills of these children. The fourth article addresses teachers' perceptions of their own professional competence and confidence and influences on these perceptions. Hartmann provides a qualitative examination of teachers' self-efficacy in teaching children who are deaf-blind. Findings suggest that training, experiences, supports, and attitudes influence teacher perceptions of their professional efficacy. The practice report discusses the issue of under-identification of deaf-blindness in children with Down syndrome. Good and Chadwick provide an overview of Down syndrome, stress the need for audiological and ophthalmological evaluations given the high risk for both visual impairment and hearing loss in this population, and outline considerations for educational services. The next article focuses on the unique communication needs of children who are deaf-blind. Bruce describes a holistic communication profile that documents a child's communication abilities through an examination of form, function, content, and context. The profile is derived from relevant research and literature on pivotal milestones that influence communication development. This issue concludes with a 20th to 21st century perspective on the influence of federal initiatives in the education of children with disabilities, particularly those who are deaf-blind. Smith and Gense pose provocative

questions to elicit consideration of current contexts and influences on educating children who are deafblind, and engender identification of ways to improve educational outcomes.

High quality educational services to children who are deaf-blind require our continued dedication and passion for seeking and implementing effective practices through coordination with families and among professionals. It seems significant that contributions to this issue represent collaborative efforts across professional disciplines and also national and international boundaries. Progress in the education of children with deaf-blindness is measured by advances in our knowledge and skills; resulting changes and application to practice; and consequently, positive child and family outcomes. This theme issue takes us one step on our journey. I hope that you will feel the same.

Deborah Chen, PhD Guest Editor

Reference

Buysse, V., & Wesley, P.W. (Eds.). (2006). Evidence-based practice in the early childhood field. Washington, DC: ZERO TO THREE Press.

Current Assessment Practices for Young Children Who Are Deaf-Blind

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Abstract

Assessment informs the development of logical, meaningful, and feasible educational goals. Practitioners face a host of challenges in conducting quality assessments of children who are deafblind. Assessments developed for children without disabilities or for children with other developmental disabilities are unlikely to be appropriate without adaptations. Some instruments have been developed for the target population, but these are not widely known. Results of an investigation of current practices in the assessment of 2- to 8-year-old children who are deaf-blind are presented. Two nationwide surveys provided information on assessment instruments used and ratings of their characteristics. An investigation of the inclusion of assessment results in individualized education plans (IEPs) and individualized family service plans (IFSPs) was also conducted. Results include a list of assessments commonly used to assess the population, ratings of the instruments, and a discussion of the degree to which assessment instruments and results inform IEP/IFSP development. Although standardized assessment instruments are rarely useful, a number of appropriate assessments instruments are available for evaluating learning skills in young children who are deaf-blind.

Keywords: assessment, deaf-blind, authentic assessment

Introduction

Assessment is the cornerstone of educational planning and intervention. Its purpose is to identify an individual's competencies, learning style, achievements, and developmental areas in need of special

attention. However, assessment of the communication and learning skills of children who are deaf-blind presents many challenges to the professional, even those who have worked extensively with children who have special abilities and needs (Holte et al., 2006). Children who are deaf-blind are often labeled "difficult to test," implying that the fault lies with the children, as opposed to the instruments used to test them. Most instruments used to assess young children are not applicable to those who are deaf-

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blind because "passing" many items requires intact sensory capacities. The presence of multiple disabling conditions typical of the vast majority of children in this "low-incidence" group (Chen, 1999) renders these tools even less appropriate. Additionally, relatively few evaluators have had training or direct experience working with young children who are deaf-blind. As a consequence of these and other factors, assessments of children who are deaf-blind often result in the identification of weaknesses rather than strengths (Rowland, 2005) and yield little information relevant for educational planning.

The field of early childhood special education has established recommended practices for assessing young children with disabilities (Division for Early Childhood, 2007; Neisworth & Bagnato, 2005) that underscore the most important assumptions underlying effective assessment of this population (Chen, Rowland, Stillman, & Mar, 2009). First, understanding a child's communication behaviors is prerequisite to gaining insight about his or her learning style, aptitudes, social competence, and concept knowledge. Many children who are deaf-blind use expressive communication forms other than speech, including reactions (e.g., smiling, crying), directed behaviors (e.g., reaching), gestures, signs, vocalizations, and picture and object symbols (Mar & Sall, 1999a; Rowland & Schweigert, 2000, 2004). The evaluator must become familiar with the ways in which a child comprehends and signals to others, not only to assess the child's communicative competence but also to gain an understanding of his or her interests, knowledge, and needs. Second, assessment approaches and instruments must consider the impact of sensory impairments on concept acquisition and the unique ways in which these children acquire information from the environment. Children with vision and hearing impairments may learn about everyday objects and spaces primarily through their tactile, kinesthetic, and/or olfactory properties, in addition to (or instead of) their auditory and visual properties. Concepts like size, for example, might be acquired by the positioning of the arms and hands during manipulation of objects of different sizes, instead of the objects' visual characteristics. Concepts such as number, shape, direction, speed, height, volume, position, and color may be extrapolated from the child's everyday hands-on experiences, rather than pictures, diagrams, or verbal

descriptions (Rowland & Schweigert, 2001). Third, unlike traditional assessment, in which children are presented formal tasks in isolated settings, assessment of children who are deaf-blind must occur and be referenced to skills and behaviors in typical contexts, such as the learning and social activities that occur in classrooms, homes, and communities (Chen et al., 2009). Measures such as age equivalents, percentile rankings, and standard scores are valid only if the child with deaf-blindness has had the same learning opportunities as the children on whom the instrument has been normed (e.g., typically developing peers).

Despite the shortcomings of the most common standardized instruments, many assessment toolsboth those designed for use with typical and lowincidence populations-can potentially be used to assess the communication, learning, and cognitive abilities of young children who are deaf-blind. However, there has been no systematic effort to examine what instruments are being used in current practice, how widely they are used, and to what extent these tools are consistent with recommended early childhood practices. This study, conducted in conjunction with a research grant funded by the U.S. Department of Education, sought to examine current practices in the assessment of cognitive, communication, and learning skills of young children who are deaf-blind. Its purposes were to (a) examine the tools used by professionals to assess young children (2 to 8 years of age) who are deaf-blind and who have additional disabilities; (b) evaluate promising tools in terms of the constructs of appropriateness, applicability, accuracy, and usability; and (c) investigate the role that assessment plays in individualized education plan (IEP) and individualized family service plan (IFSP) development. Other data from this project, including perspectives of experts, family members, and family specialists, are reported in Chen and colleagues (2009) and clinical suggestions are provided in Rowland (2009). Complete data on the 5-year project may be found at http://www.ohsu.edu/oidd/d2l/com_pro/ DeafblindAssessmentDataSummary.pdf

Method Participants

A total of 135 professionals from 24 states, recruited with the help of the National Family Association of Deaf-Blind and the state deaf-blind

technical assistance projects, provided data for this study. The professional roles of respondents were described as special education teacher/administrator (34), technical assistance consultant (25), speechlanguage pathologist (17), early intervention or early childhood special education teacher/administrator (16), vision impairment teacher/administrator (11), school psychologist (10), deaf-blind project director (7), educational specialist (6), occupational therapist (4), adaptive physical education teacher (2), physical therapist (1), and unknown (1). The highest professional degree obtained by respondents was MA/MS (79), BA/BS (20), certificate/credential/specialist training (16), and PhD/EdS (15). Years of professional experience with children who are deaf-blind reported by respondents were 0 years (2), 1 to 5 years (34), 6 to 10 years (22), 11 to 15 years (21), 16 to 20 years (17), 21 to 25 years (13), 26 to 30 years (18), more than 30 years (4), and unknown (4).

Procedures

Two nationwide surveys were conducted to obtain data on assessment practices. Both surveys were completed anonymously. A gift certificate or honorarium was offered to each respondent and provided through a third party to protect identities. Survey 1 solicited names of the specific instruments used and recommended by professionals for assessing 2- to 8year-olds who are deaf-blind. The 105 respondents then rated 14 statements about properties and characteristics of each recommended assessment instrument on a 5-point Likert-type scale. Statements reflected specific desired qualities (e.g., appropriate for children with severe vision impairment, useful for describing child's strengths/weaknesses to parents).

Based upon the Survey 1 ratings, a "short list" of 11 instruments that met predetermined criteria (see Results section) was created for further study via a second survey. Survey 2 included 13 statements from Survey 1, plus seven additional statements scored on the same 1 to 5 rating scale. This survey was completed by three different groups who were familiar with one or more of the instruments on the short list: (a) eight professionals who had not completed Survey 1, (b) 11 specialists from state deaf-blind projects who participated in a focus group during which they both reviewed and rated two of the developmental instruments on which further data were needed, and (c) 42 professionals who consented to both administer and rate specific instruments for which additional data were needed. For this last group, IEP/IFSPs were also collected for 23 of the children who were assessed.

Results

Recommended Instruments and Development of Short List

The 105 professionals who responded to Survey 1 recommended a total of 83 different instruments, most of which were listed by only one respondent. Only 11 were recommended by five or more respondents. The following criteria were developed to select a short list of instruments for further study: (a) high ratings on survey questions (we eliminated those with four or more statements rated <3.0 and none rated >4.0), (b) designed for the assessment of 2- to 8-year-olds, (c) includes sections on social-communication and/or cognitive skills, and (d) readily available in the United States. Table 1 shows the instruments recommended by at least five professionals as well as those selected for the short list.

The Battelle, Brigance, and Learning Accomplishment Profile/Early Learning Accomplishment Profile were eliminated from further consideration due to low ratings. Two highly rated instruments were included that were developed specifically for the target population but had not been widely disseminated and were recommended by fewer than five professionals: Dimensions of Communication and the School Inventory of Problem Solving Skills (SIPSS). Another instrument developed for the population, Home Talk, which is administered by parents, and thus would not be expected to be cited by professionals, was included in order to generate professionals' ratings of its usefulness. The Carolina, Hawaii Early Learning Profile (HELP), and Vineland are widely used to assess typically developing children and children with high-incidence disabilities. The Carolina and HELP cover all developmental domains, while the Vineland covers "adaptive behaviors" (communication, daily living skills, socialization, and motor skills). The Oregon Project was developed for children with vision impairments and covers all developmental areas. The remaining instruments were developed specifically for children who are deaf-blind. Of these, the Callier, Home Talk, INSITE, and Infused Skills Assessment cover all developmental areas (with varying degrees of depth).

Instrument	Recom- mended	Short Listed
Battelle (Newborg, 2005)	Х	
Brigance (Brigance, 2004)	Х	
^a Callier-Azusa Scale-G edition (Stillman, 1978)	Х	Х
Carolina Curriculum (Johnson-Martin, Attermeir, & Hacker, 2007)	Х	Х
^a Communication Matrix (Rowland, 2004)	Х	Х
^a Dimensions of Communication (Mar & Sall, 1999b)		Х
Hawaii Early Learning Profile (Parks & Furuno, 2004)	Х	Х
^a Home Talk (Oregon Health & Science University, 2003)		Х
^a Infused Skills Assessment (Hagood, 1997)	Х	Х
^a INSITE Developmental Checklist (Morgan & Watkins, 1989)	Х	Х
LAP (Sanford, Zelman, Hardin, & Peisner-Feinberg, 2004) or ELAP (Glover,		
Preminger, & Sanford, 2002)	Х	
Oregon Project (Anderson, Boigon, David, & deWaard, 2007)	Х	Х
^a School Inventory of Problem Solving Skills (Rowland & Schweigert, 2002)		Х
Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 2006)	Х	Х

Table 1. Instruments Recommended by More Than 5 Respondents and/or Short Listed for Further Study

^a Developed specifically for children who are deaf-blind.

The Communication Matrix and Dimensions of Communication address only communication, while the SIPSS addresses object interaction skills that reflect concept development.

Ratings of Instruments on the Short List

In all, 181 ratings were collected across the 11 instruments on the short list from the 135 professionals who completed Survey 1 or 2. Ratings are reported for three single-item content descriptions ("useful to assess communication," "useful to assess social interaction," and "useful to assess cognition/learning") and four major characteristics (appropriateness, accuracy, applicability, and usability), each of which was derived from mean ratings of several statements. Table 2 shows the statements that were combined to generate a composite score for each of the four characteristics. Table 3 provides mean ratings for each of the three content statements and the four characteristics. The instruments that scored lowest on appropriateness, accuracy, and applicability were the three most widely available instruments: the Carolina, HELP, and Vineland, none of which target children with sensory impairments. The two instruments that received the highest overall ratings (>4.0 on all items) were the INSITE and Home Talk, both developed for children who are deaf-blind.

Analysis of Assessment and IEP Data

Twenty-three IEP/IFSPs were collected from children on whom assessments were administered. Fourteen IEP/IFSPs omitted any mention at all of formal assessment instruments. Many of these were renewal IEP/IFSPs (although several initial IEP/ IFSPs included no reference to assessment tools, or included no assessment information at all). In IEP/ IFSPs without mention of assessment tools, present levels of performance were typically derived from classroom performance per teacher or therapist observation. Goals seemed to be selected based on the next developmental "step" from the child's present levels of performance. It is possible that teachers/therapists did refer to assessment instruments in selecting these goals; however, it is also possible that many of these professionals no longer require the assistance of assessment instruments to know what developmental step should come next.

The remaining nine IEP/IFSPs did mention use of assessment tools; however, their role varied, as did the number used. The number of formal assessment instruments mentioned per IEP/IFSP varied from 1 to 8 (averaging 3) and involved a total of 24 different instruments. Nine of these instruments were completely new ones that had not appeared on Survey 1

CS

Characteristic	Statements Averaged to Compute Ratings of Characteristi
Appropriateness	Useful for 2- to 8-year-olds Useful for children with severe cognitive impairment Useful for children without language Useful for children with severe vision impairment Useful for children with severe hearing impairment Useful for children with severe orthopedic impairment
Accuracy	Useful to assess a variety of children with broad range of skills/needs Useful to evaluate wide range of skills in each domain Useful for generating accurate picture of child skills
Applicability	Useful to generate instructional goals or for educational planning Useful for evaluating progress Useful for describing child's strengths and weaknesses to parents Useful to encourage parent involvement
Usability	Uses clear language Has clear instructions Is easy for me to understand Is easy for me to use Is user-friendly

Table 2. Component Statements Averaged to Yield Mean Ratings for Characteristics of Each Instrument

results, while seven were among those listed in Table 1. Several IEP/IFSPs mentioned that assessment instrument(s) had been administered but did not include any results. Others used formal assessments in the initial evaluation and reported detailed results to establish present levels of performance, with goals that were seemingly developed from these results. Still others used the assessments in initial evaluations, as well as for progress monitoring. In these IEP/IFSPs, goals were more clearly generated from the assessments, and performance on the formal measures indicated progress toward goals, as well as the need to determine new goals.

Discussion and Conclusions

This research on the challenges associated with assessing young children who are deaf-blind must be qualified by certain limitations. The target population is characterized by extreme heterogeneity. Although the study targeted young children who experienced other impairments in addition to dual sensory impairments, even this small slice of the population is extremely diverse in terms of functional skill levels. The survey respondents themselves also represented a diverse group in terms of their professional roles and their years of experience with the target population. Finally, the number of ratings of each instrument varied. Despite these limitations, the study sheds light on current practices in the assessment of these children and provides information on instruments deemed useful for this task.

A striking result was that there are no universally accepted instruments for assessing young children who are deaf-blind. Eighty-three standardized and nonstandardized instruments were identified in Survey 1, and an additional nine were mentioned in the 23 IEP/IFSPs analyzed. Most of the 11 recommended by five or more participants were developmental (items sequenced according to typical development) and observational (results derived from observing the child's natural behavior rather than from elicited performance using a structured testing protocol). Few highly recommended instruments were standardized ones developed for typically developing children or for children with highincidence disabilities. This presumably reflects the difficulty of obtaining valid results in formal testing situations and the recognition that the development of children who are deaf-blind cannot be meaningfully

compared to that of typically developing children. The fact that mainly standardized instruments were referenced in the IEP/IFSP sample may reflect the need for standardized assessments to qualify children for services. But such instruments are rarely appropriate or useful for identifying the abilities or learning styles of young children with disabilities (Neisworth & Bagnato, 2004). In contrast, the instruments developed specifically for children who are deaf-blind were deemed useful in their own right according to survey results, even though none of them are standardized (an accomplishment rendered impossible by the heterogeneity of the population). The results of this study suggest that there may be a trade-off between obtaining standardized results and obtaining useful results for this population.

The lack of familiarity or access to instruments appropriate for children who are deaf-blind that was revealed by Survey 1 may account, in part, for the strikingly limited use of assessments in preparing IEP/IFSP goals. It is also possible that the instruments themselves are not fully meeting the needs of practitioners. Scores and developmental levels mask the variability so typical of the skills and behaviors of children who are deaf-blind. Contextual and interpersonal factors, preferences, tolerance, arousal patterns, and health status all contribute to variability, yet rarely are accommodated on the assessment instruments that were reviewed for this study. Although most assessment instruments create a snapshot of skills and behaviors at a moment in time, the resulting profile may not yield information easily translated into goals and activities. For example, many communication items at early developmental levels describe reactions to stimuli (e.g., orientation, vocal/ motor expressions signaling pleasure or discomfort). Although these behaviors are indexes of developmental status and can serve as signals to which a partner may respond, they are not teachable skills and would be inappropriate as behavioral objectives. Instruments that directly connect such observations to effective interventions (e.g., helping educators and therapists interpret and respond to a child's reaction as a communicative event) would be more useful.

