

BRINGING IT ALL BACK HOME

Family-Driven Assessment and Intervention for Children who are Deaf-Blind

FINAL REPORT

I. General Purpose of Project

The general purpose of this project was to promote the active involvement of parents and care providers in the educational assessment and program planning of their children with deaf-blindness. Specifically, this project sought to develop a family-driven approach to assessment and intervention for the child who is deaf-blind by: (1) improving the abilities of parents and care providers to observe their children's cognitive, communication, social, and problem solving skills across natural home and community activities; (2) recognizing and enhancing the roles of parents in the formal process of educational planning for their children by helping family members to identify intervention priorities, as well as everyday opportunities for intervention; and (3) strengthening the parents' role in overseeing successful transitions as their children proceed through the educational service system.

Over the past decade, parents and care providers have become increasingly involved as full members of their children's educational teams. In addition to participating in planning meetings, parents and caregivers often contribute resources, as well as direct support in the classroom. They carry out many of the intervention strategies and training activities in the home and community to ensure that there is continuity of educational practices across family, community, and school contexts. Yet, little recognition has been given to the important roles of parents and care

providers in the *formal assessment* of their own children or in the development of home-based intervention strategies.

In the typical school-based model of the triennial evaluation and IEP (individualized educational plan) development, parents and care providers are seen, at best, as good informants. The information they provide can help the evaluators and other team members form a general impression about a child's interests, competencies and preferences, and suggest appropriate school-based activities based on their children's interests and competencies. However, parents and care providers essentially assume secondary roles in the evaluation process by serving as sources of information to "professionals," rather than as active participants in the observation, analysis, and interpretation of their child's behaviors and in determining contexts and strategies for intervention.

Through its development of assessment, intervention and transition resources for family members, the *Bringing It All Back Home* project emphasized increased involvement of parents and care providers in the planning of their children's individualized education program (IEP) and family service plans (IFSP). Under most current models of IEP and IFSP planning, initial assessments are conducted by interdisciplinary team members (e.g., psychologists, speech-language pathologists, mobility instructors, physical and occupational therapists), who subsequently meet with parents to delineate the child's educational program, objectives and activities. Although participation of parents and family members is encouraged, their input in the process is typically solicited when assessment results are reviewed. That is, parents may not be able to convey their concerns and priorities until the IEP or IFSP meeting, which typically follows the completion of the formal evaluation period. To the extent that assessment results are used to identify a child's educational needs and priorities, the roles of parents and care providers in IEP or IFSP development might be regarded

as “reactive.” Methods of evaluating a child’s skills have already been determined and findings, concerns and conclusions are presented *to* parents as the basis for considering intervention programs and services.

The *Bringing It All Back Home* project supported a model of educational program planning in which parents and care providers enter the IEP or IFSP planning process at an earlier stage with “proactive” roles. The family-driven assessment tool developed and published by this project, *HomeTalk: A Family Assessment of Children who are Deafblind*, was designed to equip parents with the means to take part in the evaluation process by objectively describing their children’s competencies across home and community activities and contexts. Ideally, other members of the interdisciplinary team would collaborate *with* parents at the onset of the evaluation process, and parents would participate in the review of results by providing summaries and interpretations of *their own* findings, gathered and reported in a systematic, objective way.

Over the course of this project, a team of parents and professionals collaborated to design, field test, and disseminate an assessment protocol for parents of children who are deaf-blind. This protocol, entitled *HomeTalk: A Family Assessment of Children who are Deafblind*, is a four-section tool designed to help parents gather and report basic information about their children, identify children’s strengths and interests, evaluate their competencies, and link the database to educational goals and intervention priorities. Although the protocol was initially designed for use by parents of 3- to 12-year-old children with deafblindness, it has been applicable to older children, as well as children with other disabilities.

II. Rationale and Identified Need

Many of the children targeted by this project experience cognitive and

orthopedic disabilities as well as dual sensory impairments. Visual impairments seriously compromise the extent to which the child can learn about events and objects that are beyond his or her physical reach, while hearing impairments limit what the child can learn about the environment from auditory sensations. Orthopedic, or physical, disabilities may limit the child's experience with manipulating and exploring the physical environment. Cognitive disabilities, including attention and memory deficits, may impede integration of the limited sensory experiences and detract from the child's ability to make sense of the social or physical environment.

