

DATA SUMMARY

Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind



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Introduction

Abstract



Quality assessment establishes a foundation for an appropriate education. Children who are deafblind are often labeled “difficult to test”, implying that the fault lies with the children, as opposed to the instruments used to test them. Assessments developed for children without disabilities are unlikely to be useful for children who experience dual sensory impairments, although they are often used to assess them. Assessments developed for children with vision or hearing impairments or for children with developmental disabilities may have some applicability, but are unlikely to be completely appropriate without adaptations. Some assessments have been developed specifically for children who are deafblind: these, however, are not likely to be supported by extensive reliability or validity studies, nor are they typically accompanied by “normative” data. If we question the quality of the assessments conducted on children who are deafblind, then we must also question the quality of the educational decisions and the instructional programs that are based upon those assessment efforts.

The goals of this project were:

- to identify the instruments used to assess children ages 2-8 who are deafblind and the purposes for which they are used;
- to conduct validation studies on instruments that are used to generate instructional goals and to monitor student progress;
- to develop final products that summarize the data generated by these studies, translating the data into recommendations for the assessment of young children who are deafblind.

The assessment instruments to be validated were ones that address communicative/social development or cognitive development. Project results are expected to promote high quality assessment of children who are deafblind, the generation of appropriate educational goals related to communication, social and cognitive development, the identification of appropriate instructional strategies, and a strong connection between assessment and the achievement of specific educational outcomes.

Personnel and Sites

This consortium effort involved four university sites that are noted for research and demonstration efforts involving children who are deafblind as well as the National Family Association for Deaf-Blind. The state technical assistance projects serving children who are deafblind also were involved in a number of project activities. Major sites and investigators were:

- Oregon Health & Science University (Dr. Charity Rowland)
- California State University–Northridge (Dr. Deborah Chen)
- University of Texas at Dallas (Dr. Robert Stillman)
- Columbia University (Dr. Harvey Mar)
- National Family Association for Deaf-Blind (Linda Syler, President)

Major Activities

To achieve the objectives of this project we engaged in a number of research activities, as listed below. Data that resulted from these activities are summarized in the remainder of this report.

- Initial review of assessment instruments and practices
- Survey 1 (nationwide survey of parents and professionals)
- Selection of assessments of interest
- Survey 2 (nationwide survey of parents and professionals who used selected instruments)
- Collection of new assessment data, further evaluations and IFSPs/IEPs
- Expert Query
- State Projects Query
- Interviews with Teachers and SLPs
- Family Specialist Query
- Focus Group on Assessment Practices
- Review of Final Product
- Dissemination

Demographics

Over the course of the project many family members and professionals participated in one or more aspects of our investigation. Demographics for all participating family members and professionals are described below.

Parent and Child Participants

A total of 105 parents provided data for this project. They represented the following states: AZ (2), CA (18), DE (3) FL (4), GA (2), IA (11), ID (1), IL (2), IN (6), ME (1), MI (2), NY (6), OH (17), OR (6), PA (2), TX (7), UT (6), WA (1), and Unknown (8). Languages used in the home were: Spanish (15), Korean (1), English (remainder).

All parents had a child who was deafblind, of whom 57 were males and 48 were females. The mean age of the children was 5.5 years, with a range of 1-15 years. The age distribution of these children appears in the table below.

Age in Years	1	2	3	4	5	6	7	8	9	10	11	12	13	15	Unknown
n	1	15	13	14	16	11	9	11	3	2	2	1	1	3	3

Ethnic or racial background of children

- African-American (5)
- Asian (2)
- Caucasian (71)
- Hispanic (27)
- Pacific Islander (1)
- SE Asian (1)
- More than one race (1)
- Other/Unknown Race (13)

Cause of deafblindness (only if listed by more than 2 respondents)

- Cerebral palsy: 14
- CHARGE or suspected CHARGE: 14
- Prematurity: 12
- Unknown: 22

Professional Participants

A total of 135 professionals provided data for this project. They represented the following states: CA (33), DC (1), DE (3), FL (4), GA (1), IA (2), IL (2), IN (5), KS (2), MA (2), MD (1), ME (2), MI (1), MO (2), MS (1), NY (17), OH (1), OR (2), PA (1), TX (27), UT (4), VT (1), WA (3), WV (1), and Unknown (13).

Professional roles of respondents

- Special Ed Teacher/Administrator (34)
- TA/Consultant/Advisor (25)
- Speech-Language Pathologist (17)
- EI/ECSE Teacher/Administrator (16)
- VI Teacher/Administrator (11)
- School Psychologist (10)
- Deafblind Project Director (7)
- Educational Specialist (6)
- Occupational Therapist (4)
- Adaptive PE Teacher (2)
- Physical Therapist (1)
- Unknown (1)

Highest professional degree obtained

- M.A./M.S. (79)
- B.A./B.S. (20)
- Certificate/credential/specialist training (16)
- Ph.D/Ed.S. (15)

Years of professional experience with children who are deafblind

- 0 years (2)
- 1-5 years (34)
- 6-10 years (22)
- 11-15 years (21)
- 16-20 years (17)
- 21-25 years (13)
- 26-30 years (18)
- more than 30 years (4)
- Unknown (4)

Survey Results

Over the course of the project we collected 234 evaluations of specific assessment instruments (78% by professionals and 22% by parents) and 192 assessments of young children (55% by professionals and 45% by parents).

Survey 1 included a professional and a parent version. Participants were recruited through the state deafblind projects and the NFADB. The professional version of Survey 1 solicited names of recommended assessment instruments as well as ratings of those instruments. The parent version included a number of questions about the quality of their child's last evaluation process and also solicited names and ratings of instruments that parents recommended. Demographics also were collected on both versions. Survey 1 was administered anonymously and respondents were provided a choice of \$20.00 gift certificates or a check through a third party to protect their identity. Both versions of Survey 1 are attached in Appendix E.

Survey 2 went only to parents and professionals who had used one or more of the 11 instruments that made our "Short List" based on the results of Survey 1 (see p.11). Participants were recruited through the state deafblind projects and the NFADB. The professional version of Survey 2 was administered anonymously and a \$20.00 gift certificate or a check was offered to respondents through a third party to protect identities. The parent version of Survey 2 was accompanied by a consent form, since parents were asked to provide copies of their child's assessment results and identifying information was collected. Parent respondents were provided a choice of \$50.00 gift certificates or a check for providing assessment results and rating instruments. Both versions of Survey 2 are attached in Appendix E.

Another group of parents and professionals agreed to both administer and rate specific instruments from the Short List on which we sought additional data. Those who participated in this activity were given an honorarium of \$50.00 for each assessment administered and rated. Parents were approached first for informed consent both to administer assessments themselves and to have professionals assess their child. For parents who provided consent, professionals subsequently provided their own consent.

Data from all of these sources are reported below. Parent and professional data are reported separately.

Parent Responses to Survey 1

62 parents completed our first survey, which focused on the assessment process and assessment instruments used on their child. Most parents did not know what assessment instruments were used to evaluate their child. Below are summaries of parent responses on the major questions from this survey.

Parents' Mean Ratings on Questions about the Assessment Process

Survey Question	Mean Rating ^a
1. How useful were the results of the latest evaluation report to you in terms of identifying the specific needs of your child?	3
2. How easy was it for you to understand the results of the latest evaluation report? That is, were the results presented in terms that you could understand?	4
3. Do the results of the latest evaluation report match your own observations about your child? That is, do they reveal the strengths and weaknesses that you see in your child?	3
4. How useful were the results of the latest evaluation report in terms of helping you participate in developing educational goals for your child?	3
5. How useful was the latest evaluation report in terms of describing your child's progress over time?	3
6. To what extent were you involved in the assessment of your child for the latest evaluation?	3

^aFive-point scale: 1 (most negative) and 5 (most positive)

The remaining questions on Survey 1 were open-ended. Answers were analyzed for major themes and grouped accordingly. Below, parent responses to the open-ended questions about the assessment process are summarized.

Least satisfactory aspects of my child's latest evaluation

- 40% - Tests inappropriate, underestimated child
- 20% - Evaluation didn't provide helpful facts or suggest things to try
- 15% - Lack of progress of child
- 13% - Tests focused on what child can't do, rather than progress
- 10% - Evaluator didn't know child
- 5% - Didn't like how child was handled

Most satisfactory aspects of my child's latest evaluation

- 40% - Child is making progress
- 13% - Child treated respectfully, supportive, caring
- 13% - Gave parents information on child's development
- 13% - Evaluator cared about parent input
- 10% - Everyone worked together as team for child
- 8% - Parents given information on what to do for child, goals for child
- 5% - Tried to adapt test to fit child

Most frequent suggestions for assessment process

- 40% - Evaluators should get to know child
- 35% - Get input from parents and classroom
- 28% - Evaluations should help parents understand how to set goals and move forward
- 20% - Use tests appropriate for child who is deafblind
- 15% - Tell parents names of assessments, what for, what doing during assessment
- 10% - Start with child's strengths and reasonable goals
- 5% - Child's needs should be paramount—not costs or difficulty of trying new things

What a Parent Wants from an Assessment

- To have everyone who is connected to their child work together toward the child's and the family's best interests.
- To have their involvement and input requested and used.
- To have the evaluators either be familiar with the child or take the time to create a rapport before testing them. Ideally, the evaluation would occur under normal circumstances, or perhaps in several typical settings, taking the time needed for a good evaluation.
- To have tests appropriate to their child's condition.
- To be educated on the assessments and to have the results of assessments explained.
- To consider the child's whole self, not just the bits and pieces that are quantifiable through an assessment.
- To emphasize what the child can do over what the child can't do.
- To be informed about their child's development, and involved and supported in setting goals and implementing them.
- To see their child progress.

Professional Responses to Survey 1

105 professionals responded to Survey 1. In Survey 1, professionals were asked what instruments they used and which ones they recommended. Respondents could recommend any number of instruments. They were also asked to rate up to three instruments that they recommended. A total of 83 different instruments were recommended, most of which were listed by only one respondent. Of these, only 17 were recommended by four or more respondents. These 17 instruments appear below, ordered from most to least recommendations.

Assessments recommended by four or more professionals

- Oregon Project
- Callier-Azusa
- HELP
- INSITE
- Carolina
- Communication Matrix
- Battelle
- Brigance
- Vineland
- Infused Skills Assessment
- Assessment, Evaluation, and Programming System (AEPS) for Infants and Children
- LAP/ELAP
- Developmental Profile II
- Dimensions of Communication
- Every Move Counts
- Receptive-Expressive Emergent Language Test (REEL)

Selection of Assessments of Interest

Based on our literature review and analysis of many assessment instruments, as well as data from Survey 1, we developed the following criteria to select a “Short List” of assessment instruments to be studied further. These criteria were:

Criteria for “Short List”

- High ratings on survey questions
- Designed for assessment of 2-8 year olds
- Includes sections on social-communication and/or cognitive skills
- Readily available in the U.S.
- Other instruments developed specifically for population were also included

Based on the above criteria and informed by the ratings of instruments from Survey 1, and the comments provided about recommended instruments, the following list of eleven instruments made it to our Short List.

“Short List”

- Callier-Azusa*
- Carolina Developmental Profile
- Communication Matrix*
- Dimensions of Communication*
- HELP-Hawaii Early Learning Profile
- Home Talk*
- Infused Skills Assessment
- INSITE*
- Oregon Project
- Vineland
- School Inventory of Problem Solving Skills*

*Developed specifically for children with vision and hearing losses

Sources of Data for Instrument Ratings

Some ratings of the top 11 instruments were obtained through the wide net cast by Survey 1, and Survey 2 specifically requested ratings of these instruments. After Survey 2 had been concluded, we sought parents and professionals to both administer and rate specific instruments on which we had collected little data. Ratings from all three of these efforts have been combined to provide ratings from parents and professionals on the instruments that made our Short List.

Parent Ratings of Selected Instruments

16 parents rated instruments on the Short List through Survey 1, which included 5 Likert-style rating items. Three more parents completed Survey 2, which included 10 Likert-style rating items. An additional 33 parents rated parent versions of instruments that they used themselves to assess their children (only the *Home Talk*, *Home Inventory of Problem Solving Skills* and *Communication Matrix...Especially for Parents* were designed for parent use). These parents used the 10 rating items from Survey 2. The table below shows the mean ratings combined over the 52 parents who rated instruments on the Short List through any of the above means.