Assessment reports of young children with disabilities should be strength-based and should describe the breadth of skills that children demonstrate (Towle, Farrell, & Vitalone-Raccaro, 2008). The more widely available instruments on the short list (the

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Table 3. Mean Ratings of Instruments on Short List^a

						Instru	ment				
	C-A	Car.	Matrix	Dimen.	HELP	Infused	H.Talk	INSITE	Oregon	SIPSS	Vineland
	29	16	23	ω	25	7	10	16	26	6	1
Jseful to assess communication	4.0	4.2	4.8	4.1	3.2	5.0	4.2	4.4	3.6	NA	3.2
Jseful to assess social interaction	4.0	3.9	4.4	4.0	3.4	4.8	4.1	4.4	3.7	NA	3.5
Jseful to assess cognition/learning	3.9	4.3	NA	NA	3.6	4.0	4.1	4.4	3.9	4.0	NA
Aean appropriateness	4.0	3.1	4.4	3.8	2.7	4.9	4.3	4.2	3.4	3.8	2.8
Jean accuracy	3.4	2.9	3.9	3.6	3.2	4.6	4.4	4.1	3.7	3.8	2.9
Jean applicability	4.1	3.6	4.4	4.0	3.2	4.7	4.3	4.4	4.0	4.0	3.4
Aean usability	4.3	4.5	4.5	3.5	4.3	3.0	4.5	4.5	4.3	4.7	4.3
C-A = Callier-Azusa; Car. = Cé Infused = Infused Skills Assess address this domain: Oregon = C	arolina; I ment; II Dredon F	Dimen. VSITE = Proiect: 3	= Dimens = INSITE SIPSS = 3	sions of Cc Developm School Inve	mmunica ental Che	ttion; HELP scklist; Matr Problem Solv	= Hawaii ix = Com ing Skills:	Early Lea munication Vineland =	rning Profile Matrix; NA ' Vineland A	; H.Talk = = instrum daptive Be	Home Talk; ent does not havior Scales.
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Carolina, HELP, and Vineland) were rated below the others. The most highly rated instruments were those specifically designed for children who have sensory impairments and multiple disabilities. However, several of those tools generated few ratings from Survey 1, suggesting low visibility or restricted distribution. Ratings from the two surveys combined showed that each instrument had a unique array of strengths and weaknesses that might aid potential users in their selection. Each of these instruments is reviewed in relation to the target population in Rowland (2009).

Perhaps the optimal approach is an "authentic" assessment process (Bagnato, 2007). In an authentic assessment, opportunities are created for children to exhibit their responses and skills in typical everyday experiences, as opposed to artificial and irrelevant tasks. This approach promotes direct links between assessment procedures, results, and intervention planning. An authentic assessment integrates information from multiple perspectives and incorporates significant interpersonal and contextual factors affecting performance in the natural environment. The result is a co-constructed image of the child's skills, capturing the variability of day-today life. Authentic assessment emphasizes a collaborative process between family members and professionals. Three of the short listed instruments were explicitly designed to encourage parent participation in the assessment of their children who are deaf-blind. The Communication Matrix and the SIPSS each have alternate versions for parents. The first three of four sections in Home Talk are designed to be completed independently by parents. while the fourth section is designed to be completed collaboratively by parents and professionals.

Conclusions

Despite the problems inherent in using the most readily available tools to assess young children who are deaf-blind, assessment instruments have an important role in organizing observations, clarifying the meaning of observed behavior, and locating skills within a developmental hierarchy. The availability of a number of highly rated instruments designed specifically for children with sensory impairments and multiple disabilities is a real advantage, especially when assessments are so often the responsibility of professionals who have had limited experience with these children. Another bonus is the fact that a number of these instruments are designed to encourage the participation of family members in the assessment process. An authentic assessment process that is structured around instruments that reveal the strengths of the child will provide results with clear implications for the education of a child who is deaf-blind.¹

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Disclaimer

Opinions expressed herein are solely those of the authors and do not necessarily reflect the official position of the U.S. Department of Education.

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¹Specific suggestions for implementing an authentic assessment approach with young children who are deaf-blind are provided in Rowland (2009), available without cost as a final product of the grant that funded this study.

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Reliability and Fidelity of the van Dijk Assessment

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Abstract

Existing assessment instruments, including norm-referenced and developmental assessments, may be inaccurate and biased when used with children who are deaf-blind and have multiple disabilities. The van Dijk Framework for Assessment of Children and Youth with Multiple Disabilities and Deaf-Blindness provides an alternative, child-guided approach to assessment that examines the processes children use as they learn and internalize information. However, the fluid nature of the child-guided assessment creates challenges for determining interrater reliability. This study examined specific quality indicators for successful implementation of the model, the ability of practitioners to implement the assessment with fidelity, and the ability of multiple examiners to look at the same child assessment and reliably come to similar conclusions. On average, practitioners in the study were able to implement the assessment with fidelity to elements delineated in the study. In addition, multiple examiners were able to reliably reach similar conclusions in all assessment areas.

Keywords: assessment, deaf-blind, van Dijk, reliability, fidelity, child-guided

Introduction

Norm-referenced tests and developmental assessment instruments often fail to provide accurate descriptions of children with severe multiple disabilities including deaf-blindness who may have extreme difficulty establishing relationships, orienting to unfamiliar settings and materials, understanding and using formal communication, performing under rapid processing-demand conditions, and performing isolated tasks (Greenspan & Meisels, 1994; Mar, 1996; Silberman, Bruce, & Nelson, 2004). Children who have multiple disabilities are often labeled as "untestable" because the range of test norms may be insufficient to cover their skill range (Linder, 2008). In addition, few standardized instruments have been specifically developed for the population of children and youth who are deaf-blind. Adaptations

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to existing instruments are often used; however, resulting information must be interpreted with caution due to the alteration of standardized procedures (Geenens, 1999; Mar, 1996). Moreover, such adapted instruments often result in information that underestimates potential (Linder, 2008; Mar, 1996; Nelson, van Dijk, McDonnell, & Thompson, 2002; R. van Dijk, Nelson, Postma, & van Dijk, in press). Finally, standardized instruments may be both inaccurate and biased because they do not account for the impact that each disability has on every area of development (Fraiberg, 1977; Linder, 2008; Nelson, van Dijk, McDonnell, et al., 2002).

In an attempt to ameliorate such difficulties. Dr. Jan van Dijk and colleagues in The Netherlands developed an alternative approach to assessment that has become known as the van Dijk Assessment of Children and Youth with Multiple Disabilities and Deaf-Blindness (Nelson & van Dijk, 2002; Nelson, van Dijk, McDonnell, et al., 2002; Nelson, van Dijk, Oster, et al., 2009; J. van Dijk, Klomberg, & Nelson, 1997). The assessment approach began as a cognitive one based on theories of Werner and Kaplan (1963) and Piaget (1964) and evolved to include theories of social learning, transaction, attachment, and neurobiology (Nelson, van Dijk, Oster, et al., 2009). It is used throughout the world and has been translated into Dutch, Russian, Spanish, and Polish (Nelson & van Dijk, 2002).

The assessment process is family as well as child guided. It begins with a family interview that includes information about the child and his or her preferences and also attempts to discover what family members hope to learn about the child from the assessment. The assessment then proceeds to follow the lead and interests of the child rather than a prescribed protocol with prescribed materials. Assessors using the van Dijk framework for assessment constantly adjust their emotions, cognitive levels, and communications to those of the child as they build conversations or interactions that incrementally build upon the child's interests (MacFarland, 1995; Nelson & MacFarland, 1997; Nelson & van Dijk, 2002). The assessment examines the processes individuals use as they learn and develop. These processes include (a) maintaining and modulating state, (b) using preferred learning channels, (c) learning, remembering, and anticipating routines, and (d) accommodating new experiences with existing

schemes. Also examined are the child's abilities to form attachment, interact socially, communicate with others, and solve problems. The end result of the assessment is a written summarization of the child's strengths and needs in each of the assessed areas, next steps for intervention, and specific suggestions for intervention (Nelson & van Dijk, 2002; Nelson, van Dijk, McDonnell, et al., 2002; Nelson, van Dijk, Oster, et al., 2009; Silberman, Bruce, & Nelson, 2004; Westling & Fox, 2009). Specific questions asked in the assessment are provided in Table 1 (Nelson, van Dijk, McDonnell, et al., 2002).

The fluid nature of the van Dijk assessment creates significant challenges for evaluation of its reliability. There is no prescribed protocol, implementation order, or specific testing materials. Each assessment is by design unique because the assessor must follow the child's interests and leads, thus making it difficult to ascertain whether the assessment was implemented correctly. Therefore, it is important that techniques deemed critical to successful implementation of the assessment be identified and delineated. Similarly, there is no set interpretation scale. The assessor must be able to extract qualitative measures of the child's learning processes and needs from each observed assessment. Consequently, an evaluation of the reliability of the instrument must determine whether multiple examiners can look at the same assessment and come to similar conclusions.

The purpose of the current study is to establish whether the van Dijk approach to assessing children is a reliable instrument for use with the population of individuals who have severe multiple disabilities including sensory impairments. To accomplish this purpose, the study is designed to answer the following questions: (a) What are the specific quality indicators for successful assessments using this framework? (b) Are practitioners able to implement the assessment with fidelity or adherence to elements considered crucial to its effectiveness? (c) Are multiple examiners reliably able to reach the same conclusions regarding the presence or nonpresence of the quality indicators? and (d) Are multiple examiners able to look at the same child assessment and reliably come to similar conclusions?

In order to answer the first question, three individuals considered to be authorities on the approach, Drs. Jan van Dijk, Catherine Nelson, and Marleen Janssen, independently wrote lists of elements they felt were essential to the implementation of the assessment method. These were compiled and described in behaviorally anchored terms and desired frequency of occurrence for each element delineated. This list constituted the fidelity checklist for the study and is provided in Table 2. The methodology for the remaining research questions is presented below.

Method

Participants and Settings

Individuals identified to conduct the assessment were nine educators who served children, youth, and school-age men and women with deaf-blindness. As part of their educational duties, they were charged with conducting both initial and ongoing assessments of individuals with deaf-blindness. All of the participating assessors had expertise and training in the area of deaf-blindness. Each participating assessor identified two individuals with deaf-blindness to assess (N = 18). The identified children and youth were between the ages of 2 and 21 years and had been identified as having severe multiple disabilities including deaf-blindness. All of them communicated primarily on a nonsymbolic level at the time of the assessments. Because the study was conducted during the summer, assessments were accomplished in home and community environments rather than in school settings.

Procedures

The participating assessors attended one 3-hour training conducted by the first author on how to conduct and score the assessment framework. Each participating assessor also received a CD-ROM that contains written instructions and filmed examples of the assessment (Nelson & van Dijk, 2002) and was provided with assessment questions to address throughout the assessment (Table 1; Nelson, van Dijk, McDonnell, et al., 2002). Each participating assessor then conducted two assessments with two separate individuals with deaf-blindness and video-taped the assessments. At the conclusion of the study, the videotapes and answers to assessment questions were given to study personnel.

To ensure accuracy in comparison observations, two individuals deemed to be experts in the assessment framework (Observers 1 and 2) provided

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responses to the assessments for comparison with those of the participating assessors. Observer 1 (the first author) looked at all 18 of the assessments and scored them according to the fidelity checklist. The point-by-point formula of agreement divided by disagreement multiplied by 100 (Kazdin, 1982) was used in calculating fidelity, and both occurrence and nonoccurrence of quality indicators were aggregated in the scores. All 18 assessments were then looked at again by Observer 1, and the answers to the assessment questions were scored independently. These answers were compared with answers provided by the participating assessors. The pointby-point formula was again used to determine interrater reliability. An outside expert in the assessment methodology and deaf-blindness, Dr. Marleen Janssen of the University of Groningen, The Netherlands (Observer 2), independently observed a randomly selected 25 percent (n = 4) of the assessments for fidelity and answered the assessment questions. Research staff members (Observers 3 and 4) who were graduate students in special education and who had received training and practice in scoring the assessments each independently reviewed approximately half of the assessments (n = 8 and n = 10, respectively) for fidelity. Finally, because the assessments involved qualitative wording, the two research staff members reviewed all the assessment responses completed by the participants and the assessment responses completed by Observer 1 to determine agreement with the obtained comparisons.

Results

Fidelity

Mean fidelity, or the extent to which assessors implemented and identified quality indicators, was high. Observer 1 found a mean fidelity of 90.1 percent with a range of 35 percent to 100 percent. Observer 2 examined four assessments for fidelity, with a mean score of 93.5 percent and a range of 86 percent to 100 percent. Observers 3 and 4 concluded that there was a mean fidelity of 89.6 percent with a range of 39 percent to 100 percent (mean scores from both observers are combined here to allow direct comparison with Observer 1). Table 3 provides a comparison of all individual scores.

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Table 1. Assessment of Individuals Who Are Deaf-Blind and/or Have Multiple Disabilities^a

Biobehavioral State

What is the individual's current state? Is the individual able to control or modulate his or her state? How much time does the individual spend in an alert state? What range of states does the individual show and what is the transition pattern between states? What variables affect the individual's state?

Orienting Response

What factors elicit an orienting response?

How does the individual exhibit an orienting response?

What sensory channels appear to be associated with an orienting response (sensory information that triggers the response and the senses the individual uses)?

Learning Channels

How does the individual appear to take in information?

How does the individual react to sound?

How does the individual react to vision?

How does the individual react to touch?

Does the individual use more than one sense at a time?

Does the individual exhibit engagement or disengagement cues in response to particular sensory information?

Approach-Withdrawal

What are the individual's engagement cues? What are the individual's disengagement cues? What appears to motivate the individual?

What does the individual seem to turn away from?

Memory

Does the individual habituate to familiar stimuli?

How long or how many presentations of stimuli are necessary before there is habituation?

Does the individual attend again if the features of the stimulus change?

Are reactions differentiated?

Does the individual react differently to familiar and unfamiliar people?

Does the individual appear to have object permanence (understands that something still exists even if it is not currently visible)?

Does the individual associate a preceding event with one that follows?

Does the individual appear to anticipate an upcoming event?

Does the individual react when there is a mismatch to expectations?

Does the individual demonstrate functional use of objects?

Is the individual able to learn a simple routine?

Is the routine learned, remembered?

Interactions

Does the individual orient to a person? Does the individual exhibit secure attachment with important individuals in his/her life? Does the individual engage in turn-taking when he or she begins the interaction? How many turns are taken before disengagement? In response to partner's interaction, does the individual add more to turn-taking interaction?

^a Reproduced with permission from Nelson, van Dijk, McDonnell, et al. (2002).

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Table 1. Continued

Communication

Does the individual demonstrate communicative intent through the use of signals, vocalizations, gestures, etc.?

Describe the communications used.

Are signals used with consistency?

Does the individual use differentiated communications? Describe the communications and their probable meanings.

When presented with options, does the individual make choices?

Does the individual use conventional gestures?

Can the individual use one item or symbol to stand for an activity or object?

Does the individual demonstrate understanding of communication symbols (auditory, visual, or tactual)? Does the individual use symbolic communication? Describe.

Problem Solving

Does the individual demonstrate cause and effect?

Does the individual demonstrate an understanding of means/ends or the use of an intermediate step to solve a problem?

Does the individual demonstrate understanding of the function of common objects?

How does the individual approach a problem?

Does the individual maintain attention and persist?

Interrater Reliability

Mean interrater reliability, or the extent to which different assessors agree on assessment findings, was generally high. Observer 1 found a mean reliability of 85.3 percent with a range between 72 percent and 96 percent. Observer 2 recorded a mean reliability of 86 percent with a range of 82 percent to 90 percent. Table 4 provides a comparison of Observer 1 and Observer 2 scores. Finally, the two research staff members examined the wording of all of the participants' assessments and those of Observer 1 and then coded whether they were materially the same (agreement). Agreement was coded if the two assessments had 80 percent similar responses. An example of agreement between the two is seen in the responses to the question "Does the individual use differentiated communications?" The participating assessor responded, "vocalized for needs attention, smiled for more, arm moved up for more." In response to the same question, Observer 1 responded, "vocalized a 'mmm' sound for continuation, smiled when she seemed to like something and wanted more of it, moved her arm to signal continuation." An example of disagreement is seen in the responses to the question "What factors elicit an orienting response?" The participating assessor responded, "person coming near, touch." Observer 1 responded, "swinging, brother crying, children squealing, scarf touching his arm, mother singing, and mother touching him." Although some of the responses were the same, all of the auditory responses noted by Observer 1 were absent from the participant's response, as was the notation of the use of the vestibular sense. Research staff agreed with agreement or disagreement coding in 97 percent of instances.