The foundations of independent behavior lie in the ability of the child to initiate interaction with the social and physical worlds and to respond to the opportunities for interaction afforded by those worlds. Mastery of the physical and social environments is critical to independence. However, few assessment tools and resources for the evaluation of children who are deafblind exist in which the evaluation is conducted within meaningful environments by persons who are most familiar with them. As part of this project's early activities, a needs assessment was conducted in which over 100 published references on the evaluation of children with sensory impairments, including deaf-blindness, were reviewed. Of over 350 existing assessment instruments, only a handful have been designed specifically for use by parents-as-evaluators. Only one, the *Home Inventory of Problem Solving Skills* (Rowland & Schweigert, 1997), was designed to help parents better understand their children's cognitive abilities in the context of everyday routines. Most parents and care providers informally document the skills and competencies of their children, and are constantly assessing their children's progress in myriad ways.

This *Bringing It All Back Home* project developed a family-driven assessment and intervention approach for children who are deaf-blind. The project represented an integration and extension of several previous research and demonstration activities of

the Project Co-Directors that addressed the development of communication, social and cognitive skills of children who are deaf-blind. Most of these research and model demonstration efforts focused on the application of research to practice in the school or clinical setting. The Bringing it All Back Home project sought to target family members, who represent the most sustained and pervasive influence on the development of their children.

This project identified several compelling reasons to develop a family-driven approach to assessment, intervention and transition. First, *parents and caregivers have first-hand opportunities to make observations of their children across natural contexts over time* and, therefore, can readily complement the process of school-based evaluation. However, parents and caregivers have not had resources to help them organize their observations, document effective home-based interventions, and monitor growth and change of their children. The *Bringing It All Back Home* project recognized that families already informally document the skills and competencies of their children, and that they are constantly assessing their children's progress in various ways and comparing their children to others. This project sought to help families by developing procedures and protocols to document skills and changes as they occur in typical contexts. Such assessment tools would "advocate" for parents in the sense that they would legitimize a parent-as-evaluator model, through the use of tools that would be as valid as more standard assessment tools designed exclusively for use by professionals.

Second, *members of an evaluation team may be more likely to regard formalized assessments conducted by parents as less biased or subjective, and to perceive parents as true collaborators with equal responsibility for the planning of a child's educational needs*. The formalizing of family-driven home-based assessment protocols would provide parents with systematic means for gathering data about their

children's breadth of skills and for presenting their invaluable knowledge in a form that professionals are more likely to respect and to integrate into their own evaluations.

Third, *validated, field-tested materials designed by and for parents can serve to promote the self-determination of the whole family.* By increasing knowledge about their children's understanding of concepts, communication behaviors, social interaction skills, and problem solving skills, parents and care providers can assume much more active roles in the consideration of intervention priorities. A family's increased sense of self-determination may directly impact upon the duration of long-term involvement and feelings of satisfaction with the provision of educational services.

Fourth, *parents who learn to recognize specific concepts and skills exhibited by their children during play, natural daily routines, and family events are better able to use those contexts for effective intervention.* A recently completed project, Project PLAI (Chen & Haney, California State University), developed "contingency games" as a means to promote infant-care giver interactions within the natural context of everyday routines. The games were designed to help parents of infants with vision and hearing impairments to recognize early cognitive, social, and communication skills, and to engage with their infants in the course of everyday routines. One of the critical outcomes of that project has been caregivers' feelings of increased competence in promoting their infants' skills. The *Bringing It All Back Home* project similarly emphasized the assessment-to-intervention link--that is, the application of parents' knowledge gained from assessment to their own actions and interactions with their children. Perhaps the most critical component in this process is the ability of parents and caregivers to recognize the number and variety of natural opportunities throughout the day during which they can provide structured interventions, and to apply educative but natural forms of support to their children (e.g., promoting child-to-sibling interactions, searching for objects within the immediate vicinity, getting around

barriers in the home, becoming aware of choices during meals).

Fifth, an underlying premise for this project was that *as families become more active in the assessment and intervention process, disruptions due to necessary transitions, including changes of personnel, are likely to be reduced.* Transitions have been of particular concern with respect to children who are deaf-blind because of the uniqueness of the services and supports they require--for example, mobility instruction, intervenors, assistive devices, teachers and peers who sign, and adapted classroom materials. When a child transitions from home to school or from one classroom or school to another, there is often disruption of intervention goals, activities, methods, and contexts. Continuity of services, reflected in the consistency of interventions across schools and service providers, may be better facilitated when parents can serve as liaisons and convey objective and comprehensive information about their children's competencies, learning styles, and social opportunities, as well as the interventions and contexts which have already proven particularly effective at home or in the community.