Parent Ratings of Instruments on Short List

Instrument	Callier-Azusa	Communication Matrix	HELP	HIPSS	Home Talk	Home Talk Section 3 only	Vineland
This instrument uses clear language		4.3	4.0	4.3	4.6	3.3	4.0
This instrument is easy for me to understand		3.9	4.0	4.1	4.5	4.0	4.0
This instrument is useful for evaluating my child's needs	2.5	4.1	3.5	4.0	4.8	3.0	2.9
This instrument encouraged me to be involved in my child's assessment process.		4.3	3.0	4.5	4.4	4.0	3.0
It is easy for me to understand the results that this instrument provides.	4.0	3.4	2.5	3.4	4.1	3.7	3.4
This instrument provides results that match my own observations of my child.	4.0	3.7	3.0	3.7	4.1	3.3	3.1
This instrument is useful for developing educational goals for my child.	2.5	4.1	3.5	4.3	4.4	3.7	2.9
This instrument is useful for describing my child's progress	2.5	4.1	3.5	3.9	4.0	3.0	2.8
This instrument has clear instructions (only for instruments that you completed yourself)		3.3	3.0	4.2	4.3	3.7	
This instrument is easy for me to use (only for instruments that you completed yourself)		3.3	3.0	4.6	4.4	3.7	

Professional Ratings of Selected Instruments

For professionals also, ratings on the instruments on the Short List were available from Survey 1, Survey 2, and from those who volunteered to administer and rate the instruments on the Short List. Survey 1 involved 14 Likert-style items. Survey 2 included 13 questions from Survey #1 plus 7 additional Likert-style items. 120 professionals rated at least one of the 112 instruments on Survey 1; 8 completed Survey 2; and 42 both administered and rated assessments from the Short List. Additionally, 11 participants from state deafblind project staff reviewed and rated the Carolina and the HELP, since we had few ratings on those instruments. (Often respondents for Survey 1 did not rate all of the instruments that they recommended; therefore we collected more recommendations than ratings of some instruments). In all, we collected 181 ratings from professionals across the 11 instruments on our Short List.

Open-ended comments were provided by many respondents to describe instruments on the Short List. These comments appear in Appendix A. Ratings were collected on five major aspects of the 11 instruments. The table below shows these five aspects and the statements related to each aspect that were rated using Likert scales.

Quality	Questions
Content	Useful to assess communication Useful to assess social interaction Useful to assess cognitive/learning
Appropriateness	Useful for 2-8 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/for educational planning Useful for evaluating progress Useful for describing child's strengths and weakness 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

Mean ratings for appropriateness, accuracy, applicability and usability appear in the following table, along with ratings for each of the three content questions (which cannot be combined).

Professionals' Mean Ratings of Selected Instruments

Instrument	Callier -Azusa	Caro- lina	Communi- cation Matrix	Dimensions of Communi- cation	HELP	Infused Skills	Home Talk	INSITE	Oregon Project	SIPSS	Vineland
n	29	16	23	8	25	7	10	16	26	9	11
Content 1: Useful to assess communication	4.0	4.2	4.8	4.1	3.2	5.0	4.2	4.4	3.6	NA	3.2
Content 2: Useful 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
Content 3: Useful to assess cognitive, learning skills	3.9	4.3	NA	NA	3.6	4.0	4.1	4.4	3.9	4.0	NA
MEAN Appropriateness	4.0	3.1	4.4	3.8	2.7	4.9	4.3	4.2	3.4	3.8	2.8
MEAN Accuracy	3.4	2.9	3.9	3.6	3.2	4.6	4.4	4.1	3.7	3.8	2.9
MEAN Applicability	4.1	3.6	4.4	4.0	3.2	4.7	4.3	4.4	4.0	4.0	3.4
MEAN Usability	4.3	4.5	4.5	3.5	4.3	3.0	4.5	4.5	4.3	4.7	4.3

In-depth Input from Professionals

Interviews with Professionals

Data were obtained from in-depth interviews of a convenience sample of 14 professionals in Texas (8 special educators – 6 with certifications in severe-profound disabilities, 1 certified in visual impairments, and 1 in auditory impairments - 5 speech-language pathologists, and 1 occupational therapist), all of whom had at least 3 years of experience in assessing young children with SI/MD. Both urban and suburban public school districts employed these professionals. Individual interviews were conducted and consisted of 7 open-ended questions which sought commentary on the assessment process, instruments, and techniques they had used, and the translation of assessment information to program planning. Interviews typically lasted 30-60 minutes and were audio recorded and transcribed. Three coders using both descriptive and interpretive coding categories independently coded transcriptions and the categories combined to reveal more general “themes.” Several iterations of the coding process took place until consensus was achieved on coding categories and themes.

Accuracy of the assessment data and applicability to intervention were the two primary themes that emerged. Accuracy required selecting assessment instruments that could identify small but significant steps in the child’s development with minimal confounds related to sensory loss and motor, cognitive, or communicative impairment. Standardized testing was viewed as having limited value with these children. When standardized tests were used, these professionals recommended modifying testing procedures to accommodate a child’s specific challenges. All 14 professionals recommended “authentic” assessment procedures, including observation across contexts and interdisciplinary teaming that allows for input from sources with different professional perspectives and different opportunities to observe the child. They sought family input and insights as complementary to their own observations, but recognized obstacles in family participation including scheduling, parent interest, and language/cultural barriers.

With regard to applicability, these professionals viewed two distinct outcomes of the assessment process: *documentation* (e.g., establishing a diagnosis, qualifying a child for special services, and obtaining a developmental level) and *action* (e.g., setting intervention goals and objectives and selecting intervention activities and contexts). Assessment activities that yielded scores and developmental levels were generally described as most applicable for documentation. Applicability to intervention required consideration of various intrinsic and extrinsic factors, not usually included in assessment instruments, but which significantly affect a child’s performance. Professionals identified important extrinsic influences or contextual influences that included activities and locations (especially home and school differences). Intrinsic factors included temperament, unique interests and preferences, and the effects of health and medications.

Expert Query

The Short List was sent to nine experts in the field along with the entire list of 83 instruments recommended by professionals. The experts were asked:

- To list any additional instruments from the list of 83-instruments that should be included on the Short List
- To list any additional instruments that they would recommend for assessing the target population
- To indicate any instruments from the Short List that they thought should be excluded from further study.

Although a number of instruments not on the Short List were suggested, none of them met our criteria. Therefore the list remained unchanged.

State Projects Query

The link to a Survey Monkey online survey was provide to all of the state projects. The survey listed each instrument on the Short List followed by these 3 questions:

- Are you familiar with this instrument? (Yes, No)
- Is the instrument used widely in your state to assess 2-8 year old children who are deafblind? (Yes, No, Not sure)
- Would you recommend this instrument for assessing children who are deafblind? (Yes, No)

Responses were provided by personnel from 18 state projects. Their responses appear in the table below.

Results of State Projects Query (n=18)

Instrument	Am familiar with instrument	Is used widely in my state	I would recommend its use
Callier-Azusa	100%	41%	94%
Carolina Developmental Profile	62%	15%	63%
Hawaii Early Learning Profile	67%	33%	100%
Infused Skills Assessment	14%	7%	33%
INSITE Developmental Checklist	75%	50%	92%
Oregon Project	87%	33%	71%
Vineland	75%	33%	60%
Communication Matrix	83%	33%	83%
Dimensions of Communication	60%	0%	100%
Home Talk	90%	20%	100%
School Inventory of Problem Solving Skills	56%	6%	91%

Family Specialists Query

A survey was e-mailed to 35 family specialists who worked with state deaf-blind technical assistance projects and whose main responsibility was working with families of children with combined visual impairment and hearing loss. These individuals were parents or siblings of children with a visual impairment and/or hearing loss and other disabilities. The survey contained questions about concerns parents express regarding the assessment of their child and ways that they encourage parents to prepare for their child’s assessment. Twelve family specialists responded representing 10 states. Appendix B. provides all answers collected through this query. Survey responses are summarized below:

Question 1: What are common questions that parents have about the assessment process?

- (a) the purpose of the assessment and procedures;
- (b) appropriateness of assessment tools;
- (c) qualifications of the assessment team;
- (d) outcomes of the assessment process;
- (e) accuracy of assessment results; and
- (f) what parents can do if they disagree with assessment reports.

Question 2: How do you suggest that parents prepare for their children's educational assessment?

- (a) develop a list of questions and concerns in advance of the child's assessment;
- (b) obtain information about assessment tools and procedures that will be used;
- (c) prepare written lists of their own observations on their child's behaviors and skills;
- and
- (d) draw on available relevant professionals and other resources to guide the assessment process.

Focus Group

A two hour focused interview was conducted at the 2007 Project Directors' meeting with 10 expert professionals (technical assistance specialists) working for the state deaf-blind projects and representing 10 states. Their professional backgrounds included advanced degrees in audiology, deaf-blindness, hearing loss, visual impairment, severe and multiple disabilities, and speech-language pathology. These individuals were invited to participate in the focused interview because they had significant experience (mean of 23 years) in providing intervention for and assessing young children with sensory impairments and multiple disabilities and because they represented a range of relevant disciplines.

Prior to the interview, participants completed a survey by mail or e-mail. First, participants were asked whether they had used any of the instruments on the Short List, whether they would use them again, and what they thought was the best use of each instrument. Responses to these questions appear in Appendix C. Second, participants were asked four general questions about the assessment process. Complete responses to these questions are provided in Appendix D. Responses to these four questions were collated and themes were identified to develop the following summary of responses.

1. **What have you found to be the 5 most critical issues in assessing the communication skills of 2-8 year old children with sensory impairments and multiple disabilities?** Three common concerns were identified:
 - (a) the dearth of assessment tools that are appropriate for these children's sensory status, that address beginning communication levels and that capture the child's abilities in natural environments;
 - (b) the lack of assessment team members with experience and expertise to assess these children; and
 - (c) the need for assessment teams to have sufficient time to conduct high quality assessments that will produce significant information for program planning and implementation.
2. **What common questions and concerns regarding assessments have parents of these children raised?** Technical assistance specialists observed that some families do not raise any issues and this lack of involvement may reflect their lack of confidence in expressing

their own perspectives, a reliance on the professional as the authority, and/or cultural and language differences. They reported that parents were primarily concerned:

- (a) that test scores do not reflect a child's abilities or provide an educational prognosis; and
- (b) that some assessment team members are unfamiliar with their child and his or her communication method.

3. What common questions and concerns regarding assessments have professionals (i.e., teachers, psychologists, speech-language pathologists) who work with these children raised?

The technical assistance specialists reported that professionals' primary concerns were:

- (a) the lack of appropriate assessment tools;
- (b) the questionable usefulness of standardized tools required for the IEP; and
- (c) that the typical assessment report does not provide relevant information to determine communication options and lead to program planning.

4. What have you found to be the most helpful strategies and approaches in assessing the communication skills of these children? Approaches identified as most helpful included:

- (a) the use of multiple observations in natural environments with familiar people;
- (b) play-based and team assessments; and
- (c) obtaining information from families and others who know the child well.

At the focused interview, technical assistance specialists were asked to discuss and clarify key issues and strategies that were identified on their surveys. They discussed their questions, frustrations and recommendations regarding assessment of children who are deafblind. They also provided suggestions for the final product. This group discussion was audiotaped, transcribed and checked for accuracy. A content analysis was conducted to reveal the following themes:

- Need for multiple and skillful observations to obtain an accurate picture of the child and to interpret a child's subtle and atypical behaviors. Documenting observations and making video recordings were suggested.
- Use of interview skills that include asking open-ended questions, particularly for obtaining information from families.
- Need for the person conducting an assessment to be familiar with the child and for joint assessments with family members and service providers that the child knows.
- Use of a team approach involving different disciplines.
- Consideration of characteristics of the family's culture, ethnicity, and language to encourage family participation in the assessment and IEP process.