Discussion

Both fidelity and interrater reliability were more than 80 percent, which is a traditional threshold for reliability (Kazdin, 1982). It is also notable that the most frequent score was 100 percent. However, the range of fidelity scores is particularly striking (35 percent to 100 percent). There are several possible explanations for this range. A primary tenet of the assessment is that the child be made as comfortable as possible. Therefore, the assessment can be facilitated by an individual other than the primary assessor. For example, if the assessor does not

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Table 2. Fidelity of Implementation Checklist^a

	Implementation Area		Indicator
1. Res	Demonstrates respect for caregivers (Only examine if caregivers are present; assessor report may be used) (Two indicators present) spect for caregiver	a. b. c. d. e.	Assessor asks questions about child interests and skills Asks what caregivers want to learn from the assessment Involves caregivers in the assessment Allows child to remain with caregiver Listens to caregiver without interrupting
2. Res	Demonstrates respect for child (All components present throughout assessment) spect for child	a. b. c. d. e. f.	Attention is focused on child Child's emotional level is responded to and activities are adjusted accordingly Child interests guide course of the assessment Child interests are the focus or subject of routines Routines are discontinued when child disengages Child is informed of what is going to happen or child's permission is sought
3. Chi	Follows the lead of the child (Minimum of four indicators occur three times each in 20-minute session) Id's Lead	a. b. c. d. e. f.	Imitates or follows child's physical action Imitates or follows child vocalization Matches child's facial expressions and voice intonation Follows child's eye gaze to establish joint attention Stops activity and moves on when child disengages Pauses assessment when child exhibits disengagement cues Returns attention to child when engagement cues are seen
4. Cor	Responds to all child behaviors as communication (All three occur a minimum of three times each in 20-minute session) mmunication	a. b. c.	Pauses to allow child to communicate Responds to all child actions and vocalizations according to what child appears to be communicating Adjusts behavior according to what child does
5. Tur	Imitates and follows what the child does in turn-taking conversational routines (Both indicators occur minimum of four times in 20-minute session) n-taking	a. b.	After each action or brief sequence of actions, words, or sentences, assessor pauses and waits for child to act or vocalize before continuing Responds to child turn in reciprocal fashion
6. Ro i	Creates routines that are enjoyable to the child (Four routines are built using all four indicators) utine	a. b. c.	Follows child's lead to establish turn-taking routines that become chains of actions Begins routines and pauses to let child take turns Expands and builds on child turns to establish routines

Table 2. Continued

Implementation Area			Indicator
		d.	Begins play sequence by following child's interests in object, action, or sound
7. ((i Start	Utilizes start-stop within routines (Technique used minimum of two times n 20-minute session) -stop	a. b.	Begin routine, continue it until child appears familiar with it, stop routine and wait for child signal to continue Action or verbalization on part of the child is responded to as communication to continue or discontinue
8. / e l Mism	Adds a surprise of mismatch to established routines (Technique used at east once in 20-minute session) natch	a. b. c.	Routine is established Surprise of mismatch is inserted into routine Assessor pauses to allow child to process and communicate about the surprise
9. 3 Retu	Routine returned to later in the assessment (Technique used at least once in 20-minute session) rn to routine	a. b. c. d. e.	Routine established Routine discontinued and another instituted Routine is begun again after minimum of three minutes has passed Assessor pauses after beginning routine and waits for child to initiate next step Assessor takes turn and again waits for child to initiate next step
10. Prob	Situations are created that allow the child to demonstrate existing skills, show ability to adapt and solve problems, and learn new skills (Each indicator should occur at least one time in each 20-minute session) lem-solving	a. b. c.	Situations allow child to utilize skills already obtained Situations allow child to solve problems Child is assisted to learn new skills

^a Implementation indicators are abbreviated in bold text immediately below each indicator area.

know the child well, the child's teacher or parent can facilitate the assessment under the direction of the primary assessor. The lowest fidelity score (35 percent) in this study was seen in an assessment that was facilitated by the child's mother under the direction of the primary assessor. Low scores related to quality indicators were seen across areas in the assessment but particularly in responding to the child's communications, responding to the child in turn-taking reciprocity, following the child's lead to establish a routine, returning to routine, and problem solving. Interrater reliability for this assessment was also quite low (72 percent). Due to problems in facilitation, several assessment points were not seen

by either rater and therefore not calculated in the point-by-point formula. For example, the memory section only had responses to the first half of the questions. Although the lack of fidelity raises serious questions about the validity of the answers, it does provide important information about parent–child interactions. The same primary assessor (educator) also had a parent facilitate the second assessment, and this assessment yielded a fidelity score of 89 percent and an interrater reliability score of 89 percent. In addition, it is important to note that three of the assessments rated as having 100 percent fidelity were facilitated by parents and the second-lowest fidelity score (65 percent) was conducted by an educator. In

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Assessment	Observer 1 (Percent)	Observer 2 (Percent)	Observer 3 (Percent)	Observer 4 (Percent)
1	89		91	
2	100			98
3	100			98
4	100	100		96
5	100	86		100
6	35			39
7	98	98	100	
8	100	90	100	
9	68			64
10	98			98
11	89		89	
12	100		99	
13	95		90	
14	65		72	
15	100			98
16	98			98
17	98			95
18	89		89	
Mean	90	93	91	88

Fable	3.	Percentages,	Point-by-Point	Agreement:	Procedural	Fidelity
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Table	4.	Percentages,	Point-by-Point	Agreement:
Reliab	ility			

Assess- ment	Observer 1 (Percent)	Observer 2 (Percent)
1	82	
2	96	
3	94	
4	87	83
5	86	82
6	72	
7	90	90
8	90	89
9	89	
10	95	
11	86	
12	82	
13	82	
14	77	
15	83	
16	77	
17	95	
18	72	
Mean	85	86

the low-scoring educator assessment, a turn-taking routine was not created and so could not be returned to nor could a mismatch be added.

It did not always follow that low fidelity led to low reliability. The assessment with the lowest reliability score (72 percent) had a relatively high fidelity score (89 percent), and an assessment that had a fidelity score of 68 percent had a reliability score of 89 percent. However, all of the fidelity scores that were 90 percent or above had reliability scores of 82 percent or above. Therefore, it can be concluded that high fidelity to quality indicators tends to lead to high interrater reliability. This may reflect that some assessors had a more thorough understanding of the assessment tool both in terms of how to facilitate best child performance and how to extract accurate observations and conclusions.

Limitations

There are some limitations associated with the study that could affect the extent to which results of the study can be generalized to other settings or individuals. The relatively small number of participants in the study is a limiting factor; it should be taken into account that all of the study participants were from one geographic area, and although they had varied educational backgrounds, they had similar job responsibilities. It is, therefore, unknown whether professionals with other educational relationships to children (e.g., school psychologists or related service providers) would generate similar results. There was a great deal of variation in the quality and quantity of answers; assessments with high fidelity scores tended to contain more detailed responses. Observer 1 frequently had more responses to individual questions; therefore, agreement was scored if the participating assessors had 80 percent of the same answers as Observer 1. Finally, although having varying facilitators may have led to increased child comfort, it also made direct comparison of the assessments difficult.

Implications for Further Research

The results of this study lend themselves to several future research activities. Participants in this study received direct training from the first author, who is experienced in conducting the assessment and in its training. It is not known the extent to which individuals could use self-study materials and achieve similar results and what types of self-study components would be most beneficial. In the same vein, because other facilitators appear to be used frequently in the assessments, it would be beneficial to know how to best train and guide facilitators as they are conducting an assessment. Another important area of research that was not examined in this study is the extent to which information gleaned from the assessment is actually reflected in education planning and implementation.

Implications for Practice

The outcomes of this study, though not definitive, have many implications for practitioners who work with children and youth who are deaf-blind. Existing assessments have significant limitations when used with the population of children, youth, and men and women who are deaf-blind and have severe multiple disabilities. The van Dijk approach to assessment is a framework that has been developed specifically for this population and, as this study suggests, can be reliably interpreted and implemented. It does require skill and careful, documented observation if accurate qualitative information is to be obtained. At the same time, attention to the quality indicators of the

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assessment, including following the child's lead to create routines, results in responses that are more reliable and therefore, presumably, more accurate. To avoid compromising the quality of the assessment, facilitators should thus be chosen with care and they should receive training and coaching in the process. Either a caregiver or teacher may possess the necessary qualities to facilitate the assessment, but it is not a given in either case. Assisting caregivers and teachers to obtain such skills may be an important component of effective intervention for individuals with deaf-blindness and multiple disabilities.

Although meaningful assessment is essential to the development of appropriate intervention, it also must have direct links to such intervention. If resulting information is not specifically utilized in the design and implementation of appropriate intervention, assessment, no matter how high in quality, will be of little value.

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Family Survey Results: Children with Deaf-Blindness Who Have Cochlear Implants

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Abstract

There has been little research conducted with children with concurrent vision and hearing loss who have received a cochlear implant. This study examined the families' feelings and perceptions about their children's implant and its impact on both the child and the family. Survey research methodology involved both Web-based and paper and pencil formats to maximize response rate. A total of 60 families completed the survey. Eighty-five percent of families (n = 51) indicated they would again decide to seek an implant for their child, knowing what they now know. The number of children with deaf-blindness who receive cochlear implants is increasing every year. In order to facilitate these children's abilities to meaningfully process and respond to sound, practitioners need to learn auditory training techniques and strategies for establishing listening environments.

Keywords: cochlear implant, family perspective, survey, deaf-blind, quality of life

Introduction

Pediatric cochlear implantation has been a major breakthrough for children with deafness and has advanced the management of profound sensorineural hearing loss for many children and their families. Criteria for cochlear implantation candidacy have been expanded over the years to include younger children, children with cochlear abnormalities, children with auditory neuropathy spectrum disorder, and children with disabilities in addition to hearing loss (McConkey Robins, Koch, Osberger, Zimmerman-Phillips, & Kishon-Rabin, 2004; Papsin, 2005; Waltzman, Scalchunes, & Cohen, 2000). However, much of the research on the outcomes of children with additional disabilities is somewhat limited (Meinzen-Derr, Wiley, Grether, & Choo, 2010). Further data are needed to assist families in making informed decisions about implantation for their child. Input from other families can supplement research studies on child outcomes and predictive factors and help to provide such needed information from the family perspective.

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Parent Evaluations of Their Children's Outcomes after Implantation

Overall, studies examining families' evaluations of their children's cochlear implants have included parents' views and satisfaction regarding outcomes after their children were implanted (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Nunes, Pretzlik, & Ilicak, 2005). In general, these evaluations were specific to the children's auditory perception and communication outcomes. Results indicate that the majority of parents were highly satisfied with their children's outcomes (Beale, Shores, & Wood, 2000; Christiansen & Leigh, 2002). These studies focused on families with children who are deaf.

Approximately 30 to 40 percent of children with sensorineural hearing loss, however, have additional disabilities (Filipo, Bosco, Mancini, & Ballantyne, 2004). It is, therefore, also important to consider parents' evaluations of outcomes for children with associated, or multiple, disabilities. In general, these children are reported to show slower gains and often more limited success with oral communication than their peers who are solely deaf (Hamzavi, Baumgartner, Egelierler, Franz, & Schenk, 2000; Pyman, Blamey, Lacy, Clark, & Dowell, 2000). Meinzen-Derr et al. (2010) suggest that therapeutic strategies may need to be implemented to achieve greater language outcomes. One study included parent evaluation of children with additional disabilities: Berrettini et al. (2008) investigated cochlear implantation in children who are deaf with multiple disabilities (no indication that any of the 23 participants had vision impairments or blindness). These researchers speculated that many participants in their study experienced positive benefits in daily life outcomes, even if language and speech outcomes were not as great as those of children who are deaf without additional disabilities.

Numerous studies have been published regarding the efficacy of cochlear implants and reasonable expectations for postimplant patterns of progress for children who are deaf. Although very few analogous data exist regarding children who experience concurrent vision and hearing loss (Dammeyer, 2009), this database is growing. One component of this expansion is the investigation reported hereresults of a survey completed by the families of children with both vision and hearing loss. The intent was to capture information regarding family perceptions of the cochlear implantation process, related services, and child outcomes that might not have been captured by formal assessments completed with their children.

As of December 1, 2008, 763 children and young adults identified as having deaf-blindness in the United States were reported to have at least one cochlear implant (National Consortium on Deaf-Blindness [NCDB], 2009). This figure represents 7.8 percent of the total national deaf-blind census (birth to 21 years of age), although not all states have up-to-date data regarding the numbers of children with implants. It is estimated that approximately 3,000 children and young adults counted in this census have severe-profound hearing loss in conjunction with vision loss (NCDB, 2009) and would, therefore, be eligible for implant consideration.

A recent study by Dammeyer (2009) involved five young children with congenital deaf-blindness and who had received a cochlear implant between 26 and 50 months of age. Parent interviews documented these children's primary benefits from implantation as increased use of objects in interactions with adults, improved attention, and increased emotional response. Although the number of participants in this study was small, cochlear implants were found to have a significant effect on communication and social interaction for children who experienced congenital vision and hearing loss, even though the children did not develop spoken language. Consistent with findings of parents of 23 implanted children who are deaf with additional disabilities (Berrettini et al., 2008), all parents of the 5 children with congenital deaf-blindness indicated they would recommend a cochlear implant to other families with children who are deaf-blind (Dammeyer, 2009).

This article describes findings from a parent survey that addressed the following questions: What are families' experiences with the process of cochlear implantation (seeking, securing, mapping, and habilitation services) for their child with deafblindness? What meaningful changes has the family observed in relation to the child's development, behavior, social interaction skills, and/or the child's participation in family activities?

Methods

Participants

The participant pool was defined by the number of children (n = 75) with whom developmental assessments had been completed as part of an ongoing research project on cochlear implants. Attempts were made to contact the families of each of the children in that project's database, to request their participation in this survey. Sixty-two percent of families completing the survey (n = 37) had sons participating in the larger cochlear implant study; 38 percent (n = 23) had daughters. The ethnic diversity of the sample included participants who considered themselves White (n = 47; 78 percent), African American (n = 6; 10 percent), Latino (n = 2; 3 percent), Native American (n = 1; 2 percent), and other ethnicities or unreported (n = 4; 7 percent). Families of cochlear implant study participants from 19 of 22 states (86 percent) completed the survey. The average age of the children whose parents completed the survey was 7 years, 7 months. The most common causes of their deaf-blindness were CHARGE syndrome (n = 14), complications of prematurity (n = 11), meningitis (n = 3), and cytomegalovirus (CMV; n = 3). On average, the children's implants had been activated more than 4 years when the survey was initiated (mean = 52.63 months; standard deviation = 30.44).

Survey Development

General Process

The researchers' initial step in developing the family survey to be utilized in this research study was to review the Children with Cochlear Implants: Parental Perspectives questionnaire developed by Archibold (sic) and Lutman (n.d.). This well-known and widely used instrument consists of 74 Likert-style items and is regarded as an important tool for assessing the impact of a child's receiving a cochlear implant on the family's quality of life, as well as the child's outcomes (Damen, Krabbe, Archbold, & Mylanus, 2007). The consensus of the current researchers was that the survey to be developed for this study should be shorter in length but that many of the items included in the Archibold (sic) and Lutman assessment should be considered for incorporation in the new survey document. Through an iterative process, items considered to be most salient were identified, while representation of each of the 11 categories was ensured. In addition, new items (n = 9), which dealt with issues or concerns not addressed in the previously existing survey, were developed for the instrument utilized in this project.

Pilot Survey

The initial survey instrument was piloted with families of four children who were participants in the larger cochlear implant study. Each pilot participant was sent an invitation, via electronic mail, that included a Web link to the survey instrument. All revised survey items were sent electronically to two of the four pilot participants for a second review. Both participants confirmed the items were now easily understandable.

Final Survey

The final version of the family survey included a total of 38 items. The first 30 survey items were Likertstyle; possible responses included "Strongly Agree," "Agree," "Neither Agree or Disagree," "Disagree," and "Strongly Disagree" (see Table 1). Six multiple choice items appeared in the survey, inquiring whether or not the child's communication/language services increased or decreased during designated periods postimplant or if the child had discontinued use of the implant. Finally, the survey included two open-ended questions that requested a description of services the child received during the first 6 months after implant surgery and the child's diagnosis. Families were offered the option to add any comments.

Survey Distribution

Both Web-based and paper and pencil surveys were utilized in the final survey process, in order to maximize response rates and minimize the impact of a family's not having access to the Internet as a barrier to participation. The modes of paper and pencil and Web-based responses to surveys have been shown to obtain comparable results (Sax, Gilmartin, & Bryant, 2003; Smither, Walker, & Yap, 2004). The survey instrument was initially distributed using a Web-based survey software program, SurveyMonkey.com. Initial invitations were sent by electronic mail or, if a valid electronic mail address was not available for a given family, a paper copy of the same survey was mailed to the home address. Invitations via electronic mail included a description of the survey, the purpose of the study, the researcher's contact information, details regarding

able 1. Complete List of Likert Items with Responses ^a			Neither		
Survey Item	Yes/Strongly Agree	Agree	Agree or Disagree	Disagree	No/Strongly Disagree
It was easy to get a referral from my child's doctor to the implant center.	38	15	ę	ю	0
We had to seek a cochlear implant for my child from more than one					
implant center before we received approval.	ო	5	. 	13	38
We experienced problems or difficulty with our insurance (or					
Medicaid).	5	9	ო	12	32
The whole process of implantation is still stressful.	11	10	9	14	14
The process of getting an implant for my child was no more intrusive					
in our family life than expected.	13	24	9	12	က
If I knew what I know now, at the time I was deciding whether to					
proceed with implantation for my child, I would make the same					
decision again.	40	1	4	. 	с С
I have noticed my child attending to common sounds in our home					
(e.g., water running, appliances, dog barking, telephone ringing)					
since receiving the implant.	29	15	4	5	7
My child now responds to feelings expressed through vocal inflections					
that he or she did not seem to notice before (e.g., excitement,					
anger).	22	18	7	4	6
Since receiving the implant, I have noticed my child using spoken					
language a lot more.	13	6	5	13	19
My child now participates in conversations during family mealtimes.	6	6	ω	1	22
Progress during the first few months after my child received the					
implant seemed very slow.	21	19	8	1	-
We are considering bilateral implants for our child or our child has					
already received bilateral implants.	16	7	10	8	18
We have trouble keeping the implant on our child because of his or					
her motor disabilities (e.g., cerebral palsy).	14	7	9	11	21
We have trouble keeping the implant on our child because he or she					
frequently pulls it off on purpose.	11	13	5	5	25

Curried from	Yes/Strongly		Neither Agree or		No/Strongly
au vey itell	Agree	Agree	ulsaylee	<u>uisayi ee</u>	ызаулее
My child pulls the implant off only in certain settings.	11	13	5	5	25
My child enjoys wearing the implant.	27	1	15	5	-
Progress after implantation has exceeded my expectations.	19	5	13	10	11
Since receiving the implant, my child now entertains himself or herself					
listening to music, watching television, or playing games more often.	22	15	က	9	14
My child is less socially isolated since receiving the cochlear implant.	12	14	14	ω	11
My child's overall behavior has improved since receiving the implant.	13	18	21	5	ç
My child is less frustrated in regard to understanding what we are					
saying to or asking of him or her since receiving the implant.	10	20	18	7	5
My child is less frustrated in regard to his or her being able to					
communicate with us since receiving the implant.	10	18	14	ω	8
My child participates in family activities more now than before					
receiving the implant.	6	14	24	6	4
My child has made faster progress in school since receiving the implant.	13	16	19	5	7
I am confident my child's school knows how to meet his or her needs					
for learning to use the implant.	21	15	6	ω	7
My child uses an FM system in preschool/school.	12	1	4	16	17
I worry that my child might not be receiving the support services he or she					
needs.	10	16	ო	13	18
My child has only received services from a speech/language					
pathologist who did not have specific training regarding how to					
teach a child to use a cochlear implant.	8	10	4	14	24
After my child's implant was activated, my family received direct					
training to teach us how to help my child learn to use the implant.	25	17	5	5	8
It has been hard to take time off work for the appointments at the					
implant center.	4	0	9	16	26
^a Responses are reported as numbers in each category. A copy (bashinskis@ecu.edu).	of the complete fam	ily survey n	nay be reques	ted from Susar	ı Bashinski

the incentive, a Web link to the survey instrument, and a Web link to opt out of survey participation. The first page of the survey reiterated the survey's description and study's purpose, as well as explaining all required informed consent information. A total of 75 electronic mail invitations were sent; 8 were returned as "undeliverable." Nine days later, a reminder e-mail was sent to each family who had not yet responded, for whom electronic mail addresses were available.