Finally, *materials developed by and for parents from diverse socio-economic and cultural backgrounds are more likely to be used by a wide variety of parents, including those from low-income, culturally or linguistically diverse backgrounds.* Materials designed for parents need to be made useful to family members who have varying degrees of knowledge and experience about their child's development and how to impact upon it. Materials developed by and for parents from diverse backgrounds are likely to be presented in ways that are sensitive to diverse cultural backgrounds, conveyed in terms that are clear to individuals without sophisticated literacy skills and will incorporate examples that resonate with the experiences of other parents. In the development of *HomeTalk*, several revisions were made to adapt the language, interest level, and readability to meet the needs of a diverse population. A

Spanish language version of *HomeTalk* was also developed.

III. Objectives and Major Activities

This project had several major objectives: (1) to develop family-driven assessment strategies and materials that family members may use to evaluate the strengths and needs of their children who are deaf-blind; (2) to develop family-driven intervention strategies and materials that family members may use to enhance the development of their children who are deaf-blind in typical home and community settings; and (3) to develop family-driven transition strategies and materials that will promote successful transitions of children who are deaf-blind within inclusive school programs.

It was important for this project to embody several principles. First, the resulting materials were to be developed primarily *by parents* (in conjunction with project staff) with feedback from an advisory board of outside professionals. Second, the materials would be developed *for parents* to use both independently and in collaboration with service providers. Third, the materials would be developed and presented from an *activity-based perspective*. That is, the assessment would not focus on isolated developmental or functional skills, but everyday activities common to home and community settings of the typical child. The materials would show families how a progression of communicative, social and cognitive skills could be embedded into these activities and how these activities could be used to promote child progress.

The primary outcome of this project was to develop a family-friendly, objective evaluation tool designed primarily for use by parents to enhance their direct participation in the process of educational planning for their children. The project relied heavily on paid parent consultants who assisted in the development of all materials, which were then field tested by additional families with children who are

deaf-blind. Specific project objectives and summaries of the activities conducted under these objectives are described herein.

A. Objective 1--Enhance ability of family members to recognize and evaluate abilities of their children as demonstrated through daily activities.

We recognized that families already informally document the skills and competencies of their children, and that they are constantly assessing their children's progress in various ways and comparing their child to others. This project sought to help families by developing procedures and protocols to document skills and changes as they occur in typical contexts. *HomeTalk: A Family Assessment of Children who are Deafblind* was conceived as an instrument to help the parent-as-evaluator to formalize the gathering and summarizing of information, and to help the parent to systematically consider what objectives and activities would be important to expand upon for the child. This tool was also designed to "advocate" for parents in the sense that it would legitimize a parent-as-evaluator model, through the use of an assessment instrument that would be no less valid than more standard assessment tools designed exclusively for use by professionals.

Activity 1.1 Collect needs assessment data. During the first project year, parent consultants were convened to discuss in focus groups the areas of development and specific skills that are important from the perspective of effective functioning in home and community settings for the young child. A total of three focus groups were conducted in Oregon and Washington State, and additional parents interviewed by phone. Additionally, a project web page through Oregon Health & Sciences University, Center on Self-Determination, was created to allow us to post questions and materials and to accept feedback from web users throughout the world. The web site was also announced in other web sites, listserves and newsletters related to deafblindness. Feedback has been obtained through the web site from a number of parents across the country. (See Appendix B for web pages announcing project and requests for parent input.) Three thousand postcards

announcing the availability of the web site and soliciting parent input were sent out by Deafblind Service Coordinators in 20 states to parents of children on the state deafblind census.

The three focus groups included from six to nine parents in the Portland and Seattle areas. Focus group members were presented with several “topical issues” for discussion regarding: the role of parents on the educational team; general assessment concepts and concerns; sharing information with professionals; areas that needed to be assessed; the membership and qualifications of members of the evaluation teams; the contexts in which evaluations are best conducted; the feedback process in which professionals discuss evaluation results with parents; and types of useful assessment instruments with which parents are familiar. The responses of focus group members to each of these areas were recorded, and following the third focus group meeting, responses were compiled and summarized.

Activity 1.2 Develop evaluation strategies for family-driven assessment. The data collected through the focus groups were then used to design and develop the concept of an assessment protocol for parents-as-evaluators with which a child’s cognitive, communicative, and social skills could be assessed in the context of naturally occurring events and activities. A point of departure for assessment strategies included protocols already developed by project personnel. In this phase of the project, which began at the end of the first project year (Summer 1999) and continued during the second year (Fall 1999 through Summer 2000), guidelines for the development of the assessment protocol were first articulated.

Guidelines were based on consensus statements of parents, and represented working concepts, rather than “requirements.” Examples of guidelines include: (a) “It is important to understand the lifestyle of children and their likes, preferences, and habits.”; (b) “It is

important to start with the concept of independence and use it as a basis for making observations of the child.”; (c) “One must gather information about the fundamentals, or the ‘little tiny steps’ that describe a child’s progress”; (d) “It is important to be able to provide anecdotal information about children’s skills and behaviors which might not be observed in school.”; (e) “It is important to provide basic information about the nature of deafblindness to the educational team as part of the evaluation.”; and (f) “Communication is the biggest skill area of concern and needs to be prominent in the assessment protocol.”