Assessment and IEP Data

Professionals and parents administered specific instruments from the Short List to children from the target population, provided assessment results and evaluated the instruments that they used. Instruments varied from state to state in keeping with the objectives of each state. Parents administered only one of the three instruments that were designed for parents (*Home Talk*, *Home Inventory of Problem Solving Skills* or *Communication Matrix...Especially for Parents*). In some states, IEPs were also collected. States participating included: CA, OR, IA, NY, UT, DE, RI, PA, WA, IL, OH and MI. The SkiHi Project in Utah also provided copies of previously completed INSITE assessments. In a few cases, two administrations of specific instruments were accomplished approximately 6 months apart on the same child. As described earlier, parents and professionals provided informed consent and were provided with an honorarium in recognition of their efforts.

IEP Analysis

Twenty-three IEPs/IFSPs were collected. They were analyzed for their relationship to assessment. Use of formal assessments in the sample of IEP/IFSPs does not follow any overall trend or pattern. In fact, a wide range of utilization of formal assessments was noted during review of the documents.

Fourteen out of the 23 IEP/IFSPs omitted any mention of formal assessment instruments altogether. Many of these were renewal IEP/IFSPs (although several initial IEP/IFSPs indicated use of no formal assessments and were based solely on observational assessment, or included no assessment information at all). In IEP/IFSPs without mention of formal assessment instruments, present levels of performance were typically given from classroom performance per teacher or therapist observation. Goals seemed to be selected based on these present levels of performance, as the next developmental “step up” from the child’s current abilities. It is possible that teachers/therapists did refer to assessment instruments (e.g. developmental checklists) 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, developmentally, should come next for a student. Measuring progress of goals was noted almost universally to be done by observation and data tracking by teacher/therapist. In several IFSPs, goals clearly were *not* derived from any formal assessment but were more general and probably selected jointly by parents and professionals.

The remaining nine IEP/IFSPs did mention use of formal assessments in some manner; however the role of formal assessments varied, as did the number of assessments used. The number of formal assessment instruments mentioned varied from one to eight. The mean number of assessments was 3.22, the median 3. Several IEP/IFSPs mentioned that assessment instrument(s) had been administered; however no results were included. Other IEP/IFSPs 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 more clearly came from the assessments, so performance on the formal measures indicated progress towards or mastery of goals, as well as the need to determine new goals. Assessments referenced in the IEPs/IFSPs appear in the table below.

Formal Assessment Instruments Referenced in IEP/IFSPs

Assessment Instrument	Type of Assessment	# of times referenced
Insite Developmental Checklist	Developmental	2
Hawaii Early Learning Profile (HELP)	Developmental	1
The Oregon Project	Developmental	1
Battelle Developmental Inventory (BDI)	Developmental	1
Learning Accomplishment Profile- Diagnostic (LAP-D)	Developmental	1
Developmental Assessment of Young Children (DAYC)	Developmental	1
Denver II	Developmental	1
Brigance Inventory of Early Development	Developmental	1
Mullen Scales of Early Learning	Developmental	1
Preschool Language Scale (PLS-4)	Language	1
Behavioral Language Assessment Form	Language	1
*Test of Language Development (TOLD)- Preschool 3	Language	1
*CELF- Preschool	Language	1
Peabody Picture Vocabulary Test	Receptive vocabulary	1
Arizona Articulation Proficiency Scale	Articulation	1
Vineland-II Adaptive Behavior Scales	Personal and Social skills	4
Behavior Assessment System for Children (BASC-2)	Behavior and Emotions	1
Language Acquisition Barriers- Quick Assessment	Behavior and Communication	1
Kaufman Brief Intelligence Test (KBIT-2)	Cognitive	1
*Stanford Binet	Cognitive	1
Bayley Scales of Infant Development (BSID)	Cognitive and Motor	1
Peabody Developmental Motor Scale (PDMS-II)	Motor	2
Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery VMI)	Visual-Motor	1
Word Association for Syllable Perception (WASP)	Auditory perception	1

* Denotes assessment that was attempted but could not be completed

Assessment Data

Over the course of the project we collected 192 assessments of young children (55% by professionals, 45% by parents). 146 of these were one-time assessments, while 46 were post-tests re-administered approximately 6 months after the initial assessment. The primary purpose of these assessments was to ensure that parents and professionals who rated the instruments had recent experience using them. Unfortunately, for most of the instruments, we did not collect enough new assessments to allow us to analyze the results in any meaningful way. We did, however examine the change scores for those instruments on which we collected both pre- and post-tests on at least five children. The instruments that afforded these comparisons were the *INSITE*, *Home Talk*, the *Communication Matrix*, the *Home/School Inventory of Problem Solving Skills* (all developed specifically for children who are deafblind) and the *Vineland-II*. Note that comparisons between these instruments are impossible because they target different age ranges, they categorize development in completely different ways, they were developed for different populations, and because the samples of children assessed by each instrument cannot be equated in any meaningful way. Nevertheless, we are able to make some general statements about the sensitivity of these instruments to change over time.

As might be expected, the Communication and Socialization domains of the *Vineland-II* showed very little gains, based on domain standard scores. In fact the % change (Pre score – Post score/Pre score X 100) was negative on average for Communication and only 5% on average for Socialization. Some children with regressive conditions would be expected to score lower over time. However, it is also the case that scores based on age-equivalencies will become lower if the child does not gain skills or gains very few skills as s/he ages, since the child lags further and further behind chronological age mates. Overall, the 5 children assessed with the *Vineland-II* showed very low scores, reflecting that very few items were score-able for these children. This is predictable, since the *Vineland* is designed for ages 3 years and above, and thus the items do not include the early pre-verbal means of expression and socialization that many young children with sensory impairments may use.

The *INSITE* contains a staggering 391 items related to Communication and Social/Emotional Development and a further 226 related to Cognitive development. This assessment showed enormous change scores for 8 children based on the use of average median age scores for Cognition, Social/Emotional and Communication domains. The average change scores of 184% for Cognition, 157% for Social/Emotional and 120% for Communication clearly reflect the fact that the *INSITE* contains many items applicable to young children who are deafblind and thus is especially sensitive to change.

The three remaining instruments (*Home Talk*, *Communication Matrix* and *Home/School Inventories of Problem Solving Skills*) all were developed specifically for children who are deafblind. In contrast to the *INSITE*, they target only the earliest stages of development and (except for *Home Talk*) only one functional domain; therefore they include relatively few items.

Data Summary

*Validation of Evidence-based Assessment Strategies
to Promote Achievement in Children who are Deafblind*

The change scores calculated for these instruments were 8% for *Home Talk* (n=6), 20% for *Home/School Inventories of Problem Solving Skills* (n=9) and 20% for the *Communication Matrix* (n=10). (For *Home Talk*, the scores were based on the sum of the sub scores for People Skills, Solving Problems, Exploring the Environment and Discovery & Learning from Part 3).

Review of Assessment Guide

Participants gathered for a presentation at the 2008 Project Directors’ meeting that solicited input on the final product. Also at this same meeting a group of four parents from the NFADB convened to review a draft of the product and to make suggestions. Finally, eight professionals from the state deafblind technical assistance projects volunteered to review and rate a draft of the final product, *Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities*. Their ratings of the guide are summarized below.

Ratings of Draft Version of Assessment Guide by Professionals—October, 2008

Clarity/Format	Strongly Agree		Strongly Disagree	
	Agree	Disagree	Agree	Disagree
1. The purpose of the guide is clear.	7	1		
2. The presentation of information is easy to follow.	3	5		
3. The forms provided in the guide are useful.	4	4		
4. The reading level is appropriate to the targeted audience.	4	3	1	
Content				
5. <i>Phase I: Getting Started</i> provides sufficient specific information to plan and prepare for the assessment process.	4	3	1	
6. <i>Phase II: Gathering Information</i> provides sufficient specific information about the kinds of information an assessment should be designed to collect.	5	3		
7. <i>Phase III: Interpreting Results</i> provides sufficient specific information on how to use assessment results to develop educational goals related to communication.	4	4		
8. <i>Maria’s Vignette</i> reinforces and clarifies the assessment process and concepts described in the previous sections.	6	2		
9. <i>Appendix: Instruments Used to Assess Children who are Deafblind</i> provides an easy-to-use resource of selected assessment tools.	6	2		
General Usefulness				
10. Overall the guide contains essential, useful information on assessing young children who are deafblind.	6	2		
11. The guide has some new information about assessing young children who are deafblind.	3	5		
12. This guide will be viewed as useful by <i>professionals</i> who conduct assessments of young children who are deafblind	6	2		
13. This guide will be viewed as useful by <i>parents</i> of young children who are deafblind.	2	5		

Dissemination Activities

Presentations

Over the years, project staff made the following presentations to regional and national audiences on the topics of assessment, communication and cognitive development in children who are deafblind or who have multiple disabilities:

- Rowland, C., Chen, D., Mar. H. & Stillman, R. *Update: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind*. Deafblind Projects Meeting, Washington, D.C. (October, 2004).
- Rowland, C. *Assessing Communication Skills in Children with Severe and Multiple Disabilities*. Hearing Speech and Deafness Center, Seattle, WA (February, 2005).
- Rowland, C. & Schweigert, P. *Parents and Teachers On the Same Page: the "Learning to Learn" Approach for Children Who Are Deafblind*. OSEP Leadership Project Directors' Conference. Washington, D.C. (July, 2005).
- Rowland, C., Chen, D., Mar. H. & Stillman, R. *Update: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind*. Deafblind Projects Meeting, Washington, D.C. (October, 2005).
- Rowland, C. *Tangible Symbols, Tangible Outcomes: Communication Strategies for Children with Severe and Multiple Disabilities*. Georgia Sensory Assistance Project, Atlanta, GA (October, 2005).
- Stillman, R.D., Stoltz, J.C. & Lalani, S.S. *Parent/professional perspectives on assessment of children who are deafblind*. American Speech-Language-Hearing Association. San Diego, CA (November, 2005).
- Stillman, R. *Educational evaluation of children who are deafblind*. Videoconference Presentation to Texas State Educational Service Centers (March, 2006).
- Rowland, C., Chen, D., Mar. H. & Stillman, R. *Update: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind*. Deafblind Projects Meeting, Washington, D.C. (October, 2006).
- Rowland, C., Chen, D., Mar. H. & Stillman, R. *Update: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind*. Deafblind Projects Meeting, Washington, D.C. (July, 2007).
- Rowland, C. & Kavulic, C. *Explorations in Communication Disorders*. OSEP Project Directors' Meeting, Washington, D.C. (July, 2007).
- Rowland, C. *Using the Online Communication Matrix to Assess Early Communication Skills in Children with Severe/Multiple Impairments: A Global Research Initiative*. OSEP Project Directors' Meeting, Washington, D.C. (July, 2007).
- Rowland, C. *Communication Matrix*. COPCS/Area IV Webinar (August, 2007).
- Stillman, R. & Bove, M. *Callier-Azusa Scale*. COPCS/Area IV Webinar (August, 2007).
- Mar, H. *Psychological Assessment of Children with Visual Impairments: An Ecological Perspective* (Keynote Address). "Insight into Sight" Conference, Association for Visual

Impairment and the New York State Commission for the Blind and Visually Handicapped., Prusmack Health Science Center, Dominican College, Orangeburg New York (October, 2007).

- Rowland, C. *Online Assessment of Early Communication Skills: a Global Research Initiative*. International Society for Augmentative and Alternative Communication, Montreal, Canada (August, 2008).
- Rowland, C., Chen, D., Mar. H. & Stillman, R. *Update: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind*. Deafblind Projects Meeting, Washington, D.C. (October, 2008).
- Rowland, C. & Chen, D. *Authentic Assessment for Young Children who Have Vision and Hearing Impairments*. National Association for Parents of Children with Visual Impairments, Costa Mesa, CA (July, 2009).
- Chen, D., Mar, H., Rowland, C. & Stillman, R. *Best Practices for Assessing Communication and Learning Skills in Young Children Who are Deafblind*. Deafblind International Conference, Senigallia, Italy (September, 2009).

Final Products

In addition to this Data Summary, final products include:

- Rowland, C. (Ed.). *Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities*. Portland, OR: Oregon Health & Science University. Copies of this product were provided to the NFADB for dissemination to parents and to each state deafblind technical assistance project.