Next, a paper copy of the survey invitation was sent to each of the families who did not respond to a second electronic invitation, or whose electronic mail address was no longer valid (n = 32). Paper invitations included a letter describing the survey, the purpose of the study, the researcher's contact information, information regarding the incentive, and a postage-paid return envelope. To help minimize differences between the two response modes, the paper and pencil version of the survey was consistent in content, format, and layout to the online version. Finally, attempts were made to contact, by telephone, each family who had not responded to the mailed invitation (n = 18); families with whom contact was made in this manner (n = 4)were asked all of the exact questions that appeared on the written survey. Each family who responded to the survey, in any format, received a small monetary compensation as a token of appreciation.

Results

Of the total number of families with whom contact was attempted (n = 75), 71 families were reached successfully; contact was lost with 4 families. Each of these families has a child with deaf-blindness with at least one cochlear implant, for whom assessment information was included in the cochlear implant study database. A total of 60 families (of the 71 contacted) completed the survey—a response rate of 84.5 percent. Forty-three families completed the survey online, 14 completed a paper survey, and 3 families completed the survey via telephone interview. Seven families were nonresponders to all attempts at contact; four families entered a few responses to the survey but did not complete it.

Process of Implantation

Items addressing the process of implantation asked parents about the ease in obtaining referrals,

insurance coverage, making appointments, and locating services and if they would make the same choice again (see Table 1 for a complete response summary). The most divisive survey item asked whether "the whole process of implantation is still stressful." Of the 21 parents who agreed or strongly agreed the process remains stressful, 16 reported their child does enjoy wearing the implant; only 1 of these parents reported their child does not enjoy the implant and 4 were neutral. The item with the highest level of agreement (88 percent) reported that most of the parents found it easy to get a referral from their child's doctor to the implant center. Most parents also reported that they did not have difficulty with insurance or Medicaid, nor did they need to seek a cochlear implant from more than one center (73 percent and 85 percent, respectively). Regarding the item stating that "knowing what they now know, they would again make the same decision" to seek a cochlear implant for their child, 85 percent agreed or strongly agreed. Only four participants disagreed or strongly disagreed with this statement; of these, all four reported difficulty keeping the implant in place on their child, and three parents reported the child was not encouraged to wear the implant at school, one even noting the "teacher seems to think it is an unnecessary hassle." Parents who agreed offered tempered comments such as, "even though the bilateral cochlear are considered failures by medical staff, [our son] enjoys hearing and uses them for environmental sound and we like that we can get his attention." Parents who strongly agreed added enthusiastic comments such as, "Getting my son implanted was the best decision I have ever made!"

Child Outcomes

Survey items related to child outcomes yielded varying responses. The item with the highest level of agreement indicated that children were "attending to common sounds in the home" since receiving a cochlear implant (73 percent agreed or strongly agreed). Most parents disagreed that their children had improved their "participation in mealtime conversations" or "use of spoken language in the home" (55 percent and 53 percent, respectively). Families more often agreed or strongly agreed that their child showed improvement in "respond(ing) to feelings expressed through vocal inflections" (67 percent), "entertaining self by listening to music, watching television, or playing games" (62 percent), or showing "overall behavior (improvement) since receiving the implant" (52 percent).

Three additional survey items regarding child outcomes targeted the child's implant-wearing patterns. Forty percent of parents (n = 24) agreed or strongly agreed their child takes "the implant off only in certain settings." When asked to list such occasions, parents most commonly identified loud environments (n = 8), if the child was angry or protesting (n = 6), or if the child was preparing for a routine activity such as bathing (n = 5). Forty percent of respondents (n = 24) agreed or strongly agreed they experienced trouble keeping their child's implant on; one half of these parents (n = 12)agreed that their child pulled off the implant intentionally. Sixty-three percent of respondents (n = 38) agreed or strongly agreed their child enjoyed wearing the implant.

Services

One critical finding is 37.5 percent of children (15 of 40) who had had a cochlear implant for more than 3 years were reported to no longer receive any services related to use of their implant or directly increasing auditory skills. Not all parents indicated a reason that services were discontinued; in some cases, however, parents reported their "insurance would only cover service for 1 or 2 years after the surgery." Other parents stated the child's services were suspended because his or her progress did not meet the criteria for services to be continued.

Many parents supplied optional comments about their child's services postimplant. Some of these remarks were negative; for example, one family commented, "The center that we are working with has not been supportive, accommodating, or listening to our [parents'] suggestions. Center does not have knowledge of children with multiple disabilities." Other criticisms were not regarding personnel, but the availability of services; one parent observed, "Our implant center is understaffed and overbooked." These sentiments were certainly not representative of all respondents, as 60 percent (n =36) reported they were "confident the child's school knows how to meet the child's needs for learning to use the implant"; this, however, leaves 40 percent (n =24) unsatisfied. One parent's comment reveals the strong effect she feels a well-trained service provider can make, "[Since] getting a new teacher of the deaf, who is more trained in auditory training, our son's progress with his CI [cochlear implant] has skyrocketed."

Discussion

Child Outcomes

Positive outcomes in the Berrettini et al. study (2008) included documentation of progress in communicating wants and needs, attentiveness, and relationships with siblings and classmates for children in this study who were reported to have intellectual disability. Comparisons of data collected from the current family survey show similar patterns but with slightly lower scores.

It is important to note that 72 percent of the children whose families were surveyed for the current study have disabilities in addition to significant hearing loss and vision loss/blindness. When considering the progress of participants in the Berrettini et al. (2008) study, it seems reasonable to extrapolate that children who experience deafblindness, and especially those children who have other additional disabilities as well, are potentially going to need (a) more intensive appropriate intervention, (b) improved strategies to keep their implants on and activated, and (c) longer duration of wearing their implants, if similar progress is to be demonstrated.

An interesting contrast is evidenced when data from the current family survey, regarding outcomes for children with additional disabilities including blindness/vision loss, are compared with data from the Berrettini et al. (2008) study with children with additional disabilities (not reported to include vision loss). Children in the current study (a) although showing overall improved awareness of sound (73 percent), demonstrated this skill 27 percent less; (b) were reported to be 52 percent less likely to communicate their wants and needs; and (c) were reported to be less socially isolated at a rate that was 59 percent lower. Further questions must be raised regarding the impact of vision loss on the social and language outcomes for children who receive a cochlear implant, in comparison to those children with deafness and additional disabilities, not including vision loss.

Reported findings from previous research regarding parental expectations indicate that parents tend to have high hopes for postimplant outcomes for their children (Nikolopoulos, Lloyd, Archbold, & O'Dono-

ghue, 2001; Zaidman-Zait & Most, 2005). Zaidman-Zait (2007) found that families indicated they expected more rapid progress in the first few months following implantation. Such appears to be the case in the current investigation as well; 67 percent of parents (n = 40) who responded to the current survey agreed or strongly agreed with the statement that "progress during the first few months" following implantation "seemed very slow."

Services

Increased social interaction involving meaningful sounds and more specific intervention in the child's home environment are recommended because only 38 percent of parents reported their child postimplant "participates in family activities more." Simply receiving a cochlear implant does not guarantee a child's increased participation. A child's participation should be facilitated by systematically teaching families to provide opportunities for meaningful use of auditory perception and oral language in natural routines and activities. A child must have opportunities to hear meaningful speech and language within the context of communicative interactions.

Children need to be taught how to use auditory skills in authentic environments. Examples of skills needing to be taught include differing responses to familiar speech, environmental sounds, music, and unfamiliar speech; use of vocalizations/verbalizations as communication, vocal inflection, and intonation; and expansion of receptive and expressive vocabularies (Bashinski, Stremel Thomas, & Durando, 2009). Forty-three percent of parents (n = 26) expressed "worry that [their] child might not be receiving the support services" needed; 30 percent (n = 18) indicated their child has only "received services from a speech/language pathologist who did not have specific training regarding how to teach a child to use a cochlear implant." Responses such as these, indicating parents' concerns regarding the frequency and/or quality of services their child is receiving, indicate the need for service providers and agencies to become more knowledgeable regarding proactive strategies for meeting the needs of the children with vision loss/blindness, motor disabilities, and cognitive delay who have received a cochlear implant.

Archbold, Nikolopoulos, & Lloyd-Richmond (2009) documented noticeable changes in the use/nonuse of a cochlear implant, child outcomes, and educa-

tional placement for as long as 7 years after implantation. Several studies investigating long-term outcomes with children who are deaf only have found that children's communication mode changes significantly over the long-term—even so much as 5 to 7 years postimplant (Archbold et al., 2009; Watson, Archbold, & Nikolopoulos, 2006). These findings are in stark contrast to this survey's finding that 38 percent of respondents (n = 23) indicated their child received no services related to learning to use the implant only 3 years postsurgery.

Process of Implantation

Although 88 percent of families in the current study indicated "it was easy to get a referral from [the] child's doctor to the implant center" (n = 53), 12 percent of families experienced some difficulty securing a referral. It is also important to note that 13 percent of respondents (n = 8) had difficulty finding an implant center that would implant their child; this finding was reinforced by a number of families who communicated informally with the researchers. From results of this survey, it cannot be determined whether various implant centers had different criteria for implantation, or if they were simply hesitant to implant children with multiple disabilities.

Berrettini and colleagues (2008) found that almost all (96 percent) parents/guardians of the participants (deaf with additional disabilities, but no mention of vision loss) indicated that, given the option to implant their child again, they would chose to do so. The results of the current family survey showed slightly lower results, with 85 percent of respondents indicating they would chose to seek an implant for their child again.

Implications for Daily Use

Survey findings confirmed through direct communication with participating families emphasize that parents need more effective strategies for ensuring the implants stay in place on their children who have motor challenges/cerebral palsy. Thirtyfive percent of respondents (n = 21) agreed or strongly agreed with having "trouble keeping the implant on [the] child because of...motor disabilities." For those children who voluntarily take their implants off, as reported by 24 parents (40 percent), more systematic procedures are needed to help them learn to tolerate, and perhaps even enjoy, wearing the device.

Limitations

Questionnaires are susceptible to limitations because they rely on the validity and reliability of the participants' responses. Possible causes for invalid/unreliable results include inadvertent errors in recall, misunderstanding the item, failing to respond to one or more questions, or responding falsely to give a socially desirable answer (Rae & Parker, 2005). To minimize these potential limitations, the survey used in this study was (a) based on an established instrument; (b) piloted for clarity prior to its dissemination; and (c) designed using an Internetbased platform, following research-based design principles (Dillman & Bowker, 2001). Results of this family survey represent only the opinions and perceptions of families who did choose to pursue a cochlear implant for their child with deaf-blindness. Families of children with deaf-blindness who had discontinued wearing their cochlear implants were not included in this study.

Suggestions for Future Research

It would be important to broaden the pool of families surveyed to include those who decided to not pursue an implant for their child with concurrent vision and hearing loss, after initially inquiring about an implant. Also, important data could be collected from the families of those children with deafblindness who have discontinued use of the cochlear implant. Finally, it would seem beneficial to create additional survey items that would solicit specific information regarding a child's use and wearing patterns for the cochlear implant (i.e., if the implant is worn only at school, on weekends, during all waking hours, for all types of physical activities, etc.) because the amount of wearing time would very likely be correlated with positive child outcomes.

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Disclaimer

Opinions expressed are solely those of the authors and do not necessarily reflect the official position of the U.S. Department of Education.

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Understanding Teachers' Self-Efficacy to Support Children with Deaf-Blindness

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Abstract

In this study, the self-efficacy of teachers who supported children with deaf-blindness was examined using an approach based on the work of Bandura (2006) and Tschannen-Moran and Woolfolk Hoy (2001). Thirteen special educators in the United States were asked to respond to open-ended questions on their judgments about their capability to educate children with deaf-blindness. Qualitative analysis identified factors that differentiated teachers with varying degrees of self-efficacy and helped to define teacher self-efficacy in deaf-blindness. Results indicated that teachers' self-efficacy was affected by contextual factors, including (a) education/training, (b) employer support, (c) past teaching experiences, (d) collaborative experiences, and (e) general attitudes toward children with deaf-blindness are offered.

Keywords: self-efficacy, teacher efficacy, children with deaf-blindness

Introduction

The concept of teacher self-efficacy (SE) is based on Bandura's (1977) social cognitive theory of learning, which states that people exercise control over what they do and their behavior is influenced by many interdependent determinants such as internal personal factors and the external environment. It is a generative cognitive ability that is closely related to the exercise of control over action, self-regulation of thought processes, motivations, and affective or physiological states (Bandura, 1997).

Bandura (1997) defined a person's perceived SE as "beliefs in one's capabilities to organize and execute the course of action required to produce given attainments" (p. 3). In other words, SE is a person's judgment about his or her capability to perform a task or accomplish a goal. It is not about the number or type of skills a person has, but rather, it is the belief that a person can accomplish desired outcomes with these skills in a variety of circumstances. Even though a person has the skills needed to perform a task well, this does not mean that he or she will. Self-doubt, low motivation, weak commitment, and other negative thoughts can overrule skills. To truly achieve an outcome, in addition to having specific skills, a person needs the efficacy beliefs to use the skills (Bandura, 1997).

SE is believed to be important in any given domain because a person's efficacy beliefs can affect behavior and outcomes. In educational settings, the SE of teachers has been defined as "teachers' beliefs or convictions that they can influence how well a student learns, even those who may be difficult or unmotivated" (Guskey & Passaro, 1994, p. 4). Bandura (1997) described teacher SE as teachers' judgments of their capabilities to bring about desired outcomes in children's learning. In addition, he suggested that this construct may be referred to as teachers' sense of efficacy to reduce confusion between teacher efficacy and teacher effectiveness.

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Research on SE has connected teachers' beliefs of their teaching capabilities to a variety of desirable teacher behaviors. For example, Ashton's (1984) study of teacher SE found that teachers with higher levels of efficacy differed from teachers with low efficacy in that they (a) feel their work with students is meaningful and important, (b) expect students to achieve and behave well, (c) take personal responsibility when children aren't learning, (d) are strategic planners, (e) feel good about teaching and their students, (f) are confident that they can have a positive impact on their students' learning, (g) feel they are learning with the students rather than struggling against them, and (h) involve students in decision making. Other studies examined teachers' SE and found that it is related to teachers' (a) frustration levels (Ashton & Webb, 1986), (b) persistence in challenging teaching circumstances (Ashton & Webb, 1986), and (c) job satisfaction (Caprara, Barbaranelli, Borgogni, & Steca, 2003).

Soto and Goetz (1998) synthesized the limited body of research on teacher efficacy in special education and found that it has yielded similar results to research on general education teacher efficacy. Special educators have been found to have high levels of SE in teaching children with special needs (Carlson, Brauen, Klein, Schroll, & Willig, 2002). More specifically, Coladarci and Breton (1997) found that teachers in special education resource rooms who had high SE felt satisfied with their position and felt instructional supervision was beneficial to them. Jennett, Harris, and Mesibov (2003) studied the SE of teachers of children with autism spectrum disorder and found that teachers with higher levels of professional efficacy had a stronger commitment to a theoretical orientation that guided their practice and experienced lower levels of burnout. Allinder (1994) evaluated the SE of teachers' instructional services to children with special needs and revealed that teaching efficacy was not related to the kind of services provided (e.g., indirect vs. direct) but was related to effective teacher practices, such as the ability to plan and organize.

Although research on teacher efficacy has shown interesting and positive connections between teachers' beliefs and educational outcomes, there are concerns about its measurement and research (Henson, 2002; Tschannen-Moran, Woolfolk Hoy, & Hoy, 1998). Historically, teacher efficacy has been studied using scales that have had construct validity and measurement integrity problems (Henson, 2002). Also, researchers have questioned the overuse of quantitative methods to measure teacher efficacy (Henson, 2002; Shaughnessy, 2004). Tschannen-Moran et al. (1998) stated that the use of qualitative methods to study teacher efficacy is an overwhelmingly neglected area of research. In addition, Henson (2002) suggested that researchers consider how teacher SE can be effectively researched through qualitative methods.

In this study, careful attention was paid to two suggestions found in the previous research on SE: (a) Bandura's (2006) emphasis on the importance of contextual factors that affect SE and (b) Henson's (2002) and Woolfolk Hoy's (as cited in Shaughnessy, 2004) suggestion that qualitative methods be used to investigate the relationship between contextual factors and teachers' sense of efficacy. As such, this study was designed to investigate SE of teaching children with deaf-blindness and focused on the kinds of skills necessary to teach these children. In addition, qualitative analyses were used to investigate what contextual factors may mediate or differentiate teachers with various levels of SE to support children with deaf-blindness.

Learners who experience deaf-blindness often have unique support needs and challenges in their development of concept and communication skills (McLetchie & MacFarland, 1995). To mediate these challenges and support these needs, researchers suggest that intervention by a teacher with specialized knowledge in deaf-blindness is necessary (e.g., Janssen, Riksen-Walraven, & van Dijk, 2002). Although specialized knowledge may be needed, the extant research has found the vast majority of teachers supporting children with deaf-blindness have limited formal knowledge or practice in deaf-blind education (Corn & Ferrell, 2000; McLetchie & MacFarland, 1995). Lang and Fox's (2004) study found that teachers of children with severe disabilities or low-incidence disabilities (e.g., deaf-blindness) did not feel confident in their capabilities to support these learners. It is not known if teachers of children with deaf-blindness feel confident in their practice; thus, the purpose of this study is to address the following research questions: (a) What are teachers' sense of self-efficacy to teach children with deaf-blindness? and (b) What factors might mediate any differences in their self-efficacy?