This product and two assessment forms included in it may be downloaded as pdf files at no cost from: http://www.ohsu.edu/oidd/d2l/com_pro/db_assess_ab.cfm

Printed coil-bound copies of this product were provided to DB-LINK for dissemination to interested parties. These are available at no cost through the National Consortium on Deaf-blindness. Contact information:

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- Chen, D. Rowland, C., Stillman, R. & Mar, H. (submitted). Authentic practices for assessing communication skills of young children with sensory impairments and multiple disabilities. *Early Childhood Services*.
- Stillman, R.D., Shehnaz, S.L. & Stoltz, J.C (in preparation). Evaluation of children who are deafblind: Convergent and divergent perspectives. *Seminars in Speech and Language Disorders*.
- At least two additional articles will be submitted to selected journals (e.g., Journal of Visual Impairment and Blindness, Young Exceptional Children).
- A new Spanish translation of *Home Talk, a Family Assessment of Children who are Deafblind* was completed. This new translation will replace the existing Spanish version available in pdf format on the following web site:
http://www.ohsu.edu/oidd/d2l/our_pro/hometalk.html

Thanks!

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Kathleen Oatis
Rebecca Stoltz

Appendix A. Comments by Professionals on Selected Assessments

Callier-Azusa
I have not used the CA in awhile simply because our school psychologist is not that familiar with it and requires the Oregon. But it provides best info on non-verbal students.
I used it MANY years ago. I don't remember at all specifically. I know it was very long but really thorough in every area.
-Examples provided are very helpful in how the developmental skills may look in a deafblind or multihandicapped child -Very thorough at young developmental levels -Very practical
This is the only instrument I am aware of that is normed on young deafblind children.
It needs to be updated to address more severely involved children. Would like parts of Lilli Neilsen's checklists incorporated in this type of scale.
Has good early skills but sometimes takes large leaps as you go higher up in the levels. Good to use for a team since different specialists can use different sections. I like the reporting sheet and can use again to note progress with the same child.
I would only use this with children with severe impairments. In children who are normal or have mild impairments, other instruments are more widely accepted.
Provides valuable information but extremely time consuming to administer.
I feel strongly that a new recording form should be generated for the Callier. The font size on the recording chart is too small, making it very difficult to clearly note the splinter skills. Since this information needs to be shared, an electronic means should be available (e.g., a chart developed in Microsoft Word). Also, I would like to include a code for "emerging skills" on the standard Callier.
Carolina
Provides accurate assessment info and leads to easy classroom application
I have had limited experience using this instrument and have never used it with deafblind children. I do think that with some accommodations, it would work. It might only be successful for children 5-8 if they were developmentally delayed.
We have not had many deafblind students at our center. The Carolina is used along with observations. Currently we do not have any better instruments that we could use.
This is my favorite instrument because it looks at a child holistically and incorporates specific guidelines for children without adequate vision and/or hearing.
This curriculum is most useful when judging age levels for all students in a self-contained classroom, including children with hearing/vision loss.
I am hung up on the PURPOSE of the evaluation/profile. Context for use? For young children this is fine, it succinctly lists some key developmental markers. This does not provide much detailed info but would be fine as a screening instrument.
Does manual suggest recommendations for use w/children with sensory impairments? Developmental reference tool--this tool is great for point of reference. Lacking other modes of communication considered in the process as well as physical impairments are not considered.
If instructions included language regarding accommodations for children who are blind, deaf, or use sign language, it would be more helpful for children who are deafblind. It also has limited number of items per 12 month periods and may not show small steps of progress for young children with more significant disabilities and significant needs. It would be difficult for a person without knowledge of sensory developmental patterns and skills to make sensory-based accommodations (for example, citing samples of sign /gesture based communication that is equivalent to oral/aural based examples).
I think the instructions are clear, concise, easy to follow. Instrument would be useful for purposes delineated in instructions, focusing on children who do not have delayed development. Only usefulness for children with DB would be as a reference point for expected typical developmental behaviors. Most items would have to be significantly modified for limited vision & hearing.

Does manual provide info on use with children with sensory impairment? Can't recall. Words--"assessing" "evaluating" don't seem appropriate to the tool. I used to provide info to program that used this tool in order to provide a familiar context/framework for familiarizing team with a young child with visual impairment.

Communication sections not useful for students with significant hearing loss who may not vocalize or verbalize; does not list ways to demonstrate communication in alternate modalities (gesture, sign, facial expr.). Reasoning section can be modified to give other examples of how to demonstrate compliance (e.g. #1 reach only in lieu of sees;

Communication Matrix

It is as reliable as the assessors ability to correctly read the behaviors of child

When a student is staying at some level, it has been that people don't look at a communication skill that may be at the next level. Usually they are pushing for abstract or language level. Parents have been grateful to see actual progress instead of repeated goals and objectives year after year.

This tool and the Dimensions of Communication support each other well and gives an excellent direction for developing communication in deafblind children

Great Format

-Scoring it takes a while to get used to

-Communication Matrix profile is a great way to depict child's current level- very easy to see where child currently is and what the next step needs to be.

Well organized and detailed lists within levels.

When we finished filling out this assessment, the parent asked me what did all this meant. Where I thought J's communication was? What I did is walk again with her through the assessment and pull out the main results and put it in a way that applies to J at home. I felt that there is a need for some kind of summary. The matrix is supposed to do that, but I find parents having problems understanding it.

(see answer to question 20) I feel that this is a good way to test a child but a lot of the possible answers seem not to be presented in a progressive order of skill. This makes it hard to measure progress.

It was not clear to mom initially that her child is level did not necessarily have to all be in ONE level. She took it back and finished on her 2nd try.

The results and process were very useful.

This is a wonderful tool that evaluates communication in a much more relevant way than typical tools.

A quick and easy way to get a picture of student's communication level. Provides baseline of students communication to assist in planning IEP objectives around communication.

The accompanying parent booklet was helpful and in language that all can understand.

Dimensions of Communication

My answer may not be as relevant as you would like as I am only slightly familiar with this tool

Somewhat hard to do with this student, but provided some good info for present level

HELP

I feel that this instrument does not allow for enough flexibility in evaluating individuals who are considered 'deafblind'.

This instrument is useful for play-based assessment of children who have single or more moderate impairments. Although it provides for a lot of flexibility, I don't think that it was intended to be used with children who have severe, multiple impairments.

If the child has more language concerns it is a very accurate tool. If the child has vision or orthopedic concerns it is much less effective.
Widely used by ECI team in this area. All educational staff have input. Parents can use data to determine progress.
Very useful for evaluation of motor functioning.
Does not provide clear objective Tool is more subjective
Parents like the white -blue flow chart to see what skills their child will be working on next. This is a more accurate instrument with a child with multiple needs.
Easy to score- great for comparing to typical development. Better in looking at motor issues. Does not take into consideration vision loss.
Hawaii requires many adaptations for use with this population. I have used it so long I can visualize pages + go through steps. Most of my work in EI is to develop routine-based interventions so it is really not that helpful to parents in planning focus of what routines + outcomes are needed. I supplement with INSITE, TPBA, TABS, Materials from VIISA + SKI-HI curriculum to plan interventions. As well as Every Move Counts.
Adaptation in all areas would be required in order to tease out the child's capabilities. Parents would have to receive instruction in order to assist with teasing out what the child could and could not do. Team members would have to agree up front to work together on the assessment in order to adapt the components for the child's disability. The parents and therapists would have to recognize that the child may fall into different categories on skills and abilities.
Some items re-grouped. Communication--needs tactile and sign (visual) pieces. It is very voice/speech based. Smell, taste, proprioceptive sense underplayed or not there. It would make a difference if the child has some useable vision/hearing or is profoundly DB.
Age-equivalency can be given but often skills may be done if wording varied such as "find item" instead "explore." Or "hear voice" respond "tactile sign". Could the student get partial credit for such items?
An experienced teacher of the deaf-blind COULD adapt this but the question is why when other tools are available that are more suitable? Much of this tool's usefulness depends on vision, hearing and neurological intactness, natural (intrinsic & extrinsic) motivators, etc. It has applications for many young children with mild-moderate disabilities but is not suitable for the current population of children who are deaf-blind.
COULD be somewhat useful for some DB kids--e.g. w/mild hearing loss, less severe visual impairment. But overall, seems to be of limited usefulness because: a) SO many items dependent on hearing and vision, and b) too few relevant communication skills (esp. pre-symbolic communication). Also, with current de-emphasis of the "silo" (domains) approach to assessment in early childhood--why use a toll that perpetuates that way of thinking about children's skills?
Home Talk
This instrument is an excellent tool. It does take a fair amount of time to complete though. I think it can be used for older children (<8 years) as well depending on the child. It is easy to use all or just sections of this tool.
From the first part of the assessment is easy to pull out likes & dislikes. J. is at the level where she prefers to play most of the time on her own. The HomeTalk assessment first area of interest is "Social Interaction", in her case she will need something else before this: a goal and activities that will help her connect more with the people close to her. Some of the other goals addressed this issue but not in a direct way. J. is only 3 yr. old totally blind and deaf and she is pretty much into herself. Several of the objectives were not applicable to her at this moment.
Too long for non-English-speaking parents. This is useful for parents who are transitioning from early intervention to preschool. I will use selected portions to make what David Brown terms a "Personal Passport" for the new educational setting. Even though I found this a very lengthy and arduous process--because of the circumstances of this family--non-English-speaking, non-literate, busy. multi-family living in a very small space--the parent felt that she learned a lot, said it made her "think about things" in ways she had not before. I also learned more about the parent and her observation skills and cognitive level.

This is a great assessment tool. It is a very comprehensive tool. I had some problems explaining the following items to the parent: "Increase exploration of varied materials". What "materials" meant? "Indicate preference for materials used during specific activities, such as music class or reading time."

I wished that there would be assessments available in this particular mother's home language (Korean). She felt intimidated by the English, especially in the more "wordy" parts.

It might be beneficial to STRONGLY recommend using photocopies of this (and others, too) instrument so progress can be recorded more easily. I like the way it involves the parents!

I think it is a great tool for a new teacher/therapists to learn about a child more than as an assessment tool.

Very long.

INSITE

This assessment is for developmental ages birth to six but is very appropriate for our deafblind children who might be older than those ages.

- print on assessment & score sheet very small & hard to read
- developmental levels are broken down into tiny steps so EVERYONE scores
- tiny steps help generate goals and objectives for students who learn at slow rates
- steps also correspond to the Oregon, HELP, and DB book to help give you ideas on how to teach the skills
- very thorough at young developmental levels

1. Draws from other sources, e.g. Oregon Project, Hawaii and includes notes and references. 2. Requires training (brief) to score. 3. Have used graph to demonstrate progress, regardless of age ranges. 4. Many items per age range- sensitive, yet less user friendly for some. 5. For 0-6, not 0-86. Uses coactive signing for receptive language items.

Very detailed for very young children. Good for infants with multiple impairments and sensory loss.

I find that for students with unusual sensory sensitivities, the tool does not help determine specific sensory issues, and sometimes these appear as sensory delays and are misinterpreted as sensory impairments rather than sensory integrative issues or sensory sensitivities.

Oregon Project

I think it is a useful instrument and is helpful in addressing the student's strengths and weaknesses.

Parents appreciate detailed activities which are sequenced.

This instrument applies only for children up to age 6. It is not designed for hearing impaired. But a lot of items could apply. It is a checklist so it's easy to administer.

It is normed on visually impaired children only. Best for "vanilla" blind but can be used w/ deafblind to multiply impaired.

The Oregon Project provides a great way to visually track a child's progress. (concrete for parents) It is limited in assessing children w/ multiple impairments/ not broken down enough.

I like this instrument because it is very easy for parents to see their child's skill level in it's easy chart format. Helps the team see area of need (if a speech therapist is needed, for example).

Skills sequences follow those of typically developing children. Compensatory skills are included, as well as visual skills for children with residual vision. I do not like using this instrument for children who are functioning below age 12 months because I don't think the skills are broken down enough between birth-1 year. It is designed more for VI than DHH children.

I wish this was a standardized instrument.

Excellent tool- very thorough. We use it in consultation with our VI service provider. Generates "next step" ideas. Easy to chart and review.

The Oregon Project provides decent empirical data on students for evaluation purposes. However, many items are not appropriate for Deaf/blind. I often combine the Oregon w/ the Maxfield Bucholz because both are based on expected development of "normal" children with VI. I feel sort of stuck w/these procedures because not much else exists. Furthermore both procedures were put together when a larger proportion of VI children had no additional handicaps.