Methods

Participants

Purposeful, typical sampling was used (Creswell, 2008) to collect a range of teachers' SE beliefs from a variety of professionals. A total of 13 teachers were asked to participate in open-ended interviews. These teachers were chosen from a larger group of teachers in the United States who had participated in a study to develop a scale to measure teacher SE in deaf-blindness education. The researcher selected teachers with specific specializations in special education to ensure that the sample would include teachers who were likely to have taught or likely to one day teach children with deaf-blindness.

All 13 participants held at least one teaching credential and six held multiple credentials. They held credentials to teach children with visual impairments and blindness, children with moderate/ severe disabilities, children with mild/moderate disabilities, children who are deaf/hard of hearing, and credentials in orientation and mobility. The participants' teaching experience ranged from teaching less than 1 year (n = 2) to having worked 20 plus years in the field of education (n = 4). The majority of participants had taught at least one to five children with deaf-blindness (n = 8), three participants had never taught a child with deafblindness, one had taught approximately 30 children with deaf-blindness, and one participant had taught more than 100 children with deaf-blindness.

Procedure

Participants were contacted through e-mails sent directly by the researcher, special educators, administrators of special education schools or programs, and a federally funded organization that serves children with deaf-blindness. Recruitment emails included a short description of the study and a hyperlink that connected the potential participant to the beginning of an online survey hosting Web site. The first page of the hosting Web site consisted of an informed consent statement that explained the purpose and a general description of the study. Thirty-five teachers expressed interest in participating in an open-ended interview and provided their contact information. Out of the 35 special educators contacted directly by the researcher, 13 teachers were chosen to participate in follow-up interviews, either by phone or in person (see Table 1 for interview questions). All interviews were recorded digitally and then transcribed for analysis.

Results

Analytic Strategy

Initial analysis involved consideration of the existing data set and how to best organize it. Responses were coded for statements of teachers' judgments about their capabilities to teach children with deaf-blindness and the factors that either supported or hindered these judgments. A graduate student in the field of special education served as the peer coder. Coding was compared for over 25 percent of the transcripts analyzed. Reliability was measured by dividing the total number of coding agreements by total number of agreements added to the total number of disagreements (Miles & Huberman, 1994). Intercoder agreement of the selection of transcripts was measured at 94 percent. In addition, the codes were compared and contrasted through the process of writing memos and participating in workshops with two other researchers (Glesne & Peshkin, 1992). These activities led to the emergence of four groups of teacher SE: low SE (n = 2), moderately low SE (n= 3), moderately high SE (n = 4), and high SE (n= 4). Teachers were placed in these groups based on their responses to interview questions and confirmed by triangulating their responses with their scores from a related study of the development of a SE measure.

Next, data from each case (i.e., each response from a participant) was reduced into a one-page document that included demographic information about the teacher (e.g., certifications, number of years as a teacher) and a summary of their responses. These one-page summaries were then coded using the contextual factors identified in the previous stages of analysis. A cross-case display matrix was created to organize the data and allow for making contrasts, comparisons, clustering, and identifying similar patterns or themes (Miles & Huberman, 1994; Strauss & Corbin, 1990). The teachers were arranged on the matrix from the group with the least amount of efficacy (low SE) to the group with the most (high SE). Five prominent contextual factors that emerged from early analysis were listed across the top of the matrix (employer support, education/training, past teaching experi-

Table 1. Follow-Up Interview Questions

- 1. In general, how would you describe deafblindness to someone with no previous knowledge or experience with children who are deaf-blind?
- 2. How do you feel about your abilities to teach children who are deaf-blind?
 - (a) Are you satisfied? Why are why not?
- 3. How confident are you that you can bring about desired outcomes when teaching children with deaf-blindness?
- 4. How prepared are you to teach children who are deaf-blind?
- 5. How much do you think your teaching impacts children with deaf-blindness' learning?
- 6. How much support are you given by your employer to teach children with deafblindness? Are you supported by other agencies?
 - (a) If so, what support?
- 7. How much do you agree with the following statements?
 - (a) When it comes right down to it, a teacher can't do much when teaching a child with deaf-blindness because most of the child's motivation and performance depends on his or her home environment.
 - (b) If I try hard, I can get through to even the most difficult or unmotivated student with deaf-blindness.
- 8. In your own opinion, what kind of teacher (or teacher qualities) is best suited to teach children with deaf-blindness? Why?
- 9. What is the biggest challenge teachers face when teaching children with deaf-blindness?
- 10. Would you like to teach children with deafblindness in the future?
 - (a) If you were told that a child with deafblindness was added to your class or caseload, how would you feel?
- 11. Do you have any comments and feedback about completing the survey? Do you have any suggestions on how to improve the survey?

ence, collaboration, and perspective of children's needs) and the responses to each factor were summarized in the appropriate cell. Each cell in the matrix was coded for being positive (presence of support), negative (absence of support), or neutral/ mixed (support present but not ideal). Each teacher's response to each factor was summarized in the appropriate cell.

Teachers with Low SE

Two teachers in the low SE group (teachers L1 and L2) had similar profiles. Both had no formal training or education in how to teach children with deaf-blindness. They had past teaching experiences that they were unhappy about, they had little or no support from their administrators, and they had negative attitudes toward teaching children with deafblindness. For example, when L1 discussed her past experience teaching a child with deaf-blindness she stated, "I don't think it was the best situation...(the child) had so many issues that although they were able to learn they weren't learning as quickly or as well as if they were with (a teacher) who had been totally trained in deaf-blind."

Teachers with Moderately Low SE

The next group consisted of three teachers with moderately low SE (teachers ML1 through ML3). Similar to L1 and L2, these teachers had no or limited positive teaching experiences. Two of these teachers, ML2 and ML3, were novice teachers and unsure of the administration support they would get. ML1 felt that her administrators were supportive because "they leave me alone." Each of these teachers felt that they would be up for the challenge of teaching children with deaf-blindness because they knew who to contact for resources and who to collaborate with. Their willingness to teach children with deaf-blindness and their knowledge of where to go to get help distinguished them from the teachers with low SE.

Teachers with Moderately High SE

The four teachers with moderately high SE (teachers MH1 through MH4) also had a willingness

to teach children with deaf-blindness, a basic knowledge of where to go for help, and no formal teacher education or training in deaf-blindness. These teachers differed from the previous teachers in that they had recent experiences they would use to help them in the future that they benefited from and wanted more collaborative supports (e.g., time to work with other educators on a day-to-day basis) to teach children with deaf-blindness.

For example, MH2 stated that she would like more time to prepare and collaborate with experts from different fields, "But, one in absence of the other is not going to be effective so we need to be allowed to work together and spend extra time with each other to develop a meaningful program." Echoing her concerns, MH4 stated that she would like to have more exposure to people who are willing to talk with her and figure things out, "I just think it is a matter of exploration and problem solving and finding out how to get through to a kid and unlock their world." And in protest of inadequate support, MH4 stated, "They've been giving us a lot of books and saying, 'Here you go!' but we haven't talked about any of it yet."

Teachers with High SE

In the group of teachers with the highest levels of SE (teachers H1 through H4), there were three teachers with graduate degrees and multiple years experience in deaf-blindness education. One teacher, H4, had limited experience and knowledge about deaf-blindness and seemed to be out of place in this group. She may have been an example of a teacher who is unrealistic or naïve in assessing her efficacy. In her opening remarks she stated, "Well, I tell you, maybe I am overconfident but I am the kind of person who likes a challenge....I would be willing to take it on." In contrast, H1, H2, and H3 were more measured in their responses; all three were extremely confident in their skills but also identified areas of need in their own professional development. For example, H2, a veteran teacher and deaf-blind specialist stated

I have the confidence but I see the challenges...I feel I am as prepared as I can be. I could always learn more, I could always read more journal articles more carefully. But, again, since I immerse myself in deaf-blindness, I feel like I have the knowledge to do a lot. The question is do I have the skills to apply that knowledge. And really, I would only know when I tried it. And then I would discover there are gaps in my knowledge base that currently don't seem like gaps but would all of a sudden open up...like sink holes in front of me.

This sentiment was also reflected in the responses of H1 and H3 and illustrates how that even with a formal education in deaf-blindness, many past experiences, collaborations, and a positive outlook, there are realistic concerns in teaching an idiosyncratic and often complex group of children.

Discussion

Overall, this study contributes to a growing body of research that studies teacher SE and is one attempt toward understanding teacher efficacy to educate children with deaf-blindness. Analyses of the data found several key findings. Teachers varied in their judgments of their capabilities to support children with deaf-blindness and analysis yielded information that began to differentiate these teachers.

Teachers with low SE had little to no belief in their capability to bring about positive outcomes for children with deaf-blindness and felt that there must be other educators who were better suited to the task. Teachers with moderately low SE believed that they could teach children with deaf-blindness but were unsure of exactly how. These teachers may not realize that intense, hands-on support is needed and underestimate the additional time they will need to discuss and reflect on their practice with others. The next group, the teachers with moderately high SE, knew they could do it and knew what they needed to do it effectively. They wanted professionals, whether they have specific knowledge of the child with deafblindness or deaf-blindness education, to come in and collaborate with them to successfully meet the needs of these children. The majority of teachers with the highest levels of SE had rich experiences and thorough education in deaf-blindness, but they held realistic concerns and stated that they needed the access to others to help them, albeit in a less intense way.

Analyses also found five contextual factors that were identified during teachers' discussion of their conceptualizations of their SE: (a) education/training, (b) employer support, (c) past teaching experiences, (d) collaborative experiences, and (e) general

attitudes toward children with deaf-blindness. These factors appeared to mediate teachers' sense of efficacy. In addition, the data showed that teachers, in the absence of education and experiences teaching a diverse and challenging group of students, need specific supports that are varied and particular to their situations.

Limitations

There were many limitations to this investigation of teacher SE in deaf-blindness. For one, this was a pilot study and, as such, marks the first attempt at understanding the construct of SE as it relates to teaching children with deaf-blindness. In addition. the composition of the group of 13 teachers chosen for the study may have contributed to themes that emerged and the stated findings. The purposeful sampling technique used in the selection of the teachers yielded rich data for analysis, but it is not possible to know how these teachers compare or contrast to others that support learners with deafblindness. Despite these limitations, this study identified themes that are useful for our understanding of the concept of teacher SE and provides a foundation for future research on teacher efficacy and the contextual factors that may mediate it. Future research could replicate this study using a different group of teachers with varying backgrounds.

Conclusion

Teachers who support children with deafblindness are a useful population for the study of SE given the unique challenges they face in educating a low-incidence population of learners with unique and specialized needs. Perhaps the fact that there are so few children with deafblindness and so few teachers trained to teach these children is one reason why researchers of SE can study factors that mediate varying levels of teacher efficacy and the contextual factors that affect these levels. Teachers supporting children with deaf-blindness must go beyond the resources they currently have, including their education, training, and past teaching experiences, and take a problem-solving approach to instructing these children. A highly individualized and collaborative approach to support children with deaf-blindness is warranted

The theoretical implications of this study were limited, but analyses revealed that factors within teachers' environments and their own experiences affect their sense of efficacy, which is consistent with the model of teacher efficacy presented by Tschannen-Moran et al. (1998). Future research could investigate how teachers formulate and sustain their efficacy beliefs across a career (Tschannen-Moran & Woolfolk Hoy, 2002) or how teachers' efficacy beliefs vary when supporting certain subgroups of children with deaf-blindness (e.g., infants/toddlers or children with CHARGE syndrome). Further research on teacher SE beliefs in a variety of contexts and with a variety of students, such as children with deaf-blindness, may contribute to this growing corpus of work.

Practical Implications

The findings of this study may have practical implications for those interested in teacher education, on a preservice and in-service level, in special education. The issues and factors that the teachers discussed in their interviews appear to affect their judgments of their abilities to teach. Perhaps future research could study if teachers' SE is affected by providing educators resources and supports to effectively teach these children. For example, does teachers' SE change when administrators give extra release time or decrease the caseloads of individual education plan (IEP) team members of children with deaf-blindness? What happens to teachers' SE to support children with deaf-blindness if they meet more frequently to collectively solve issues and support each other? When outside agencies with specific expertise in deaf-blindness support IEP teams of children with deaf-blindness and provide them with the on-the-job support they need, does it affect their judgments of their capacities?

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Practice Report

Deaf-Blindness and Preschoolers with Down Syndrome

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Abstract

Children with Down syndrome are at risk for vision and/or hearing impairments. This dual sensory impairment is seldom recognized in this population, although much can be done through appropriate early intervention, education, and health care to minimize the impact of deaf-blindness on the lives of these children. Trisomy 21, its associated health conditions, and the syndrome's effects on hearing and vision are described. A brief discussion of early intervention and education is provided as well as the future for children living with Down syndrome and dual sensory impairments. This article highlights the need for research in dual sensory impairment in those with Down syndrome and provides basic guidelines for professionals and parents in understanding and addressing complex learning needs.

Keywords: Down syndrome, dual sensory impairment, deaf-blindness

Introduction

There is a lack of research on hearing and vision impairment in those with Down syndrome. Seldom is it recognized that most children with Down syndrome have hearing impairments, and many have both vision and hearing impairments (Nehring, 2010). An estimated 60 percent to 80 percent of children with Down syndrome have hearing impairments (Chen, 2000; Moss, 1998; Roizen, 2002). An estimated 70 percent have vision problems (Owens, Kerker, Zigler, & Horowitz, 2006; Parents, Relatives & Others Understanding Downs [P.R.O.U.D.], 2009). In a calculation of probability, it is reasonable to expect that at least 49 percent or more have both hearing and vision impairments. It is important for parents, educators, researchers, and those who prepare professionals to work in the blindness field to understand Down syndrome and its effects on vision

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and hearing. This article discusses daily living and educational implications of dual sensory impairment for those with Down syndrome and provides a snapshot of the current state of early education and services for children living with both these conditions. Future needs for children growing into adulthood with Down syndrome and dual sensory impairments and for those who educate and support them are also discussed.

Down Syndrome

Down syndrome occurs in about 1.3 per 1,000 live births and affects all races equally (Nehring, 2010). There are therefore approximately 78,050 people in the United Kingdom, 401,560 in the United States, and 5,670 in New Zealand with Down syndrome.

The condition was first described in 1866 by John Langdon Down, after whom it is named, who noted a number of characteristics commonly shared by those with the syndrome (Down, 1866). Because affected individuals tend not to possess every characteristic, the condition was difficult to diagnose until 1959,

when Lejeune and colleagues discovered the genetic abnormality common to all those with the syndrome (Lejeune, Gautier, & Turpin, 1959).

Down syndrome occurs when there is an error during cell division that leads to a triplication of the genetic information stored on the 21st chromosome. Three forms of the condition have been identified. The most common, comprising 95 percent of cases, is known as trisomy 21 or nondisjunction, due to the fusion of a normal sperm or egg with its abnormal opposite (which in 90 percent of cases is the egg) to produce a fetus with three lots of the 21st chromosome in each of its cells. Occasionally a triplication only occurs on part of a chromosome, and this form is known as partial trisomy 21. Trisomy 21 cannot be inherited (Maxson & Daugherty, 1992).

Three percent to four percent of cases of Down syndrome are caused by Robertsonian translocation, which occurs when part of the genetic material stored on chromosome 21 fuses with chromosome 14. This condition is heritable. The remainder of cases are due to mosaicism, in which individuals possess some cells with three copies of chromosome 21 and other cells with the normal two (Modi, Berde, & Bhartiya, 2003).

The presence of the extra chromosome (or part thereof) produces a variety of phenotopic features. These traits, both mental and physical, vary in severity, and because individuals with Down syndrome tend not to possess every characteristic, a chromosomal test called a *karyotype* is required to confirm diagnosis.

Physical markers of Down syndrome (a combination of which those with the condition are likely to possess to a greater or lesser extent) include the following:

- A small mouth with a slightly enlarged tongue
- A larger than average space between the first and second toes
- Broad hands with short fingers and a little finger that curves inward
- An unbroken line across the palm of the hand (known as a *single transverse palmer crease*)
- Smaller than average bowels
- Narrower than average airways and ear canals
- Hypotonia (reduced muscle tone), resulting in excessive floppiness that improves with age
- A below-average weight and length at birth

Down Syndrome and Deaf-Blindness

- The epicanthic fold (a fold of skin running vertically between the two lids at the inner corner of the eye) and eyes that slant upward
- A flat facial profile, flat nasal bridge, and a relatively small nose
- Brushfield spots (gray, brown, or pale yellow spots at the periphery of the iris)

The last three of these can severely affect the sensory functioning of the individual, as will be discussed later.

The impact of Down syndrome on mental abilities varies greatly with each individual. As with the general population, the IQ level varies from person to person, but overall, those with the condition possess an IQ of between 30 and 60, placing them in the mild to moderate intellectual disability range. As a result, physical and mental milestones tend to be reached somewhat later than for members of the general population, as do overall abilities. For example, children with Down syndrome might sit alone between 6 and 16 months (whereas a child with typical development would generally take 5 to 9 months), say their first words between the ages of 12 and 36 months (compared with 10 to 23 months for the typical child), and are toilet trained between 2 and 7 years old instead of 1 to 3 years.

Children with Down syndrome are also more prone to a variety of behavioral difficulties including autism (10 percent) and compulsive behaviors that tend to be expressed more intensely and therefore are more likely to hinder the learning of everyday skills (although these behaviors tend to disappear with age) (Evans & Grey, 2000). It is, however, important to note that individuals with Down syndrome are as capable as other people of forging deep social and emotional (including sexual) relationships (Van Dyke, McBrien, & Sherbondy, 1995). Likewise, their emotions are equally variable and are often expressed far more honestly, which can be a positive aspect but has the potential to be inappropriate (McGuire & Chicoine, 2006).