SIPSS

Almost all the items were too high level for this child so it wasn't useful in this situation. I don't have a fair sense of how it might be with a child with more skills. I like the format--pictures and descriptions.

I really like the format of this instrument. It is easy to mark progress and easy to use.

I like the ways this instrument is laid out; it is easy to use and can be used to show progress and generate goals. I also benefitted from the use of examples.

Most of this tool was not appropriate to his development.

Vineland

Useful in gathering an accurate picture of the child who may not perform for a stranger.

Can be the most useful tool if observation is objective

Again, comparison ratings are helpful.

I didn't know how to compile the data on the last pages. I suppose you would need further instruction for that. The assessment is not broken down into small enough steps for severe DB children.

I do not see this as a useful tool to evaluate the majority of the DB students I serve. These students have severe vision, hearing, motor and cognitive disabilities. I also believe this tool would be discouraging to the parent of these students because it its hard to concentrate on strengths among all the "zeros."

Appendix B. Family Specialist Feedback

Question 1: What are common questions that parents have about the assessment process?

Assessment purpose and procedures

- Why is it necessary?
- Is it really necessary?
- What is it for?
- Why the assessment is important and what can we expect to achieve?
- Why does their child have to be assessed?
- Can you explain the process and the purpose of the assessment?
- How does the assessment process work?
- What is the purpose of the assessment?
- How can we do this?
- What can I do to provide input?
- Who will be there to support us?
- Will it hurt my child?
- What areas are required to be assessed in my child?
- How can we make sure assessments address all essential areas of a quality program for the child who is deaf/blind?
- What areas would the assessment cover?
- What the child does well, likes to do?
- Is the assessment going to be performed in a place that's familiar to the child or in a different location?
- What is the timeline for an assessment? What if it is a bad day? Can it be tried again on another day?
- Why does it take so long?

Outcomes of the assessment process

- What will I learn through this process?
- How will my child and I benefit from this process?
- Who benefits?
- How can the data be used to make my child's life better?
- What interventions should we take?
- Can you help me prioritize what comes next? (Will you provide a plan of action?)
- What can we do at home to make life better for our child?
- How do the state assessments required by NCLB tie into their child's IEP?
- How to ensure that the assessment information is used to build an appropriate IEP?
- Will you be able to tell me how severe the disabilities are?
- Can you tell what caused the disability?
- How is my child different from other children?
- What deliverable will you give us? (i.e.-Why should we do this? What are the benefits? What problem will it solve?)

Assessment tools

- Are there appropriate assessments for students with combined vision and hearing losses?
- What assessment tools do we think are acceptable for children who are deaf-blind?
- How to determine if the assessments conducted by the educational staff are appropriate for students who are deaf/blind and will provide meaningful information?
- How do I know if the assessment is appropriate for a child like mine?
- Is the assessment appropriate for their child and will it really reflect their child's abilities?

Accuracy of results

- How accurate is the assessment?
- Are you really getting a true picture of my child?
- Parents are concerned that their children's true abilities and potential are not being captured because of inappropriate testing instruments, rushed or inattentive delivery of assessments, pre-conceived notions about the child's ability/potential, disinterest (teacher/assessor/district) in the child's unique accommodation needs and specific strengths.
- Will the results of the assessment be accurate?
- How to interpret the results of the assessments?
- What are the long term effects (especially negative) of this diagnosis?
- Why is it so negative?
- Will it label or stigmatize my child?
- Will the negative aspects "stick" with him/her for a lifetime?
- Can their child lose some services based on the results of the assessment?

Disagreements

- What can I do if I disagree with the assessment?
- What actions can they take if they feel the assessment was not accurate or appropriate accommodations were not given?
- If there are questions on an assessment's validity, how can I work with the team in addressing them?
- If parents do not agree with the assessment, can they ask for a second assessment or do they have to accept the results?
- How do we convince them (school team) that the results are not necessarily accurate?
- Do they have to sign the permission form to assess or what happens if they do not sign it?
- What about if the student looks different on paper than in person, would that affect the placement the student is in?
- How to avoid having assessments done that are intended to push through hidden agenda (i.e., cognitive testing in an attempt to justify moving the student out of a regional program for the deaf)?

Question 2: How do you suggest that parents prepare for their children's educational assessment?

Key points

- **Make a list of questions and concerns**
- **Ask about the assessments that will be used, accommodations, etc.**
- **Prepare your own observations, information about child to share**
- **Draw on resources to guide assessment e.g. state projects, VI, DHH teachers**

- We encourage families to focus on and pose “referral questions” so that assessment team knows and can address their concerns and questions during the assessment process. We try to provide families with information regarding the assessment process and systems that are involved in this process. We want our families to be informed consumers in this process.
- Recommend that they find out what area their child is going to be assessed on.
- Ask what tool is going to be used or how their child is going to be assessed.
- Make sure that their input is part of the assessment's. Research what are appropriate assessment tools for a child like theirs (ask state DB project, go to DB-Link etc.). Most important, know from beginning what your child's needs are and what your goals are for the future for your child!
- Prepare a list of questions in advance.
- Make sure the child gets plenty of rest and peace beforehand.
- Keep an open mind.
- Ask questions when you don't understand something.
- Prepare a list of your concerns and fears and request someone to go over them with you.
- Take one thing at a time.
- I believe that many parents want to help with getting this done. However, through word of mouth or through personal experience the family has to have trust.
- There needs to be trust established between the family and the person who is doing an assessment. The family needs to know that this person who is assessing is looking for the things that are important to this child how this child achieves those things. I think the family can only really prepare by building trust and relationship with this person who they may feel is “judging” their child. This trust building does not have to take a long time but it needs to happen. It may happen through conversation or watching the assessor work with other children or their own child. It may happen by the assessor pointing out something positive that the child is doing during a visit. If the assessment is being done by a team often parents will talk to other parents about their experience with this team. I personally believe the parents need to believe the person assessing their child has “it”.
- Write all the questions which are not clear to you.
- Write or take notes of your conversation with the professional.
- If you are not clear about an answer, ask again.
- If not satisfied with the assessment ask for another chance to repeat it. (Sometimes the little ones are not too cooperative because of unfamiliar places)
- Use written observations of student and suggestions from CDBS staff as a core background for assessment.
- Suggest some tools that our staff recommends for assessment.

- Ask if the family has considered an assessment by CSB with exit strategies from CDBS.
- Find out what, who and what tools will be used for the assessment.
- Make sure their children are healthy, well fed and well rested during the assessment period.
- Parents who are well organized (have information in a file or 3-ring binder) and can provide accurate information to the team, represent their child well.
- Be aware of the importance of the assessment – that it is the foundation of the IEP.
- Do your own data collection at home and provide that input.
- Parents need to feel that what they know about their children is valuable and relevant. I suggest that they collect the information they have in a format like HomeTalk or the SPARKLE database, so that they can present it effectively and succinctly.
- Discussing with whoever is going to be administering the assessment their concerns.
- Ask to see the assessment ahead of time.
- Ask what accommodations will be made if needed.
- Ask who will be administering the assessment and if they have knowledge and expertise in deaf-blindness.
- Ask what the assessment is going to be used for.
- Talk to one of our specialists about the type of assessment that will be used and the accommodations that will be made.
- Let the assessor know that you as the parent want to give your input in the assessment.
- I suggest that parents prepare a parent report for assessments, IEP meetings, etc., outlining the student's strengths, interests and receptive and expressive modes of communication. I encourage them to be involved and ask questions. It is especially important that, if the team is not familiar with the student's sensory losses, that the parent(s) help to educate them on how their child communicates and how he/she may need to be accommodated.
- Understand the Special Education process, including how assessment serves as the foundation for the IEP as well as measuring progress.
- Go through the medical reports that will be used as the basis for the assessment to make sure they understand everything. If not, get with someone who can help them understand.
- Identify any reports or documents, including parents' own observations and assessments that the team can consider while conducting the assessment.
- Know before hand what assessments will be used and if there are any questions on validity, bring concerns to the team. Make sure the teacher of the visually impaired and/or auditory impaired teacher are being consulted on what assessment tools are selected, how to administer them and how to interpret them.
- If necessary, involve state DB Project in providing guidance to the team.
- Once assessment are completed, request a written copy well in advance of the meeting they will be discussed to make sure completely understand results (if not, seek out clarification) and identify anything that needs clarification and/or correction.
- Use the assessment material to drive the development, implementation and measurement of the IEP.
- I usually suggest the parents to write down all the questions they have about the assessment process (example, what assessment tools/materials will be used, who will be conducting the assessment, where the assessment will be conducted, and what areas will be covered. What benefits will it bring to the student.)?

- Inform the child about the assessment. Let the parents know what assessments are good. If the parent is present during the assessment answer all the questions made by the assessment team as accurate as possible. Inform the assessment team if the child is not having a good day that might affect his performance to ask questions and expect answers. As much as possible know Special Ed. Terminology, it is very helpful. Finally, know the timelines of the assessment process.

Appendix C. Opinions of focus groups attendees about selected instruments (n=10)

% who have used it	% who would use it again	What do you believe is the best use for this instrument?
Callier-Azusa		
90%	70%	When motor is not an issue
		With students with sign, additional disabilities, portfolio assessment
		I like the examples in the scales to show parents other ways their children might communicate, and the variance of development for children who learn things tactually
		Quick assessment
		All kinds of children - nonverbal and verbal communicators
		Very young
		Gives a general idea as to what the child can do and can be used with a child who is deafblind
Carolina Developmental Profile		
30%	20%	Vision impaired rather than D/HH
		With young children, single disability
		Gives you an idea as to where the child is developmentally
Hawaii Early Learning Profile		
70%	40%	Young children
		With young children, single disability
		Provide overall adaptive view of student in a variety of areas
		Giving people more of a road map
		Incorporate in total program
		I have only used this in conjunction with INSITE
Infused Skills Assessment		
10%	0%	(no comments)
INSITE		
70%	60%	Starts at a simple level that allows child to demonstrate some basic skills
		With young children, multiple disabilities
		As appropriate, I use it to demonstrate how cognition and communication are commensurate with vision and hearing, but tactile modes may be more successful
		Used with DB projects
		Use with ideas from INSITE program, not as separate tool
		This is the best developmental skills checklist for infants and toddlers because of the minute gradations between skills and sub-skills.
Oregon Project		
70%	60%	With young children, single disability
		To compare vision and compensatory
		Providing teaching ideas, strategies
		Does give people with no experience of visual impairment aspects to consider
		All kinds of children - nonverbal and verbal communicators with other educational assessments
		I have only used this in conjunction with INSITE although I recently heard the authors present the new version at a conference and was impressed with the updates
		If child doesn't have significant additional disabilities

% who have used it	% who would use it again	What do you believe is the best use for this instrument?
Vineland		
50%	40%	Parent interview, when working directly with child not as productive
		Better with adolescents
		So much of it becomes no opportunity for many of the students with whom I work. There are better processes to use to get at this information in a way that is useful to families and schools.
		All kinds of children - nonverbal and verbal communicators with other educational assessments
		This has relevance for assessing independent living skills among older students
Communication Matrix		
90%	90%	Non symbolic communication
		DB, significant additional disabilities
		To explain how communication skills can be increased by mode, complexity, function, etc.
		Assessing communicative intent and alternative communication
		For nonverbal, deafblind children it is a great way to look at how they do communication and how we can shape behaviors to move to concrete and then possibly abstract communication.
		All kinds of children - nonverbal and verbal communicators
		SLPs (and other team members) make sense of this - and can extrapolate "where to go from here"
		This is an excellent tool for use with all students who have limited communication skills because of the minute gradations between skills
Found this to be extremely helpful and provides good information as to how and what the child communicates		
Dimensions of Communication		
40%	40%	Show what child can do, not need scale scores
		All ages, significant additional disabilities
		Assessing communicative intent and alternative communication
		Great confirmation tool for the Communication Matrix and it gives some excellent examples of how to work with students in developing communication
Home Talk		
70%	70%	Parent inventory
		All ages, significant additional disabilities
		I have provided this to parents as their children turn 2.6-2.9 to help them set priorities for transition
		Much more friendly language. I have used it with group home staff and even school staff.
		All kinds of children - nonverbal and verbal communicators
		As a tool that becomes a documentation and history of a child - to pass on to next teacher/team. A "connector" to the family
This is an excellent tool to use with families, particularly in the IEP planning process		
School Inventory Problem Solving Skills		
10%	10%	I use it especially when staff really don't know how to get cognitive translates to children with significant multiple disabilities and who are deafblind.