Health Complications Associated with Down Syndrome

It is important to appreciate the extent and variety of other health complications associated with Down syndrome because these additional complications can

hinder the well-being of both the individual and his or her family and lead to developmental delay. Dual (or multiple) diagnoses are the norm rather than the exception and often occur early in life. Attending to more immediate health concerns (those requiring surgery, for example) can mean that the issue of sensory impairment becomes secondary, which is clearly unsatisfactory from a developmental point of view.

Congenital heart defects are the most common health complication associated with Down syndrome, affecting almost half of those born with the condition. The most common is atrioventricular septal defect, occurring in 60 percent of babies born with heart defects. This occurs when the valves separating the atrium from the ventricle leak, allowing blood to flow in the wrong direction. It is a serious problem and requires surgery shortly after birth. Also common is ventricular septal defect, which occurs when heart tissue fails to fuse in the womb, producing holes in the upper chamber of the heart. Though small holes usually close themselves, larger ones may require surgery (Freeman et al., 1998).

Though the precise reasons are unclear, those with Down syndrome are at a higher risk than the general population of developing bowel problems such as celiac disease, a chronic gluten intolerance that causes the small bowel to become less effective at water and nutritional absorption (George, Mearin, & Bouquet, 1996). Although those with celiac disease typically display symptoms including irritability, vomiting, and undernourishment leading to anemia, those with Down syndrome often do not exhibit these symptoms and so are considered to be affected by what has been termed "silent celiac disease" (Lee, 2009). Left untreated, the disease can lead to stunted growth and even bowel cancer, and it is therefore important to undergo an annual test for gluten intolerance to enable a glutenfree diet to be adopted in the case of a positive diagnosis (Swigonski, Kuhlenschmidt, Bull, Corkins, & Downs, 2006).

Epilepsy, characterized by abnormal brain activity that produces seizures, affects up to 10 percent of those with Down syndrome compared with 0.5 percent to 0.7 percent of the general population (Bergin, Sadleir, & Walker, 2008). The onset of the condition can occur at any age but tends to happen more during the first 2 years, when the seizures are generally classed as short infantile spasms lasting a few seconds (although tonic-clonic seizures do also occur) and during the 20s, when the seizures are mainly of the tonic-clonic variety (Pueschel, Louis, & McKnight, 1991). In the majority of cases epilepsy can be controlled with anticonvulsant medication, but left untreated it can lead to delayed or regressed development, which is particularly problematic for individuals with Down syndrome.

A sleep disorder affecting as much as 45 percent of children with Down syndrome is obstructive sleep apnea (OSA), a condition during which the individual stops breathing for short periods of time-10 to 20 seconds-during sleep (Marcus, Keens, Bautista, von Pechmann, & Davidson Ward, 1991). Children with Down syndrome are more likely to have the condition due to their tendency to have smaller airways, enlarged adenoids and tonsils, and hypotonia of the muscles in the throat and upper airways. Those with OSA tend to snore and to adopt atypical sleeping positions. Although children with Down syndrome are prone to fragmented sleep, OSA can compound the problem by leading to partial or complete wakenings (Levanon, Tarasiuk, & Tal, 1999). A lack of sleep can affect optimum daytime functioning, whereas apneic episodes produce lower blood oxygen levels and force the heart to work harder, which can lead to raised blood pressure and a number of heart problems including strokes. Given the prevalence of heart defects mentioned previously, this has particularly serious implications. OSA can be diagnosed through a comprehensive sleep study, and treatment includes the removal of tonsils and/or adenoids and the wearing of a continuous positive airway pressure mask at night to keep the airways open.

Other health complications affecting those with Down syndrome include musculoskeletal disorders (Pueschel & Solga, 1992) and thyroid problems, either hypothyroidism (which can restrict growth and produce hypotonia, dry skin, and constipation) or the rarer hyperthyroidism, which can lead to an increased heart rate (tachycardia), sweating, and a decreased attention span. Those with Down syndrome are also 20 to 50 times more likely to develop leukemia (Maxson & Daugherty, 1992).

Each of these health complications presents additional challenges in the care of individuals with Down syndrome for parents and professionals alike, particularly because such concerns can take precedence over activities designed to promote personal and social development. A higher tendency

toward vision and hearing impairments can compound these challenges and make intervention all the more important.

Sensory Issues Related to Down Syndrome

Although vision and hearing impairments in children with Down syndrome often appear mild and these children may have some usable hearing and vision (Moss, 1988; National Consortium on Deaf Blindness, 2007), a large proportion have documented functional impairments of both vision and hearing, though perhaps not severe hearing loss or legal blindness.

Baldwin (1993) defined deaf-blindness in functional terms such that children are considered deafblind if they need adapted instruction for both hearing and vision to result in maximum learning. The current U.S. federal definition of deaf-blindness from the Individuals with Disabilities Education Act (IDEA) regulations is "concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness" (IDEA, 2004). Thus, even with mild hearing and vision impairments, children with Down syndrome could often be classified as deaf-blind and therefore be eligible for and require special interventions and programming beyond what is offered for children who experience only hearing, vision, or intellectual disabilities.

Vision problems associated with Down syndrome include structural abnormalities of the eye such as Brushfield spots, an extra fold of skin (epicanthic fold), upward and outward slant of the eyes, strabismus (squint or crossed eyes), infantile glaucoma, and the flattened facial features associated with Down syndrome, which present difficulties in fitting spectacles (Pueschel & Sustrova, 1997).

Lens and corneal problems associated with Down syndrome include cataracts, which can begin to develop in adolescents, and keratoconus (anterior bulging of the cornea). Accommodation and refractive problems such as nearsightedness, farsightedness, nystagmus, and astigmatism are the most common ocular disorders of those with Down syndrome (Pueschel & Sustrova, 1997). Eye infections common in children with Down syndrome are due to the narrowed nasolacrimal duct that gets blocked. Blepharitis (inflammation of eyelids and eyelash follicles) and conjunctivitis are also common.

Almost every structure of the eye can be affected by Down syndrome, and conditions and infections can develop at any time. Thus, frequent ophthalmological assessments should occur so that quality of life, education, and vocational goals can be attained by those living with Down syndrome. It is recommended that children with Down syndrome be screened for vision problems by 6 to 12 weeks of age, be evaluated by a pediatric ophthalmologist by 6 months of age or earlier if problems are evident, and continue regular eye exams every year thereafter, looking specifically for keratoconus and cataracts (Cohen, 1999).

Hearing problems associated with Down syndrome include chronic middle ear infections, especially in the preschool years, and otitis media (fluid in the middle ear) in adolescents. These children can have sensorineural, conductive, or mixed types of hearing impairment. Small ear canals, immune deficiency, excessive ear wax, and sinusitis are also associated with Down syndrome and can contribute to hearing loss related to chronic infections (Nehring, 2010).

Early detection of impairments and early intervention and treatment of infections, along with family involvement, are associated with better hearing versus when diagnosis and treatment are delayed (Maata, Kaski, Tanila, Keinanan-Klukaanniemi, & livanainen, 2006). Cohen (1999) recommends that infants with Down syndrome undergo an auditory brainstem-response test at birth and then every 6 months until age 3. After that, yearly hearing tests should be conducted to detect hearing losses.

Children with Down syndrome can experience speech and language delays due to hearing loss. Moreover, for a majority of children living with deafblindness who also experience cognitive or physical disabilities, health care needs, and/or behavioral challenges (Killoran, 2007), these added complexities can mean profound developmental, communication, and educational needs.

Bird and Buckley (1994) explained that even a mild hearing loss has been seen to impact negatively on learning in children with Down syndrome. McGuire and Chicoine (2006) noted that hearing

and vision impairments can impact the mental health of those with Down syndrome in the form of anxiety, depression, apparent loss of cognitive skills, agitation, and aggression. Vision or hearing loss can be frightening, and when combined with intellectual disability, sensory losses can be more traumatic and it may be more difficult to develop compensatory skills.

Early Intervention

Interventions to assist the child with vision impairment can include corrective lenses, contact lenses, sunglasses, special spectacles designed to fit the facial features of children with Down syndrome, magnification, enlargement, teaching of eccentric viewing, head tilting or gaze shifting, appropriate use of lighting, and rest after concentrated close work, with the intervention dependent upon eye condition (Smith & Lovack, 1996). There is evidence that children with Down syndrome may have sensory awareness deficits (Kumin, 2003), yet children with severe vision impairment and moderate intellectual disability can benefit from tactile forms of communication, including braille (Chen & Downing, 2006; Creech & Golden, 2009; Robinson, 2009). Research into techniques for tactile communication for children with impaired vision and other impairments have concluded that tactile input should be used to support information received through other senses in order to help them link gestures and abstract symbols (Chen & Downing, 2006; Rowland & Schweigert, 2000). Research has also concluded that augmentative and alternative communication methods can be used effectively with preschoolers with Down syndrome (Branson & Demchak, 2009). Yet more research is needed that specifically includes children who have impaired vision and hearing and Down syndrome.

Despite the difficulty in assessing hearing in young children with Down syndrome, refined audiology testing has resulted in early interventions, such as fitting of hearing aids and introducing speech and language therapies and multisensory teaching methods, sign language, and increased use of visual cues, gestures, pictures, and reading (Kumin, 2003).

There is much evidence of the advantages of early intervention services for children with Down syndrome. Although there is a history of controversies related to specific therapies such as vitamin and mineral therapies, cell therapies, and Doman's treatment of brain injury (Foreman, 1988; Jacobson, Foxx, & Mulick, 2005), physical therapy, early education, social work, nursing, occupational therapy, speech therapy, audiology, and vision therapy have resulted in feelings of improved morale and support for parents (Pueschel, 1990). There is also evidence that children with Down syndrome can directly benefit from early therapeutic interventions. This is especially the case if programs are comprehensive; provided over a sufficient period of time and with a selected number of qualified professionals; and are initiated with very young children, involve parents, and are structured yet flexible and adapted to the individual needs of each family (Van Hooste & Maes, 2003).

Health and Educational Services

Early intervention services vary from community to community. For children with Down syndrome who have additional hearing and vision impairments, services may include:

- Services related to vision impairment such as play groups, early intervention education with teachers of children with vision impairment, developmental daily living skills instruction, and developmental orientation and mobility; orthoptists (specialists who assess and provide therapy to those with binocularity or ocular motility difficulties) and pediatric ophthalmologists and optometrists may also be available
- Services related to hearing impairment such as audiology and speech therapy, hearing-aid specialists, and teachers of those who have hearing impairments
- Services related to intellectual disability can include special education services, respite care, occupational therapy, music therapy, specialized play groups, and parent support programs
- Services related to physical disability can include physical therapy, horse-riding for people who are disabled, and nursing services
- Services for children who are experiencing deafblindness or deaf-blindness and intellectual disability may include the assistance of service coordinators, family specialists, social workers,

assistive-technologies specialists, skilled communicators, developmental preschools, developmental interventionists, transition specialists, and in-home special education

Through the National Consortium on Deaf Blindness, there is a wealth of resources for those working with this population. However, there are problems in the provision of quality services to this population due to lack of experts in deaf-blindness, lack of experts with experience in working with infants with multiple disabilities, and lack of resources within communities (Chen, 1999).

In many communities, children with Down syndrome and dual sensory impairment may typically experience a myriad of medical interventions in their first year, with a focus on heart, gastrointestinal, and respiratory health. Because a majority of these children will have hearing, vision, and muscle-tone problems (Chen, 1999), an interdisciplinary team approach will be needed. Occupational or physical therapy is useful for developing skills in feeding, muscle tone, and gross motor skills. A vision teacher can assist in promoting visual or compensatory skills. A teacher specializing in hearing can provide aids and teach listening skills and sign language. A speech-language therapist can work with children in developing speech and/or augmentative communication modes, and special educators can work with children in motor, communication, play, and social skills (Chen, 1999).

As preschool children transition to more formal schooling programs, more complex educational tools must be introduced. Communication methods can include alternative and augmentative strategies, sign language, braille, keyboarding, tactile signing, and computing skills (Robinson, 2009). More research and development is needed regarding the use of such technologies in teaching children with Down syndrome and deaf-blindness, especially for those who may not achieve the use of language.

The Future: Beyond Preschool with Down Syndrome and Deaf-Blindness

Children with Down syndrome are no longer expected to remain dependent or sheltered and so

they need skills for transitioning into postsecondary education, independent or semi-independent living, work, recreation, community living, and adult relationships with other people (Pueschel & Sustrova, 1997). Sensory problems in adolescents with Down syndrome can interfere with these transitions and can be misdiagnosed as mental health problems (McGuire & Chicoine, 2006). Sensory problems in teens with Down syndrome may make the stresses of adolescence even more difficult. It is therefore important to continue to monitor vision and hearing for those with Down syndrome, so these losses can be identified and addressed as early as possible and throughout life.

People with Down syndrome now live longer and are prone to age-related health problems (Maata et al., 2006). But they also have improved health, cognitive, social, and occupational skills that can be nurtured as long as their needs related to their individual intellect, ability, health, and sensory abilities are acknowledged and considered in their life planning.

Those with Down syndrome are at risk for dual sensory impairment, and this issue has not been addressed thoroughly in literature, research, social services, or education. There is a need for research into this area and for parents and professionals to be aware of the unique needs of those experiencing this combination of multiple impairments so affected individuals can reach their greatest potential.

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Theory Paper/Thought Piece

Holistic Communication Profiles for Children Who Are Deaf-Blind

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Abstract

This article presents a holistic communication profile to support structured informal assessment and individualized communication programming for children with multiple disabilities including deafblindness. The four aspects of communication (form, function, content, and context) are used as the profile's primary organizational structure. This holistic communication profile provides a format by which to record the child's level of communication and the development of pivotal social and cognitive milestones that influence communication development. Research literature on the profile components is shared to establish the relationships among the pivotal milestones and communication development. A sample holistic communication profile on a child who is deaf-blind is included.

Keywords: communication profile, deaf-blind

Introduction

Children who are deaf-blind have limited access to the communication and language of others, which severely restricts their opportunities to benefit from visual and auditory observation of models. They require explicit communication programming grounded in an understanding of how communication interacts with other domains of learning. There is an abundance of research evidence that pivotal cognitive and social milestones are positively correlated with achievements in communication and linguistic development and that direct instruction of those pivotal milestones may yield benefits in communication development (Bruce, 2005b). This article describes the primary components of a holistic communication profile that has been successfully used by teachers, university students, and the Helen Keller Fellows (teacher candidates prepared for leadership roles under a project of the Teaching

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Research Institute). A sample profile is shared to illustrate how the concepts discussed in this article may be applied to support structured informal assessment and individualized communication programming.

Levels of Communication and Mental Representation

Appropriate communication intervention begins by determining the child's current level of communication. Rowland and Schweigert (2000) used the following schema to describe communicative competencies: Level 1: preintentional behavior (behavior is reflexive); Level 2: intentional behavior (acting purposefully on objects); Level 3: intentional, presymbolic (and nonconventional) communication (expressing for the purpose of impacting another person); Level 4: intentional, presymbolic, conventional communication (expressing in more conventional ways with the purpose of impacting others); Level 5: concrete tangible representations (an optional level often using objects or partial objects as representations); Level 6: single abstract symbols;

and Level 7: combinations of two to three abstract symbols (which marks the beginning of linguistic performance). A child may express various communicative functions (such as requests, protests, and comments) across more than one level of communication. The *Communication Matrix* (Rowland, 2004) is an assessment tool that captures the levels of communication used to express four functions. Results from this assessment may be included in the holistic communication profile.

When planning communication programming, it is critical to select or develop representations that are appropriate for each child. In addition to considering what the child might want or need to communicate. daily activities to be represented, and opportunities to rehearse the use of representations, it is important to determine the appropriate level of representational complexity. Park (1997) described the following three levels of representation: icons, indices, and symbols. Icons bear a strong perceptual resemblance to the referent (what they represent). Perceptual similarity may be grounded in vision, hearing, touch, or movement (such as the iconicity of photographs over line drawings or some signs over others). Indices share a relationship, such as smoke to fire or car keys to going for a ride in an automobile. Symbols are the most abstract level of representation because they do not look or feel like the referent. It is possible for a child to use some symbols (especially those that have been rehearsed within routines) prior to being a symbolic communicator. The achievement of symbolic communication occurs when distancing is resolved, allowing the child to now use abstract symbols to express ideas with separation in time and space between the symbols and the referents (Bruce, 2005a).

The Four Aspects of Communication

The four aspects of communication (form, function, content, and context) is a well-established framework for thinking about the development of communication in children who are deaf-blind. Miles and Riggio (1999) and Downing (2005) used this framework to organize content in their communication textbooks. Form refers to the receptive and expressive modes of communication (such as verbalization, body language, gestures, and braille). Function is the perceived intent of the message sent

(across forms). Content is the message itself, simplistic to identify when spoken or signed but complex to determine when expressed through vocalization. Bruce (2002) defined the following five components of the aspect of context: physical environment (such as lighting and noise level), individual characteristics (personality and disability characteristics), activities and routine (which determine the range of sensible messages and opportunities to communicate), communication partners (including their skills and the opportunities they create), and the process of communication (initiating, sustaining, and terminating conversation across forms). The four aspects serve as the primary organizational structure for the holistic communication profile described in this article.

The Influence of Pivotal Milestones on Communicative Development

The following cognitive and social milestones are considered to be "pivotal" because their achievement influences development in multiple domains, including communication: joint attention, imitation, meansend, object permanence, discrimination, and categorization (Bruce, 2005b). Although there is research evidence on the importance of these milestones for children with intellectual disability, visually impairment, and deafness, there is a need for research on children who are deaf-blind.

Joint attention is attention that is shared between two people and then extended to include shared attention over objects. While sharing attention over objects, adults are able to teach children about the properties of the objects. Understanding communicative representations of objects is founded on knowing the properties of the objects, on being able to discriminate one object from another, and on the ability to hold thoughts about the objects (Pennington, Lloyd, & Wallis, 1991; Werner & Kaplan, 1988).