Appendix D. Answers to Questions Provided to Focus Group Attendees Prior to Meeting

Question 1: What common questions and concerns regarding assessments have been raised by *parents* of 2-8 year old children who are deafblind?

Theme	Responses
Belief that assessments do not accurately reflect child's abilities / Belief that evaluators focus too much on child's deficits and do not understand child's strengths	<ul style="list-style-type: none"> • Do the assessments really reflect my child's abilities? Is my child really cognitively delayed – or is it the dual sensory loss? • Scales that do not give clear picture of student's capabilities • Results appear "demeaning" to their child, especially when age is reported in months when the child is one or more years old • The continued emphases on deficits rather than strengths • Parents are frustrated by educational team members who see their child's successes (demonstrated at home) as "wishful thinking" • They gave my child a score on this test, I know he is smarter / communicates more than that, is it fair to use that assessment
Parents want assessments to tell them the child's potential/prognosis	<ul style="list-style-type: none"> • Whether determinations of potential can be made by assessment of young children • What is the educational prognosis of my child?; how come the doctor tells me something different (educationally)? • What does this mean for the future? - this is the single most asked question - what does this mean for my child as he/she grows? • What is my child's IQ?; What is my child's potential?; Will my child be able to learn to read or write or learn Braille?
Parents question credentials of evaluators	<ul style="list-style-type: none"> • Reliability; experience/qualifications of evaluator • When questions/concerns are raised, it is most often about the qualifications of the educators doing the assessments. Parents are sometimes aware of the legal requirements that LEAs have to provide assessment personnel who are knowledgeable in the areas/disabilities they are assessing. • How can this person assess my child when they don't know anything about deafblindness? • How does anyone know what to teach and how to teach my child? Who is qualified to do this and where do I find that person?
Lack of understanding of scaled scores/proper interpretation of tests	<ul style="list-style-type: none"> • Children test at low month skill levels; fear low communication scores reflect low cognition, do not understand the assessment tools and some of the scaled scores • Results appear "demeaning" to their child, especially when age is reported in months when the child is one or more years old • What are good scores?
Concerns about how the results of the assessment will be used/ Want to know howto apply the results of the assessments	<ul style="list-style-type: none"> • After the assessment, what happens? • What will happen with the results? • Tell me what to do next

Concerns about the appropriateness of the assessment	<ul style="list-style-type: none"> • The assessment isn't appropriate because it relies on the child's use of vision or hearing • They gave my child a score on this test, I know he is smarter / communicates more than that, is it fair to use that assessment • Will the assessment be fair to my child?
Concerns that evaluators cannot communicate appropriately with the child	<ul style="list-style-type: none"> • How can you assess my child if they can't communicate? • They just talk to my child, don't they know he can't hear?
Concerns about specific programming decisions or strategies	<ul style="list-style-type: none"> • If we use these objects or pictures, will my child forget about talking/signing; I do not want my child in a life skills class, they don't do any academics • The inability of team members in seeing the value of sign language, or language to accompany tangible symbols
Educators feel parents not involved enough in assessment process	<ul style="list-style-type: none"> • Strangely—or at least so it seems to me—many parents raise few concerns about assessments. I believe there are many reasons for this, but I'll highlight two: 1) they accept the knowledge and authority of educators, and 2) they do not understand the relationship between quality assessments and quality programs. Assessments seem like procedural requirements and not much more. • Parents are not (or minimally) involved – not even in functional assessments
Fear low communication = low cognition	<ul style="list-style-type: none"> • Children test at low month skill levels; fear low communication scores reflect low cognition, do not understand the assessment tools and some of the scaled scores

Question 2: What have you found to be the most helpful strategies and approaches in assessing the communication and cognitive skills of 2-8 year old children who are deafblind?

Theme	Responses
Multiple observers, assessors	<ul style="list-style-type: none"> • More than one person involved in the observation of the assessment • Joint assessment with other professionals • Working as a team with the administrator of the test and the OT / PT / Speech Language Therapist to ensure that all areas of the test make sense for the student. • Team approach • Unobtrusive observation by two persons – and then a debriefing with the team • Listening to what all of the team members (not just specific professionals) say they have experienced, seen, or have concerns about
Thorough observation	<ul style="list-style-type: none"> • Observation • Observation • Allow plenty of time to observe the child/student in a variety of environments • Using observations to identify how and what the child is communicating and what the child likes to do • Spending time observing the child in different environments and with different people • Recording the child's responses to activities, situations, object, toys, etc
Interviews with parents/caregivers	<ul style="list-style-type: none"> • Focus on what the child can do, and ask parents to tell you what they have observed: How do you know when your child likes something? What tells you that your child is happy/unhappy? • Talk to caregivers and service providers who have worked with the child • Interviews • assessment information needs to be effectively gathered from family members • Listening to what all of the team members (not just specific professionals) say they have experienced, seen, or have concerns about; Asking specific questions to find out how they know what the child wants or doesn't want
Assess in familiar/functional contexts	<ul style="list-style-type: none"> • Within natural environments; functional use of materials; familiar person in natural environments • Using functional assessments rather than any standardized tools • Use familiar toys and materials to begin. • Assessments need to assess skills that are relevant to each child's unique situation.
Play-based assessments	<ul style="list-style-type: none"> • Use of play-based and arena assessment to gather information • Play-based assessment • Playing and interacting directly with the child
Assess in multiple contexts	<ul style="list-style-type: none"> • Multiple settings • Spending time observing the child in different environments and with different people • Recording the child's responses to activities, situations, object, toys, etc.

Assess child's strengths and abilities	<ul style="list-style-type: none"> • Focus on what the child can do, and ask parents to tell you what they have observed: How do you know when your child likes something? What tells you that your child is happy/unhappy?; • assessments need to focus more on what children can do and not lists of what they can't do • Over-estimate rather than underestimate a child – the child will, more often than not, surprise one otherwise!
Teach/demonstrate the instrument to relevant staff members	<ul style="list-style-type: none"> • The other strategy is teaching the assessment tool to staff (i.e. Communication Matrix) then the staff completes the tool. We then sit down and teach them what to do with the results for goal setting, developing activities, developing sufficient opportunities throughout the day, and collecting data. • Demonstration and coaching educational teams; providing educational resources, where to find educational materials; step-by-step procedure to implement specific teaching/behavior strategies
Use multiple assessment instruments/assess over a period of time	<ul style="list-style-type: none"> • Do “assessment” over more than 1 time • Assessments must be carried out over a period of time so that data accurately reflects children’s knowledge and skills and is not just a snapshot of how children were functioning at a particular time on a particular day • Using pieces of multiple tools for a variety of perspectives • Referring to checklist and developmental scales to provide some direction for my observations or activities I might try with the child • Knowing which mainstream assessment may be pertinent for some youth who are deafblind, either in part or whole, and why they are pertinent for some deafblind children • Using tools that provide examples of non-auditory, non-visual skill examples
Provide information that is accessible to parents and caregivers/easily translated into goals	<ul style="list-style-type: none"> • The most helpful strategies are those that result in information that can be readily accessed by family members and educators who may have limited knowledge and experience related to deaf-blindness. Home Talk, for example, leads towards goals that can be directly applied to the IEP process. By using this tool, families go into IEP meetings with more clearly articulated visions of what they expect from educational programs. This is very helpful, since IEP meetings can be highly charged and stressful for parents, and it is difficult to be creative or even emotionally “present” when under that kind of stress.
Person assessing should be knowledgeable about deafblindness	<ul style="list-style-type: none"> • Assessors need to be knowledgeable about deaf-blindness • Don't be afraid to use touch, and be physically close, with a child who is deafblind – that might be the only way; Remember that children who are “tactile sensitive” are usually not so when they don't feel threatened or unsure
Person-centered plan for assessment	<ul style="list-style-type: none"> • We have used a person-centered plan to do an assessment. Within the discussion of the questions raised in the PCP, the group has decided what they need more information on. An assessment process or tool was then identified and done with the plan of meeting again once those assessment tools and/or processes were completed – which then led to determining immediate goals and objectives and also to having goals 2-5 years down the road
Keep total child in mind	<ul style="list-style-type: none"> • Keep the “total child” in mind while assessing discrete areas/skills • Asking “Why am I doing this?” – from the point of view of what use something would be in the future

Question 3: What common questions and concerns regarding assessments have been raised by *professionals* (i.e., teachers, psychologists, speech and language therapists) serving 2-8 year old children who are deafblind?

Theme	Responses
How to translate results into programming IEP and educational goals	<ul style="list-style-type: none"> • Lead to what IEP goals/objectives and targets to work on, current level of functioning • How can I use this information for planning educational needs? • Even if trained in use of assessment tools that are appropriate, the lack of training to know how that fits into the total educational program • I don't know how to turn these assessment results into programming for this deaf-blind child • Some of the tools used provide little more than IQ scores or some kind of equivalent scores that do not provide relevant information about a child's abilities and needs and information that can be used to guide IEP planning • After completing the assessment, what should I recommend?
Determining communication strategies/technologies best for a particular child	<ul style="list-style-type: none"> • Whether assessment results should lead to the choosing of ONE mode of communication instruction • What type of augmentative communication devices are able to meet student's needs as result of assessment, as well as technology to access devices
Lack of training/experience with instruments appropriate to the population or of in applying results	<ul style="list-style-type: none"> • Lack of training in assessment tools that are appropriate for use with children who are deafblind (especially the population who have additional disabilities) • Even if trained in use of assessment tools that are appropriate, the lack of training to know how that fits into the total educational program • I don't know anything about deafblindness so I don't know what to do with the child • What are the impacts of a vision and hearing loss? For example, is it normal for a child who is deafblind to not do this or that?; How do I know if the child can't do something because of being deafblind vs because they don't have the ability to do it? Should I expect the child to do these things?
Appropriateness of assessment tools	<ul style="list-style-type: none"> • I know these are not the right assessment tools, but I don't know enough about this to help the teacher • Are there tests specific for a child who is deaf-blind • Assessment materials and tasks are not familiar to the child • Assessment materials and tasks are not relevant • Assessment tools are not standardized for children who are deaf-blind • What are appropriate tools to use with a child who is deafblind?;
Difficulty communicating effectively with the child during assessment	<ul style="list-style-type: none"> • How to give complex information to a child with minimal vision/hearing and little movement (how complex can body signs be and still discriminated from a different sign); • Inability to use ASL or other sign system, and no access to someone who uses this (plus whatever other modes a child may use), in order to assess a child • How do I communicate with the child? • What type of communication strategies should be used with the child?

Concerns about meeting state standards vs. meeting real needs of child	<ul style="list-style-type: none">• The assessment is meant to help know where to put the child on the state standards, but the child's real needs, especially in light of family information, makes it hard to respond to the most important needs of the student• Teachers commonly raise concerns about the usefulness of psychological assessments, particularly those conducted to meet IEP requirements
Determining cognitive abilities/IQ	<ul style="list-style-type: none">• Where's the IQ from the assessment?• If the assessments were able to determine whether cognitive skills warranted the educational resources required to further communication skills
Questions about accuracy/validity of results	<ul style="list-style-type: none">• Hard to get accurate results because child performs inconsistently• Issues related to need for prompts and assistance; hard to score results• Would I be willing to attend during the test and adapt it as necessary to receive more accurate results?

Question 4: What have you found to be the 5 most critical issues in assessing the communication and cognitive skills of 2-8 year old children who are deafblind?

Theme	Responses
Lack of appropriate assessment tools	<ul style="list-style-type: none"> Finding non-visual and non-auditory examples of behaviors that express beginning cognitive and communication skills Age scores that do not provide good info on what students can actually do Many tools do not capture performance in functional, natural environments Reliable social/adaptive scales that lend a positive perspective of student, to develop educational planning Communicating to teams that assessments must be planned individually for each child – and not just to jump on the “band-wagon” with whatever assessment is popular! No one tool will give you the information you need Some of the best “assessments” are completed without the use of any packaged tools Finding good questions to determine if there has been a lack of opportunity to learn a skill Determining the impact of sensory loss versus cognitive challenge
Lack of educational value of assessment results	<ul style="list-style-type: none"> Often scores do not lead to next steps/strategies How we deliver the results of the assessment in a way that service providers can truly use that information in a way that facilitates that child’s learning? After all, what good is an assessment if people don’t know what to do with it? To emphasize to team members that assessment should be a part of the process of teaching, not separate from it. Assessments are often conducted before the question is asked, “What is it we want this child to know or do?” Assessment instruments are often used that gather information about skills that may have little relevance to the needs and interests of families. Good assessments take time and must include gathering information from families about what they want their children to learn in school. With this information, assessments can provide relevant information that can then truly guide program planning and implementation. Results showing what the child can do versus what they can’t do
Impact of additional impairments on assessment process	<ul style="list-style-type: none"> Additional disabilities – medical, Rx Assessing technology to meet visual auditory and motor needs Assessing skills of children with other disabilities as well as deafblindness Medications, sleep patterns, and time of the day and the effect of these upon the child when seen.
Lack of familiarity of evaluator with child	<ul style="list-style-type: none"> Knowing the child’s visual condition, fields, and visual capabilities such as seeing colors, perception, etc. Getting to know the child well enough to read sometimes subtle messages Who is best able to relate to the child? Are they a part of the evaluation? How do they communicate with the child? Knowing the available sensory modes, determining the preferred modes, and comparing similar skills as expressed through available vs. impaired modes Assessing communication skills within the language mode chosen by the family, as appropriate Knowing and considering cultural variations leading to issues with opportunity, family priorities and language issues

Lack of experience of evaluators	<ul style="list-style-type: none"> • Teachers understanding child's communicative intent of behavior • Teachers using a variety of communication modes to meet students' needs • The preschool staff and the school districts do not always understand the ramifications of the dual loss, and so do not understand communication delays and cognitive delays related to the sensory loss • The preschools do not know how to adapt their skill assessments • Many of the districts do not have a TVI on staff and none of them have a deaf-blind specialist so in many cases the results on the tests do not accurately reflect the abilities of the students • Trained professional who understands deafblindness to assess child • Many educators operate on a deficit model and have difficulty identifying what children <i>can</i> do. It is often said that almost anyone who has had experience with children can look at a child with disabilities and identify the discrepancies between what the child can do as compared to what a typically-developing child of the same age could do. I believe the ability to find strengths primarily comes from experience and requires an individual to have had contact with many deaf-blind children throughout her or his career. This is not possible in rural/remote areas in which deaf-blind children are scarce. • Family members of young children are typically the most knowledgeable of children's strengths and needs and yet many educators do not have the skills and/or tools to adequately obtain this information from families. As a result, the current levels of functioning described by family members (typically parents) are inconsistent with those obtained by educators. • Many children do not have educators on their educational teams who have knowledge and/or experience with children who are deaf-blind. As a result, there is no one who understands what and how to assess and team members receive assessments that do not truly reflect children's functional levels. • Training team members to be good "observers" and confident in their observations • Getting team members to understand that it is important to document – starting with a baseline • Predetermined set of ideas as to what child can or can't do and recognizing behavior as communication
Lack of time to conduct thorough evaluation	<ul style="list-style-type: none"> • Time to do a thorough job. • Most children who are deaf-blind require assessments that are longitudinal in nature (i.e., conducted over the course of days/weeks and at different times of the day, in different locations, etc.). There are too many factors that can influence a particular assessment session, such as hunger, fatigue, arousal states, seizure activity, anxiety about unfamiliar people, places, and materials, etc. A "snapshot" does not provide an accurate assessment, and yet this is what most children receive because assessments are often conducted at the last minute to satisfy the requirements of upcoming IEPs. • The child often has little or no opportunities built in to explore independently and to develop concepts along with the communication we provide. People jump into the cognitive or communication assessment without looking at the lack of opportunities to first learn. • Most assessment tools can provide some helpful guidance, but a good assessment requires time spent in the child's natural environments, observing and interacting

Appendix E. Surveys

Survey 1 for Professionals

Survey 2 for Professionals

Survey 1 for Family Members

Survey 2 for Family Members

SURVEY # 1 for PROFESSIONALS

Instructions: Survey for Professionals

Please do NOT sign or put your name on this survey.

When you have completed the survey, please place it in the stamped self-addressed MANILA envelope and mail it.

**PLEASE RETURN THE SURVEY WITHIN TWO
WEEKS OF RECEIVING IT. THANK YOU.**

Survey on the Assessment of Communication and Cognitive Skills in 2-8 Year Old Children who are Deafblind

Oregon Health & Science University, under the direction of Dr. Charity Rowland, has received a grant from the U.S. Department of Education to study and validate methods for assessing the communication and cognitive skills of 2 – 8 year old children who are deafblind. This is a collaborative effort with Dr. Deborah Chen (California State University, Northridge), Dr. Harvey Mar (St. Lukes/Roosevelt Hospital and Columbia University, New York), Dr. Robert Stillman (University of Texas at Dallas) and the National Family Association for Deaf-Blind. This survey is designed to collect information from practitioners across the country on recommended assessment instruments. Your participation in this survey is much appreciated. We will send you a \$20.00 gift certificate for completing this survey.

FIRST, SOME QUESTIONS ABOUT YOU AND YOUR BACKGROUND:

1. What is the nature of your current professional role involving children who are deafblind?
(e.g., Special Education classroom teacher, Speech-Language Pathologist)

2. Please list any degrees or certifications that you have earned related to your work in this role
(e.g., Certification in Moderate and Severe Disabilities, Master's degree in Psychology).

3. For how many years have you worked with children who are deafblind? _____ years

4. Please list any instruments that you have used to assess communication or cognitive skills in 2-8 year old children who are deafblind.

NOW WE WOULD LIKE MORE INFORMATION ABOUT SPECIFIC ASSESSMENT INSTRUMENTS **THAT YOU WOULD RECOMMEND** FOR USE WITH CHILDREN WHO ARE DEAFBLIND, AGES 2 TO 8. PLEASE DESCRIBE UP TO 4 ASSESSMENT INSTRUMENTS. ON EACH PAGE, WRITE DOWN THE NAME OF ONE INSTRUMENT. THEN READ THE 15 QUESTIONS, AND RATE THE INSTRUMENT AS INDICATED.

Please Briefly Identify and Describe Instrument A:

Is the use of this instrument mandatory? ____YES____NO

Questions 1 through 13 are rated using the following scale:

Not Useful	Of Limited Use	Somewhat Useful	Useful	Very Useful	Not Applicable
1 - - - - -	2 - - - - -	3 - - - - -	4 - - - - -	5 - - - - -	NA

Using the key above, please indicate how you would rate this instrument in terms of its usefulness for:

- ___ 1. Assessing **communication skills**
 - ___ 2. Assessing **social interaction skills**
 - ___ 3. Assessing **cognitive and learning skills**
 - ___ 4. Assessing children **aged 2-8 years**
 - ___ 5. Assessing children with **severe cognitive impairment**
 - ___ 6. Assessing children **without symbolic language skills**
 - ___ 7. Assessing children who have **severe vision impairment**
 - ___ 8. Assessing children who have **severe hearing impairment**
 - ___ 9. Assessing children who have **severe orthopedic or physical impairment**
 - ___ 10. Generating **instructional goals** and for **educational planning**
 - ___ 11. Evaluating **progress**
 - ___ 12. **Describing a child's strengths and weaknesses to parents**
 - ___ 13. Generating an **accurate picture** of the child's skills
14. How **“user-friendly”** do you find this instrument (using a scale of 1-5, with 5=Extremely User Friendly and 1=Not at All User Friendly)? _____

15. Please provide any other comments you think relevant about this instrument:

If you would like to recommend another instrument, please continue. Otherwise, thank you for your assistance in this effort.

WHEN YOU HAVE COMPLETED THE SURVEY, PLEASE MAIL IT IN THE ENCLOSED MANILA STAMPED ENVELOPE.

To receive the \$20 gift certificate, please complete the separate BLUE form and mail it in the enclosed white stamped envelope. This information is kept separate from your survey to preserve your anonymity.

APPROVED: Apr. 5, 2006

INSTRUCTIONS: SURVEY # 2 FOR PROFESSIONALS

Please do NOT sign or put your name on this survey.

When you have completed the survey, please place it in the stamped self-addressed MANILA envelope and mail it.

PLEASE RETURN THE SURVEY BY _____.

THANK YOU.

**Survey #2 on the Assessment of Communication and Cognitive Skills
in 2-8 Year Old Children who are Deafblind**

Oregon Health & Science University, under the direction of Dr. Charity Rowland, has received a grant from the U.S. Department of Education to study and validate methods for assessing the communication and cognitive skills of 2 – 8 year old children who are deafblind. This is a collaborative effort with Dr. Deborah Chen (California State University, Northridge), Dr. Harvey Mar (St. Lukes/Roosevelt Hospital and Columbia University, New York), Dr. Robert Stillman (University of Texas at Dallas) and the National Family Association for Deaf-Blind. This survey is designed to collect information from practitioners across the country who use specific assessment instruments that we are studying. Your participation in this survey is much appreciated. We will send you a \$20.00 gift certificate for completing this survey.

FIRST, SOME QUESTIONS ABOUT YOU AND YOUR BACKGROUND:

1. What is the nature of your current professional role involving children who are deafblind?
(e.g., Special Education classroom teacher, Speech-Language Pathologist)

2. Please list any degrees or certifications that you have earned related to your work in this role
(e.g., Certification in Moderate and Severe Disabilities, Master's degree in Psychology).

3. For how many years have you worked with children who are deafblind? _____ years

4. Did you complete our first assessment survey? _____ YES _____NO _____NOT SURE

NOW WE WOULD LIKE MORE INFORMATION ABOUT SPECIFIC ASSESSMENT INSTRUMENTS FROM OUR LIST THAT YOU HAVE USED TO EVALUATE 2-8 YEAR OLD CHILDREN WHO ARE DEAFBLIND WITHIN THE LAST 5 YEARS.

5. Please circle the ONE instrument you are rating from the following list:

Callier-Azusa **Carolina Developmental Profile** **Hawaii Early Learning Profile**
*Infused Skills Assessment (L. Hagood, in Communication—a Guide for Teaching Students with
Visual and Multiple Impairments*
INSITE *Oregon Project* *Vineland* *Communication Matrix*
Dimensions of Communication *Home Talk* *School Inventory of Problem Solving Skills*

<p>6. Is the use of this instrument mandatory? _____YES____NO</p> <p>7. About how long does it take you to complete an assessment using this instrument?_____</p>

Questions 8 through 22 are rated using the following scale:

Not Useful	Of Limited Use	Somewhat Useful	Useful	Very Useful	Not Applicable
1 -----	2 -----	3 -----	4 -----	5 -----	NA

Using the key above, please indicate how you would rate this instrument in terms of its usefulness for:

- ___ 8. Assessing **communication skills**
- ___ 9. Assessing **social interaction skills**
- ___ 10. Assessing **cognitive and learning skills**
- ___ 11. Assessing children **aged 2-8 years**
- ___ 12. Assessing children with **severe cognitive impairment**
- ___ 13. Assessing children **without symbolic language skills**
- ___ 14. Assessing children who have **severe vision impairment**
- ___ 15. Assessing children who have **severe hearing impairment**
- ___ 16. Assessing children who have **severe orthopedic or physical impairment**
- ___ 17. Assessing a variety of **children with a broad range of skills and needs** (not just children labeled deafblind)
- ___ 18. Evaluating a **wide range of skills** within each domain.
- ___ 19. Generating **instructional goals** and for **educational planning**
- ___ 20. Evaluating **progress**
- ___ 21. **Describing a child's strengths and weaknesses to parents**
- ___ 22. Generating an **accurate picture** of the child's skills

Questions 23 through 27 are rated using the following scale:

Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
1 -----	2 -----	3 -----	4 -----	5

Using the key above, please rate the extent to which to agree or disagree with each statement below:

- ___ 23. The instrument uses clear language.
- ___ 24. The instrument has clear instructions.
- ___ 25. The instrument is easy for me to understand.
- ___ 26. The instrument is easy for me to use.
- ___ 27. The instrument encouraged parent involvement in the assessment process.