Human infants demonstrate the ability to primitively imitate (copy the behavior of others) and to recognize when they are being imitated (Meltzoff & Decety, 2003). These skills are shaped to become more complex synchronous and deferred imitation. Research conducted by McLean and Snyder-McLean (1991) suggests that the achievement of

motor and verbal imitation is critical to the development of language in children with intellectual disability with prompted imitation alone being insufficient to support language development (Warren, 1991). The ability to imitate others supports efficient learning and allows the child to imitate the communicative expansions that adults provide.

The achievement of means-end occurs when the child can carry out a sequence of steps that includes overcoming an obstacle to achieve a goal (Willatts, 1999). Early means-end behaviors share a strong positive correlation with the development of intentional communication, and later means-end behaviors are correlated to understanding the intent of others, critical skills in communication development (Bates, Carlson-Luden, & Bretherton, 1980; Bruce, Campbell, & Sullivan, 2009).

Full mastery of object permanence (knowing that an object still exists when it is out of sight and touch) is associated with the achievement of mental representation, symbolic play, and language (Lee, 1993; Wright, Lewis, & Collis, 2006). In studies of children with severe intellectual disabilities, Kahn (1983, 1984) concluded that both object permanence and means-end were essential to the achievement of language; however, Bigelow (1990) found that children who are blind were able to gain about 50 vocabulary words before full mastery of object permanence. Tactile experiences (not auditory experiences) are the foundation for object permanence mastery in children who are blind (Fraiberg, 1977; Schwartz, 1984). Kahn (1984) demonstrated that speech acquisition was enhanced when communication programming included direct instruction of object permanence and means-end.

Discrimination is the process of treating a single object as different from another single object (Rakison & Oakes, 2003). One must be able to discriminate one representation from another (in at least one form of communication) to support vocabulary development. Categorization is an outgrowth of the maturing ability to discriminate. With categorization one can classify or group objects or events by some perceptual or conceptual principle or rule that requires discrimination (Berk, 2006).

Visual self-recognition is another milestone that is often reported as pivotal to language development (Nielsen, Suddendorf, & Dissanayake, 2006). More research is needed to explore nonvisual forms of self-recognition and the relationship of self-recognition and the broader concepts of individuation and self-awareness to the development of communication and language in children with multiple disabilities and blindness or deaf-blindness.

The Influence of Object Handling and Play

Object handling (preplay) and play are essential areas to assess when planning individualized communication interventions. This is because play is an important context in which we may observe communication and because of the strong positive correlations between select play, cognitive, and communication skills (Finn & Fewell, 1994). The development of intentional communication and symbolic expression are pivotal periods in communicative development that have parallels in play (McCathren, 2000; Siegel-Causey & Downing, 1987; Yoshinaga-Itano, Snyder, & Day, 1999).

Ogura (1991) identified the following 13 levels of categories of play behavior: simple manipulation, sensory effects manipulation, inappropriate relational manipulation, container relational manipulation, grouping manipulation, functional relational manipulation, conventional naming act, pretend self-play, pretend other-play to dolls, pretend other-play to other people, substitution play, combinations of a single scheme, and planned play. Ogura's schema is helpful because it includes simple and more complex object manipulation. Ogura's framework may be used to develop questions for structured informal assessment or to analyze findings based on the use of commercial assessments. For example, Pizzo and Bruce (2010) demonstrated how to apply Ogura's schema to an analysis of the items on the Play Assessment Questionnaire (Yoshinga-Itano et al., 1999). Children who exhibit preplay skills (object handling skills) may be assessed using Assessing Interactions with Objects (Friedman & Chen, 1989). In addition, readers should consult occupational therapists about object handling and play development skills.

The Structure of the Holistic Communication Profile

The structure for the holistic communication profile described in this article was developed by the author

during a communication research study and then used in preservice and in-service teacher preparation. Profile categories were grounded in an extensive review of the literature, with a small segment of that literature shared previously. The following additional characteristics of communication have been cited as important or even predictive of language development by some researchers and are included in the holistic communication profile: rate of intentional communication acts, persistence (repetition and repair), and one-to-one correspondence (lacono, Carter, & Hook, 1998; Rowland & Schweigert, 2000; Sarimski, 2002).

A sample holistic communication profile on Thomas, a young boy who is deaf-blind, is presented in the Appendix. Profile findings were based on observation with review and feedback from those who interacted with Thomas daily. In addition to the sample profile, the reader may want to review the prototype on which this profile was based. The prototype is a more extensive structure because it contains information that could be relevant to other children who are deaf-blind but was not relevant to Thomas's individualized holistic communication profile. Readers may access the prototype at http://www. nationaldb.org/documents/Holcommprofile.doc. Items within the prototype structure may be used to plan either observations or interviews for structured informal assessments. The completed holistic communication profile is a record of how one child communicates in multiple settings.

Conclusion

Schemas such as the four aspects of communication support teachers, therapists, and parents to broaden their lenses when considering how a child communicates and what interventions are necessary for improvement. Without such a framework, the team might consider forms but not think about intents/functions and the interaction of the two (how a child communicates specific functions in specific forms), or the team might view communication as an isolated domain of learning. Holistic communication profiles express findings about one child's communication development, including closely related social and cognitive milestones. This record may be useful for home-school collaboration as the child transitions from one grade to another or as the child transitions from school to adult living and vocational settings. Holistic communication profiles can support team members to manage the complexity of communication intervention while supporting children who are deaf-blind to communicate more effectively.

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Child: Thomas

Age: 8 years, 9 months

Etiology/-ies/Syndromes: CHARGE syndrome

Visual Condition(s)/Vision Status: Colobomas of iris, optic disc and maculae; superior field loss; pendular nystagmus; legal blindness with a measured acuity of 20/260

Hearing Condition(s)/Hearing Status: Severe, bilateral hearing loss

Motor Status: Although Thomas ambulates independently, he has an amputation below the knee of one leg, and he wears an orthotic. He uses a variety of equipment with and without support, including a scooter that he rides on with support.

Psychological: Developmental delays (no specific IQ is cited due to congenital deaf-blindness) **Placement:** Deaf-blind classroom in private school; nearly 1:1 teacher to student ratios

Level of Communication: Thomas's levels of communication were determined by assessing him on the Communication Matrix (Rowland, 2004).

Refuse/Protest: Thomas expresses at Level V (able to refuse by selecting alternative or by redirecting). He continues to use frequent Level III refusals (pushing and pulling) and Level IV refusals (vocalizations with specific intonations).

Obtain/Request: Thomas displays emerging Level VII requests as demonstrated by the use of emerging two word utterances, such as "want book" and "more _____."

Social: Thomas communicates social functions at Level IV (directs attention of others physically). Information: Thomas expresses the information function at an emerging Level VI. He labels in single signs, including "book" and "light."

Overall: Thomas is expressing at different communicative levels according to the function expressed. For example, while he can refuse at Level V, he more often reverts to protesting at Level III. He is most advanced at the obtaining/requesting function, which is at emerging Level VII (two word utterances.)

Expressive Forms:

Vocalizations:

Thomas uses several vocalizations that are understood by others. Examples follow:

Thomas uses vocalization to protest (such as when the computer screen switches off when he is in the middle of drawing).

He uses vocalizations when unhappy or frustrated (such as when toys drop and he can't get them or when frustrated while working).

He vocalizes to indicate when he is finished with activities such as swinging.

Pictures/line drawings:

Thomas uses pictures and line drawings (in color) with understanding and can point to pictures to express thoughts about daily objects and activities.

Gesture:

Thomas uses the gesture of reach for multiple purposes. Examples follow:

Uses reaching to access pictures on communication board

Reaches so therapist holds book up more

Reaches for teacher's hand (when he wants to be done with Sensory Integration room)

Reaches toward book and other preferred objects

Reaches for teacher's hand to gain assistance

Thomas expresses proximal and distal pointing. Examples follow:

Points to self as a form of self-reference.

Exhibits directional point while on scooter. He points to the door to indicate a desire to exit the room on the scooter. He points to indicate direction and to direct another to turn in a particular direction (a request).

In addition, Thomas uses the contact gesture of pushing people and objects away to express refusal/protest. He claps to express excitement (especially during computer sessions).

Thomas also moves his arms all about as an invented gesture (also known as a "home sign") for requesting an opportunity to draw on the computer.

Appendix. Thomas's holistic communication profile: Integrating pivotal social and cognitive milestones in communication programming*

*Note that at the time Thomas's profile was written, the communication context considerations were not yet part of the profile structure. These were added later and are included in the prototype.

Signs and sign combinations (initiated by child):

- more
- book
- more book
- finished
- want basket
- broken
- light

Signs and sign combinations (imitated but not yet initiated by the child):

- truck book
- bye
- basket
- circle
- more work

Receptive Forms:

Pictures/line drawings:

Thomas understands the meaning of pictures and line drawings (in color). For example, when shown the picture for a swing in the Sensory Integration room, he goes directly to it. (He demonstrates this ability even when the pictures/line drawings are not paired with verbalization.)

Gestures:

Thomas understands some gestures used by others (even when they are not paired with verbalization or formal signs), although his vision loss interferes with gaining this skill. For example, the teacher gestures for him to face a particular direction and he does (even though the gesture was not paired without verbalization).

Signs:

Thomas understands some signs. With repeated exposure, he learns to imitate the signs and later produces the sign spontaneously.

Verbalizations:

Thomas understands the verbalizations of others, both adults and other students. He is also able to infer the appropriate action to take even when it is not explicitly expressed. Examples follow:

When asked to take off his coat, he does.

When asked to put a disk into the computer, he does.

When asked to take off his shoes/socks, he does.

When asked if he wants his weighted vest, he sticks out his arm.

When a student tells him to mail his letter, he reaches up to the mail slot and mails it.

At the end of work time, the teacher asks, "Are we all done?" and he gets up, takes off his vest, and attempts to hang it on the chair.

Mental representation—use of icons, indices, and symbols:

Thomas understands icons, indices, and some symbols, across forms. Some of his line drawings are iconic; others are not. He associates the computer disk outside the computer room with working on the computer (an index). He recognizes the shoebox symbol for the Sensory Integration room. This is because he has a routine that involves taking off his shoes just prior to entering that room. He also invents signs and uses signs that are not perceptually similar to a referent (thus, they are symbolic).

Intents/functions expressed

Answering: Thomas expresses answering by performing physical actions that demonstrate his comprehension.

- *Protest:* Thomas expresses refusal/protest through vocalization and gesture. He pushes and pulls away from adults. He pushes an adult away when he is not finished with an activity, and he anticipates that the adult may interfere. On rare occasions, he will leave an area or room to protest. He also uses vocalizations to protest.
- Requests for actions and objects: Thomas requests help by reaching and pulling an adult toward himself and through vocalization. He also shakes his body when he wants someone to rub his tummy (a motor reenactment). He requests more of an activity. He points to self for a turn. When riding on the scooter, he requests to be steered in a particular direction by pointing in that direction. He requests objects by reaching out toward an object.

Labels/names: Thomas can see an object or picture and name it (such as "light" and "book"). Greeting: Thomas expresses exit greetings (signing "bye") but not entrance greetings ("hi").

Appendix. Continued.

Rate of intentional communication acts per minute/hour and/or high frequency rate contexts:

Thomas's highest rate of communication was 49 intentional communication acts (ICAs) in 16 minutes, 12 seconds, during tabletop activities with the speech therapist, within the classroom setting. His second highest rate was 49 ICAs in 28 minutes while working with his teacher on tabletop activities (academics) in the classroom.

Imitation (other than words expressed in signs):

Thomas imitates fine motor and some gross motor movements. He is able to follow the snail's path to make a number (imitation in the context of using computer software). His computer teacher traces a "T" for his name, and he imitates her movement.

Sharing joint attention (may include sharing affective states with others, gaze shifts, and/or tactual shifts for children who are visually impaired):

Thomas exhibits both gaze shift and tactual shift. He understands the need to gain the attention of another before communicating to that partner. He shares both visual and tactual attention with other adults and visual attention with peers. He also shares positive affective states with adults, especially when he initiates interactions. For example, he hugs his teacher and simultaneously touches her face to identify her facial expression.

Object permanence:

Thomas has mastered object permanence. He consistently remembers where familiar objects are located and returns to those locations at a later time.

1:1 correspondence:

Thomas demonstrates 1:1 correspondence when he uses signs for specific things.

Means-end/cause-effect/problem solving:

Thomas has means-end understanding and he demonstrates problem solving. Examples follow: Understands that if he makes particular movements on the computer screen, he will be drawing.

Knows that if the elevator door is closed, he can open it by touching the correct elevator button.

When the bubbling fish tank does not bubble, he shakes the tank, and when that doesn't work, he seeks adults for help (using adults as tools).

Discrimination/Categorization:

Thomas discriminates in many ways (such as discriminating objects and line drawings). He does not yet categorize, although it is being addressed in his school program. Thomas engages in a lesson involving two containers, each with an affixed line drawing (in color). He then is given an object to place in the container with the corresponding line drawing attached. This lesson requires him to match the object (such as a car) to the line drawing and place it in the correct container. It is a form of matching that can become a sorting lesson later. It is also a categorization lesson because one of the containers is for "animals." and he will eventually be placing different types of animals into the container.

Self-recognition/individuation:

Thomas expresses his sense of individuation by pointing to himself. While he does not yet sign "no," he does assert his opinions.

Repetition/Repair (measures of persistence):

Thomas engages in both repetition and repair. He repeats his signs and will repeatedly point to select a line drawing. He was even observed to correct an adult who used informal one-handed sign for a sign that is usually signed with two hands. He lifted her other hand as a repair for her communication. When repairing, Thomas most often expresses himself in a different form, including gesture, body language, and vocalization.

Object Handling or Play: Thomas's teacher and parents completed the *Play Assessment Questionnaire* (PAQ) (Yoshinaga-Itano, Snyder, & Day, 1999) to determine his level of play skills. Twelve of the 45 items were rated differently by the teacher and parent(s). In most cases, the teacher gave full or partial credit, and the parent did not. This may be due to different interpretation of the items or differences in Thomas's performance in the home and school settings.

Teacher and parents rated items 1, 3, 4, 5, 6, 7, 10, 11, 12, 13, 14, 16, and 29 as mastered. This means that Thomas has mastered the following play skills across environments: viewing and mouthing objects (achieved when young), stimulating senses with objects, manipulating objects, functional use of objects (using as intended), banging objects together, putting one object in another (whether or not the objects belonged together), bringing objects to adults, basic play with props that are everyday (wearing play glasses or drinking from empty cups, for example), and put objects in a sequence (such as stacking nesting cups or blocks by size).

Appendix. Continued.

Some of Thomas's emerging play skills (based on positive or emerging ratings by either the teacher or parent) include: Grouping objects that belong together, making a specific sound with a particular toy or part of toy, repeating sound or action adult makes on toy, and repeating action performed on person or object on another person or object.

The following items were not yet performed (as rated by both the teacher and the parents): 19, 22, 25, 26, 28, 30, 31, 34, 35, 37, 39, 41, and 42. This means that Thomas has not yet achieved the following play skills: treating doll as baby, bringing all parts of activity/game to the play area, performing two different actions with the same toy or object, performing the same action on two different people or objects, using object as something else (substitution in play), acting for a doll or figure, using sound effects with toys (note hearing loss), sequencing three or more related play actions, organizing props for play, helping a doll to act on his own, two substitutions in play, using appropriate size props for bigger or smaller dolls or objects, and use of body part instead of prop. Summary of Play Results: In applying Ogura's (1991) schema of play, we can say (based on the PAQ results) that Thomas has mastered the following types of play: simple manipulation, sensory effects manipulation, inappropriate relational manipulation, functional relational manipulation, and pretend self-play. He has some achievements but has not yet mastered the following types of play: container relational manipulation and conventional naming act. In addition, he exhibits one behavior, within the categories of pretend other play and the planned play category. He does not yet demonstrate pretend doll play, substitution play, combinatorial symbolic play, or most of the planned play schemas.

Summary and Recommendations for Communication Programming Emphasis:

Thomas expresses himself through gestures, line drawings, pictures, and sign. In addition, he has receptive understanding of verbalizations. Thomas is on the cusp of linguistic performance. He is already an emerging linguistic communicator when expressing requests. He points for a variety of purposes and expresses some signs and even a few two-sign combinations. Thomas has mastered the pivotal milestones described earlier, with the exception of categorization (which is being addressed in his school program). Thomas has a strong self of self. He expresses his opinions, and he persists (through communicative repetitions and repairs) until others understand his message.

Thomas expresses a variety of requests, protests, and answers. Although on occasion he expresses an exit greeting ("bye"), it is not consistent, and he does not yet spontaneously express "hi." His vision may be presenting some barriers to recognizing individuals he might greet. Stooping down to his eye level and then pausing may support him to recognize opportunities to greet. He might also rehearse greetings when a peer joins him for a tabletop lesson. Thomas would also benefit from additional instruction on how to express comments. Adults may model the expression of comments on actions and objects. These same objects should reappear systematically in a similar context to support Thomas to recognize when he might make similar comments.

A strong relationship is shared between some play skills and specific communication achievements (such as the appearance of symbolism in play and communication). Thomas's primary needs within the area of play are in planning play and in symbolic play (including the use of substitutions). Thomas would benefit from opportunities to engage in play schemas involving multiple objects and toys. If an anticipated toy or object is missing, he can then be encouraged to make substitutions for that object. Gathering the necessary play materials and then grouping related toys within play schemas will move him toward engaging in more complex play and may also support his development of categorization skills. Thomas can also engage in pretend play schemas with others. He should also focus on performing two different actions with the same toy and the same action on different people or objects.

Much of the communication Thomas shares with others occurs in the context of 1:1 relationships with adults. He is showing interest in at least one of his classmates. He takes turns with this child and engages in parallel play near that peer. It is good to see these behaviors, and it is recommended that the classroom staff continue to build opportunities for Thomas to express a variety of functions with his peers.

Appendix. Continued.

Theory Paper/Thought Piece

Special Education, Related Services, and Supports for Children Who Are Deaf-Blind

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Abstract

The purposes of this article are (a) to create opportunities for meaningful discourse, (b) to promote shared understanding of the situated perspectives of stakeholders, and (c) to stimulate solutions-focused collaborative problem solving among stakeholders for improved design and delivery of special education and related services for children who are deaf-blind. An overview of the history and evolution of service delivery for children who are deaf-blind, as well as a presentation of deaf-blind child count demographic data, serves as a platform from which to ponder both lessons learned and to highlight considerations of future directions for the design and applications of policy, practice and research. This information is timely as education legislation (i.e., the Elementary and Secondary Education Act and the Individuals with Disabilities Education Act of 2004) is under review for reauthorization; these laws will determine the future of education that will impact all of America's children including children who are deaf-blind.

Keywords: deaf-blind, current services, future needs

We can, whenever and wherever we choose, successfully teach all children whose schooling is of interest to us. (Edmonds, 1979, p. 23)

As we enter the second decade of the 21st century, a post 9–11 America is mired in "The Great Recession" in a world that has become "increasingly hot, flat, and crowded" (Friedman, 2008). Civility, diversity of opinion, and respectful discourse have lost ground as Americans increasingly self-segregate to associate with like-minded groups, and it appears that polarization and intolerance are the result of shielding ourselves from uncomfortable realities

(Kristof, 2009). In contrast, our population of 300 million has become increasingly diverse across a number of dimensions and social institutions (e.g., economic, political, social, cultural, linguistic, religious, geographic, dis/ability, gender, age, housing, employment, health, social services, transportation, and education). Education is viewed as a ladder to opportunity and great equalizer, and since the "War on Poverty" began in 1965, education policy has been driven by goals of equity and excellence to overcome disadvantage.

However, consider the complexity, enormous costs, and competing agendas as public education operates with oversight from local, state, and federal governance authorities across 15,000 school districts or local education agencies (LEAs). Multiple stake-holders with diverse perspectives regarding the role

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and purpose of education often compete for resources, recognition, and respect. Consider the concerns of those who are members of minority groups and who experience discrimination, marginalization, and exclusion as a result of the historical legacies of racism and the differential treatment of immigrants and English-language learners (adults as well as children). The disadvantages these groups face intersect with poverty in complex ways that continue to confound public educational policies and practices (Kozleski & Smith, 2009).

Now consider the challenges presented by children who are deaf-blind and who represent one of the lowest incidence and most diverse groups of learners receiving early intervention, special education, and related services (Muller, 2006). Of the nearly 10,000 children identified as having combined hearing and vision loss, 90 percent experience concomitant physical or intellectual disabilities or complex medical and behavioral challenges (Killoran, 2007).

The purposes of this article are (a) to create opportunities for meaningful discourse, (b) to promote shared understanding of the situated perspectives of stakeholders, and (c) to stimulate solutions-focused collaborative problem solving among stakeholders for improved design and delivery of special education and related services for children who are deaf-blind. This is an earnest attempt to grapple with difficult issues and "wicked problems" (Deshler, 2009) in an era of unprecedented knowledge production. societal change, budgetary crises, and concern about the future. An overview of the history and evolution of service delivery for children who are deaf-blind, as well as a presentation of deaf-blind child count demographic data, serves as a platform from which to ponder both lessons learned and to highlight considerations of future directions for the design and applications of policy, practice, and research. This special issue of AER Journal is timely and occurs as education legislation (i.e., the Elementary and Secondary Education Act and the Individuals with Disabilities Education Act [IDEA] of 2004) is under review for reauthorization; these laws will determine the future of education that will impact all of America's children including children who are deaf-blind.

A Review of the Past

The worldwide rubella epidemic of 1963–1965 was followed by the birth of children with multiple

disabilities or concomitant vision and hearing loss due to maternal prenatal exposure. The epidemic heightened awareness of the needs of children with severe disabilities, including those with deaf-blindness.

Initiatives to address the needs of these children and their families began during the Kennedy Administration and were followed by the Johnson Administration's "War on Poverty" and "Great Society" initiatives, including passage of the Elementary and Secondary Education Act in 1965. Public Law 90-247 (1968) included authorization establishing regional centers to meet the needs of children with deaf-blindness, and, in 1969, the Department of Health, Education, and Welfare established eight, increased shortly thereafter to ten, centers under the Centers and Services for Deaf-Blind Children Program, funded by a \$1 million appropriation. The regional centers' charge was to prepare teachers and school personnel to provide educational services for children with deaf-blindness and to develop methods, materials, and intervention models for children and support for their families. The centers served as a foundation for regional and national training and technical assistance (TA) networks.

In 1975, Public Law 94–142, the Education for All Handicapped Children Act (EHA), established requirements for all children with disabilities to be provided a free, appropriate, public education (FAPE) based on an individualized education program (IEP) in the least restrictive environment (LRE). Children who were previously excluded from public schools based on arbitrary determinations of "educability" were now entitled to an education. Notably, this legislation brought heightened attention and focus to making services available in local school programs throughout the country. By 1976, the 10 Centers for Deaf-Blind Children were funded by \$16 million in federal appropriations and were providing direct services to children and TA to regional, state, and local agencies. In subsequent years, these 10 centers were decentralized as multistate and single-state deaf-blind projects were established during the 1980s.

Since its inception in 1980, the U.S. Department of Education's Office of Special Education Programs (OSEP) has funded TA projects and personnel preparation programs to build state and local

capacity to serve children who are deaf-blind and their families. Since 1986, a series of national TA centers have worked with regional, multistate, and state deaf-blind TA projects to increase state and local capacity in the provision of appropriate educational and related services to students identified as deaf-blind. As a result of those projects and programs, professionals, advocates, individuals who are deaf-blind, and parents have collaborated to make progress in identifying evidence-based intervention practices for children who are deaf-blind, developing high-quality training materials and resources, and developing networks across states to share information. OSEP support for these projects continues to this day, with program authorization outlined by the Department of Education in the March 25, 2008 Federal Register, which articulates the ongoing challenges and needs of children who are deaf-blind:

Children who are deaf-blind are often isolated and disconnected from people and activities in their homes, schools, and communities both because they cannot access visual and auditory information and because they are not provided the individualized supports necessary to access this information. Without individualized supports to access visual and auditory information (i.e., environmental information, such as who is present, what is being said, and what activities are occurring), children who are deaf-blind are at greater risk for not attaining age-appropriate milestones in communication and language, movement/orientation and mobility, social skills, and activities of daily living, which in turn affects educational outcomes. Consequently, students who are deaf-blind often exit school at age 22 without viable postsecondary education, employment, or independent living options. (U.S. Department of Education, p. 15744)

Most state educational agencies, Part C state lead agencies, and LEAs lack sufficient numbers of personnel with the specialized training, experience, and skills that are needed to provide appropriate early intervention, special education, and related services to children who are deaf-blind (Collins, 1992; Markowitz, 2001; McLetchie, 1992). The critical shortage of personnel to serve children who are deaf-blind can limit access to a FAPE for these children. The National Deaf-Blind Child Count Registry data show that although there has been significant growth in the number of children served in local community schools, 85 percent of school-age children who are deaf-blind continue to receive their services in separate settings. More work is needed to ensure that early intervention, special and regular education, and related services personnel have adequate skills to appropriately serve infants and toddlers in natural environments, which may include home and community settings, and school-age children in the LRE (U.S. Department of Education, 2008).

IDEA 2004 Part D legislation allocates \$12.8 million to "address the educational, related services, transitional, and early intervention needs of children with deaf-blindness" (IDEA, 2004, [HR1350, Sec. 682 (d)(A)]). With these funds, OSEP supports 52 state TA projects to improve results and services to children who are deaf-blind (i.e., 50 states, Puerto Rico, and the Pacific Basin), and a national center, the National Consortium on Deaf-Blindness (NCDB), as well as professional development grants to improve teacher preparation. The state deaf-blind TA projects and NCDB are part of the OSEP Technical Assistance and Dissemination network and provide TA, resources, data/information, and materials to states, local schools, educational professionals, and families.

A Demographic Snapshot of Children Who Are Deaf-Blind (Birth to Age 21)

NCDB is charged to collect, coordinate, report, and maintain data from an annual National Child Count of Children and Youth Who are Deaf-Blind. NCDB, and its predecessors, have completed the child count since 1986 by collaborating with the state deaf-blind TA projects to gather data on children who are deaf-blind, based on the following IDEA 2004 definition for deaf-blindness: "Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness" (Child with a Disability, 2007).

The 2008 National Child Count of Children and Youth Who Are Deaf-Blind identifies 9,872 infants,

Table	1.	Age	of	Students	Who	Are	Deaf-Blind
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Age	Number of Students	% of Total (Approximate)
Birth to 2	615	6
Ages 3 to 5	1,225	13
Ages 6 to 11	2,851	29
Ages 12 to 17	3,255	33
Ages 18 to 21	1,816	19
Over the age of 21 but still eligible, or "age not reported"	65	

children, and youth (birth through age 21) that meet the federal eligibility criteria for deaf-blindness (NCDB, 2009). This number has remained relatively stable over the past 10 years. The vast majority (91 percent) of these students who are deaf-blind live at home with parents, extended family members, or foster parents. Table 1 provides numbers of students by age group; Table 2 provides numbers of students by ethnicity.

Etiology

Given the role the rubella epidemic played in stimulating early federal support for services for children with deaf-blindness in the 1960s, rubella syndrome as an etiology associated with deafblindness has declined significantly. Presently, data are collected on over 70 possible etiologies underscoring the challenges in identifying impact and need. Of the most commonly identified etiologies 24 percent of students are identified as experiencing deaf-blindness due to hereditary/chromosomal syndromes and disorders, another 12 percent due to prematurity, 7 percent due to prenatal complications, and 6 percent due to postnatal complications. The single most commonly identified syndrome is CHARGE syndrome, representing 7 percent of all students reported. In fact, the prevalence of students identified with CHARGE syndrome has increased over 130 percent in the last decade.

Concomitant Disabilities

Over 90 percent of children and students have one or more additional disabilities. Sixty-six percent have a cognitive impairment (the most frequently reported additional impairment), followed by physical impairments (60 percent), and complex health care needs (49 percent). The trends associated with concomitant disabilities have remained relatively consistent over the past 10 years.

Educational Settings

There have been significant shifts in the location where educational services are provided for children with special education needs. Prior to EHA, children with moderate to severe disabilities were typically denied entry to public schools, although some states did provide services in special schools. Despite gains in early intervention settings, however, the pace of integration and inclusion for school-age children who are deaf-blind lags behind other students identified under other eligibility categories. In 2008, the educa-

Table 2.	Ethnicity	of Students	Who Are	Deaf-Blind
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Reported Ethnicity	Number of Students	% of Total (Approximate)
White (non-Hispanic)	5,657	58
Hispanic	1,929	20
Black	1,523	16
Asian or Pacific Islander	408	4
Native American or Alaska Native	170	2
Unknown	140	1

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tional settings for infants and toddlers, preschool-age children, and school-age children were as follows.

Early Intervention Settings (Birth through Age 2)

The data for infants and toddlers are consistent with national data reflective of settings for students with other disabilities. About 82 percent of infants and toddlers who are deaf-blind are served at home and 8 percent are served in community settings.

Early Childhood Settings (Age 3 to 5)

Data reflect that 14 percent of children in this age group are served in regular early childhood settings, with approximately 8 percent served in regular early childhood settings between 40 percent and 79 percent of the school day. Approximately 20 percent of preschool students are served in separate classrooms and 17 percent are served in separate schools.

School-Age Settings (Age 6 to 21)

Approximately 11 percent of school-age students are served in regular classrooms, with 7 percent served in regular classrooms between 40 percent and 79 percent of the school day. Thirty-eight percent are in regular classrooms less than 40 percent of the day and 29 percent receive services in separate schools or residential facilities.

Questions, Observations, and a Look Toward the Future

How does America identify best and promising practices to address the needs of the 10,000 students identified as deaf-blind by NCDB and state deaf-blind TA project child counts? What local, state, and national systems need to be in place to ensure quality implementation of these practices? Contemplating these questions can be daunting, particularly when considering the large number of individuals involved in present efforts to provide quality educational services for students who are deaf-blind (e.g., the students themselves, families, teachers, teaching assistants, principals, school personnel, university personnel, state and local education agency personnel) and how the influence of their respective interests and perspectives can support or hinder implementation efforts. Questions arise about shared understandings and differing perspectives of this wide variety of stakeholders. However, it is imperative that strong partnerships and shared visions among all stakeholders, including parents, researchers, state and local education agencies, service providers, and consumers be established to address standards-based curriculum alignment, instructional coherence, and system and program accountability.

A further complicating scenario is that NCDB deafblind child count data differ widely from IDEA Part B and Part C State Child Count data reported annually by state education agencies. Although the reasons for this are beyond the scope of this article, readers are encouraged to read the NASDSE Forum article by Muller (2006) for insights on this discrepancy. IDEA Part D discretionary grants require the state deaf-blind TA projects to work with NCDB on the deaf-blind child count based on the rationale that these data are essential for the design and delivery of effective TA to assist states in providing appropriate services based on descriptive data regarding current demographics needed to inform current and future needs. How can we ensure that no child who is deaf-blind is left behind or denied opportunities for access, participation, and progress in the general education curriculum?

Disability labels are not benign. Some disability labels carry greater stigma than other labels, and the degree or level of involvement of disability is a cofactor in stigmatization and segregation (Smith, 2001). Students who are served under the disability categories of mental retardation, multiple disabilities, autism, and deaf-blindness are less likely than their peers who fall into high-incidence categories to spend their school day in inclusive classrooms (Smith, 2006).

Great strides in medicine and health have led to improved identification of children who have special education and related service needs, and identification of specific etiologies have informed policy, research, and practice for children with complex and specialized health and education needs. Consider how perceptions, public expenditures, and service delivery have changed since "autism" became "autism spectrum disorders." Smith (2008–2009) argues that our view of "the medical model" would

be informed by the World Health Organization's (2010) International Classification of Functioning, Disability, and Health (ICF):

The ICF puts the notions of "health" and "disability" in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus "mainstreams" the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metricthe ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a "medical" or "biological" dysfunction. By including Contextual Factors, in which environmental factors are listed, the ICF allows [for] the impact of the environment on the person's functioning.

For example, in 2010, The American Association of the Deaf-Blind (AADB) suggested the following definition that appears to have been influenced by the ICF:

Deaf-blind or deafblindness is a combination of hearing and vision loss of any varying degrees that affects a person's ability to communicate, get environmental information, participate in the community, obtain and keep a job, and maintain independence. (AADB, 2010)

In contrast, the IDEA definition of deaf-blindness appears to focus on special education programs rather than IEP provisions:

Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. ([34 CFR 300.8 (c) (2)])

Do shared eligibility labels and programmatic concerns trump individual student needs and family preferences? Advocates of inclusive education argue that such policy implementation is inconsistent with policy, research, and practice and incongruent with the promise of FAPE in the LRE. Conversely, other families and professionals contend that children who have intensive or specialized support needs are best served in separate school programs (e.g., Garvue, 2009). Some argue that center-based service delivery configurations are the most efficient, efficacious, and cost-effective and cite IDEA language regarding the continuum of services despite guidance stating:

The process for determining the educational placement for children with low-incidence disabilities (including children who are deaf, hard of hearing, or deaf-blind) is the same process used for determining the educational placement for all children with disabilities. That is, each child's educational placement must be determined on an individual case-by-case basis depending on each child's unique educational needs and circumstances, rather than by the child's category of disability, and must be based on the child's IEP. We believe the LRE provisions are sufficient to ensure that public agencies provide low-incidence children with disabilities access to appropriate educational programming and services in the educational setting appropriate to meet the needs of the child in the LRE. (Department of Education, 2006, p. 46586)

A review of the IDEA funding related to children who are deaf-blind has fluctuated from \$1 million in 1969 to slightly under \$15 million under IDEA Part D deaf-blind services program authority in the 1980s. The deaf-blind program authority was augmented by an additional \$12.4 million from the mid-1980s until IDEA 97 Part D program authorities were reduced from 14 to 5 and specific authority for both deaf-blind and severe disability was eliminated. However, IDEA 97 and 2004 retained a \$12.84 million funding floor dedicated to this population.

Several key special education initiatives are being implemented across the country, including response to intervention, early intervening services, universal design for learning, and positive behavioral interventions and supports. How are the interests of children who are deaf-blind or have other low-incidence disabilities or complex support needs currently included in these efforts? How can they be included in these school improvement efforts? Such complex and important questions require thoughtful discourse

among stakeholders regarding equity, access, participation, and outcomes for the individual as well as a focus on how we configure the design of educational service delivery systems. How do we best ensure that policy-makers and program implementers are informed by stakeholders? How do we efficiently prepare and deploy human resources to meet the needs of children who are deaf-blind? In this era of fiscal concerns and state budget cuts, how will children with complex support needs fare in the context of macro education issues regarding costbenefit and efficiency as education systems race to the top? Do professionals in deaf-blindness inadvertently identify children who are deaf-blind as "other" in our attempts to describe their needs? Do we convey the message that teachers must be "miracle workers"? How can we increase use of individualized supports by using paraprofessionals and interveners?

How can we best foster civil and scholarly exploration of stakeholders' perspectives when so many have such great needs? Passions are high, and we must promote shared understandings of the "wicked problems" confronting us. Any real and perceived slights and old wounds from the past must be put aside to mobilize resources. We must identify how both the "bottom-up" and "top-down" school improvement efforts converge across federal, state, and local levels to best leverage systemic change to benefit children who are deaf-blind. As we contemplate these important issues and questions it is our fervent hope that we can capitalize on stakeholder passions and commitments to employ solutions-focused problem solving and use of data to improve the design and delivery of needed special education and related services. Our field has learned a great deal since 1965 and our collective knowledge, skills, and abilities can inform and improve education systems in a manner that is "value-added" and increases the capacity of education systems to differentiate instruction and provide individualized supports to learners that will improve outcomes for all children including those who are deaf-blind.

Disclaimer

This paper is intended to promote the exchange of ideas among researchers and policy makers. The views expressed in it are part of ongoing research and analysis and do not necessarily reflect the position of the U.S. Department of Education.

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