28. Please provide any other comments you think relevant about this instrument:

29. *Have you or your school system designed your own assessment instrument(s) to use with 2-8 year old children who are deafblind?* _____ YES _____ NO

WHEN YOU HAVE COMPLETED THE SURVEY, PLEASE MAIL IT IN THE ENCLOSED MANILA STAMPED ENVELOPE.

To receive the \$20 gift certificate, please complete the separate BLUE form and mail it in the enclosed white stamped envelope. This information is kept separate from your survey to preserve your anonymity.

SURVEY # 1 for PARENTS

Instructions: Survey for Parents

Please do NOT sign or put your name on this survey.

When you have completed the survey, please place it in the stamped self-addressed MANILA envelope and mail it.

**PLEASE RETURN THE SURVEY WITHIN TWO
WEEKS OF RECEIVING IT. THANK YOU.**

Parent Survey on the Assessment of Communication and Cognitive Skills in 2-8 Year Old Children who are Deafblind

Oregon Health & Science University, under the direction of Dr. Charity Rowland, has received a grant from the U.S. Department of Education to study and validate methods for assessing the communication and cognitive skills of 2 – 8 year old children who are deafblind. This is a collaborative effort with Dr. Deborah Chen (California State University, Northridge), Dr. Harvey Mar (St. Lukes/Roosevelt Hospital and Columbia University, New York), Dr. Robert Stillman (University of Texas at Dallas) and the National Family Association for Deaf-Blind. This survey is designed to collect information from parents across the country on recommended assessment practices. We will send you a \$20.00 gift certificate for completing this survey.

NOTE

- To complete this survey you will need to refer to the latest evaluation reports (for example, the IEP) on your child. Information in the report about your child's educational, psychological, social, cognitive and communication/language skills will be relevant to this survey.
- It will take approximately 35 minutes to complete the survey.

FIRST, WE WOULD LIKE TO KNOW A LITTLE ABOUT YOUR CHILD WHO IS DEAFBLIND.

Your child's age _____

Your child's gender ___ Male ___ Female

Ethnic or racial background with which your child is most closely identified (you may check more than one). This information helps us to insure that we are including people from all backgrounds in our research efforts.

___ African American
___ Asian
___ Hispanic/Latino
___ South East Asian

___ Caucasian
___ Pacific Islander
___ Native American
___ Other _____

Primary language spoken in your home _____

What is the cause of your child's deafblindness? Please be as specific as you can (for example, CHARGE association, prematurity, unknown) _____

My child's Vision Impairment is classified as:

- ___ Cortical visual impairment
___ Diagnosed progressive loss
___ Legally blind (20/200 or less or field restriction of 20° or less in better eye with correction)
___ Light perception only
___ Low vision (visual acuity of 20/70 to 20/200 in the better eye with correction)
___ Totally blind
___ Not sure

Additional information about your child's vision _____

My child's Hearing Impairment is classified as:

- Diagnosed progressive loss
- Mild
- Moderate
- Severe
- Profound
- Not sure

If known, please provide decibel loss in each ear:

Right Ear _____dB loss Left Ear _____dB loss

Additional information about your child's hearing _____

Please indicate any specific impairments your child experiences:

Mild	Moderate	Severe	Specific Impairment
			Cognitive Impairment/Developmental Delay/Mental Retardation
			Emotional/Behavioral Disorder
			Health or Medical Problems
			Physical/Orthopedic/Motor Impairment
			Other Impairment (specify) _____

NOW, WE WOULD LIKE TO KNOW WHAT YOU THINK ABOUT THE OVERALL EVALUATION PROCESS USED WITH YOUR CHILD. PLEASE REFER TO YOUR CHILD'S LATEST EVALUATION REPORT.

1. How old was your child at the time of his or her last evaluation? _____ Years _____ Months

2. How **useful** were the results of the latest evaluation report to you in terms of identifying the specific needs of your child?

Not Useful Limited Somewhat Useful Very Useful
 Usefulness Usefulness Usefulness Usefulness Usefulness
 1 ----- 2 ----- 3 ----- 4 ----- 5 Don't Know

3. How **easy was it for you to understand** the results of the latest evaluation report? That is, were the results presented in terms that you could understand?

Very Difficult A Challenge to Not Difficult, Easy to Very Easy
 to Understand Understand but Not Easy Understand to Understand
 1 ----- 2 ----- 3 ----- 4 ----- 5

4. Do the results of the latest evaluation report **match your own observations** about your child? That is, do they reveal the strengths and weaknesses that you see in your child?

Not At All Very Little Somewhat Yes, Mostly Yes, Completely
 1 ----- 2 ----- 3 ----- 4 ----- 5

5. How useful were the results of the latest evaluation report in terms of helping you participate in **developing educational goals** for your child?

	Limited		Somewhat			
Not Useful	Usefulness		Useful	Useful	Very Useful	Don't Know
1 -----	2 -----		3 -----	4 -----	5 -----	

6. How useful was the latest evaluation report in terms of **describing your child's progress** over time?

	Limited		Somewhat			
Not Useful	Usefulness		Useful	Useful	Very Useful	Don't Know
1 -----	2 -----		3 -----	4 -----	5 -----	

7. To what extent **were you involved in the assessment** of your child for the latest evaluation?

			Somewhat		Quite	
Not At All	Very Little		Involved	Involved	Very Involved	
1 -----	2 -----		3 -----	4 -----	5 -----	

8. What was the most satisfying aspect of your child's latest evaluation?

9. What was the most dissatisfying aspect of your child's latest evaluation?

10. What suggestions do you have for professionals related to improving the assessment/evaluation process?

NOW WE WOULD LIKE TO KNOW WHAT YOU THINK OF SPECIFIC ASSESSMENT INSTRUMENTS THAT WERE USED TO EVALUATE YOUR CHILD.

11. If you know what specific assessment instruments (tests) were used to assess your child, we would like to know how you rate those instruments. In the table below you may write in the names of up to 4 assessments (such as the Hawaii Early Learning Profile, Communication and Symbolic Behavior Scales). Only list assessments that relate to your child’s communication, social and cognitive development. Then rate the value of each assessment you named according to the five characteristics listed to the right of the table. Using the following scale, place a number (1-5) or NA in each of the five columns next to any assessments you named.

Not at all Valuable	Of Limited Value	Somewhat Valuable	Quite Valuable	Extremely Valuable	Don't Know
1 - - - - -	2 - - - - -	3 - - - - -	4 - - - - -	5 - - - - -	NA

Assessment Instrument	Useful for evaluating my child’s needs	Easy for me to understand results	Results match my own observations of my child	Useful for developing educational goals for my child	Useful for describing my child’s progress over time

Thank you for your assistance in this effort.

WHEN YOU HAVE COMPLETED THE SURVEY, PLEASE MAIL IT IN THE ENCLOSED MANILA STAMPED ENVELOPE.

To receive the \$20 gift certificate, please complete the separate BLUE form and mail it in the enclosed white stamped envelope. This information is kept separate from your survey to preserve your anonymity.

INSTRUCTIONS: SURVEY # 2 FOR PARENTS

1. Please sign the white consent form (keep the blue one for your records)
2. Please make copies of any of the following instruments that have been completed on your child within the past 2 years.

Callier-Azusa

Infused Skills Assessment

Carolina Developmental Profile

INSITE

Communication Matrix

Oregon Project

Dimensions of Communication

School Inventory of Problem Solving Skills

Hawaii Early Learning Profile (HELP)

Vineland (home edition)

Home Talk

3. Please make a copy of the latest IEP or IFSP for your child.
4. Please complete the attached survey.
5. Place the white (signed) consent form, the copies of completed assessments on your child, and the survey into the stamped self-addressed manila envelope and mail it.

PLEASE RETURN BY _____ . THANK YOU

Parent Survey on the Assessment of Communication and Cognitive Skills in 2-8 Year Old Children who are Deafblind

Oregon Health & Science University, under the direction of Dr. Charity Rowland, has received a grant from the U.S. Department of Education to study and validate methods for assessing the communication and cognitive skills of 2 – 8 year old children who are deafblind. This is a collaborative effort with Dr. Deborah Chen (California State University, Northridge), Dr. Harvey Mar (St. Lukes/Roosevelt Hospital and Columbia University, New York), Dr. Robert Stillman (University of Texas at Dallas) and the National Family Association for Deaf-Blind. This survey is designed to collect information from parents across the country on recommended assessment practices. We will send you a \$50.00 check or gift certificate for completing this survey.

NOTE

- To complete this survey you will need copies of your child’s latest assessments and evaluation reports. Information in the report about your child’s educational, psychological, social, cognitive and communication/language skills will be relevant to this survey.
- It will take approximately 45 minutes to complete the survey and to make copies of your child’s assessments and IEP or IFSP.

FIRST, WE WOULD LIKE TO KNOW A LITTLE ABOUT YOUR CHILD WHO IS DEAFBLIND.

Your child’s age_____

Your child’s gender ___Male ___Female

Ethnic origin: Is your child of Hispanic or Latino origin? ___YES___NO___DON’T KNOW

Racial identification: Please check the racial background with which your child is most closely identified (if you are of Hispanic or Latino origin you may be of any race):

- | | | |
|--|--|---|
| <input type="checkbox"/> American Indian or Alaskan Native | <input type="checkbox"/> Native Hawaiian or other Pacific Islander | <input type="checkbox"/> Unknown or other |
| <input type="checkbox"/> Asian | <input type="checkbox"/> White | |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> More than one race | |

Primary language spoken in your home_____

What is the cause of your child’s deafblindness? Please be as specific as you can (for example, CHARGE association, prematurity, unknown)_____

My child's Vision Impairment is classified as:

- Cortical visual impairment
- Diagnosed progressive loss
- Legally blind (20/200 or less or field restriction of 20° or less in better eye with correction)
- Light perception only
- Low vision (visual acuity of 20/70 to 20/200 in the better eye with correction)
- Totally blind
- Not sure

Additional information about your child's vision _____

My child's Hearing Impairment is classified as:

- Diagnosed progressive loss
- Mild
- Moderate
- Severe
- Profound
- Not sure

If known, please provide decibel loss in each ear: Right Ear _____ dB loss Left Ear _____ dB loss

Additional information about your child's hearing _____

Please indicate any specific impairments your child experiences:

Mild	Moderate	Severe	Specific Impairment
			Cognitive Impairment/Developmental Delay/Mental Retardation
			Emotional/Behavioral Disorder
			Health or Medical Problems
			Physical/Orthopedic/Motor Impairment
			Other Impairment (specify)

When do you expect that your child will be assessed again? _____

**NOW WE WOULD LIKE TO KNOW WHAT YOU THINK OF SPECIFIC ASSESSMENT INSTRUMENTS
THAT WERE USED RECENTLY TO EVALUATE YOUR CHILD**

11. We would like to know what you think of any of the following instruments that have been used to assess your child.:

- | | |
|--------------------------------------|--|
| Callier-Azusa | Infused Skills Assessment |
| Carolina Developmental Profile | INSITE |
| Communication Matrix | Oregon Project |
| Dimensions of Communication | School Inventory of Problem Solving Skills |
| Hawaii Early Learning Profile (HELP) | Vineland (home edition) |
| Home Talk | |

Please use the forms on the next 3 pages to evaluate up to 3 assessment instruments (from the list above) that have been used to assess your child within the last two years.

Please answer the 10 questions below about each of the instruments that you have provided copies of. We are providing 3 forms so that you can evaluate up to three assessments.

NAME OF INSTRUMENT # 1 _____

Using the key below, please rate the extent to which to agree or disagree with statements 1-10				
Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
1	2	3	4	5

- ___1. This instrument uses clear language.
- ___2. This instrument is easy for me to understand.
- ___3. This instrument is useful for evaluating my child's needs.
- ___4. This instrument encouraged me to be involved in my child's assessment process.
- ___5. It is easy for me to understand the results that this instrument provides.
- ___6. This instrument provides results that match my own observations of my child.
- ___7. This instrument is useful for developing educational goals for my child.
- ___8. This instrument is useful for describing my child's progress.
- ___9. The instrument has clear instructions (only for instruments that you completed yourself).
- ___10. The instrument is easy for me to use (only for instruments that you completed yourself).