The six Parent Consultants hired to participate in all phases of this project then received a series of several specific assignments to assist in the conceptualization and design of the assessment tool. Parent Consultants were asked to define areas of child development which needed to be assessed, consider organization of the assessment protocol, provide examples of the types of skills that children could exhibit at home and in the community, and identify critical information that schools and educational teams would find useful during IEP and educational planning meetings. A total of six assignments were sent to the Parent Consultants, with each new assignment incorporating suggestions from the previous one. The intent of this project was to have parents take the lead in conceptualizing and constructing the family-driven assessment tool that was eventually named *HomeTalk: A Family Assessment of Children who are Deafblind*.

The first assignment was for Parent Consultants to read the consensus statements from the focus group meetings about “working concepts” for the assessment protocol. Then, they had to provide specific ideas for assessment tool characteristics, scope, and detail. For example, one question on the first assignment was, “Think about how your child interacts with objects and the physical space of your home or the community. What kinds of things should other members of your child’s educational team know about how your child interacts with the physical environment?” Based upon the responses and comments of Parent Consultants, the next assignment was then developed. Each assignment progressed toward

the development of a blueprint of the assessment protocol. For example, once Parent Consultants completed the first assignment, they were given specific tasks of (a) identifying and defining domains, or skill areas, to be assessed by parents-as-evaluators; and (b) determining the content and format of assessment items and questions.

Activity 1.3 Develop family-driven assessment materials. Several initial drafts of the assessment materials were developed and revised during the third year of the project (April 2001). This initial development phase involved project personnel, the six Parent Consultants, and nine Professional Consultants in the field of deafblindness who were asked to review the first major working concept of the assessment tool.

After receiving feedback from Parent and Professional Consultants, a first illustrated draft of the protocol was developed during the third year of the project. The illustrated version then went through several additional revisions in an effort to better organize and sequence the parts of the assessment tool, make the assessment items succinct, and to make the language simple. A final draft for the first field test was developed toward the end of the third year, in May 2001.

Activity 1.4 Field test home-based assessment materials. A total of 19 families were recruited to field test the first full-text version of *HomeTalk: A Family Assessment of Children who are Deafblind*. Field-testing occurred during the end of the third project year (June 2001 through September 2001). The families were recruited from various sources. These included recommendations of family members from state project directors of Washington, Oregon, and New York. The National Family Association for Deaf-Blind (NFADB) also printed a request for participation in their organization's newsletter to members. The request for participants was posted through *Deaf-Blind Perspectives*, published by the National Information Clearinghouse on Children who are Deafblind (DB-LINK), and the project's web page, as well.

Each family member who volunteered to participate in this field-testing process had

a child who was deafblind. Each parent reviewer was paid an established rate based upon the estimated amount of time it would take to complete the entire protocol. Parents and family members were instructed to make observations of their own children, and to work with members of their children's educational team to review the section (Part 4) on development of educational goals and activities. They were asked to return the completed protocols and their reviews within two weeks of receiving them. In addition to completing the entire assessment protocol, parents were instructed to provide specific comments directly on the instrument pertaining to difficulty of language, appropriateness of the question or item, organization of questions within sections, etc.

The nine Professional Consultants first became involved in the project during this phase. Each of the Project Consultants either worked directly with children who are deafblind and their families (e.g., providing technical assistance, training, administrative support, educational services) or developed assessment tools and other professional resources for children with deafblindness and other disabilities. They agreed to serve as reviewers of the assessment instrument and to make critical comments about content, organization, language, relevance, strengths, and weaknesses of the protocol. Different feedback (review) forms were used for the parents and Project Consultants, as their roles in this phase of the project differed from each other. Activity 1.5 Review feedback from field-testing of assessment materials. Written, extensive feedback was received from the 19 parents who field-tested the instrument and the 9 Project Consultants who reviewed the assessment protocol.

All of the 19 parent respondents were mothers. Their children ranged in age from 4 years to 17 years, with an average of 9 years of age. The average amount of time it took parents to complete the assessment protocol was 3.4 hours (ranging from 1 hour, 15 minutes to 6 hours). In response to a question about the most useful feature of the assessment instrument (which had been introduced as *HomeTalk*), several comments were made which

were consistent with the original “guidelines” or working concepts developed during the initial phases of the project, e.g.:

- “It (the tool) met my child where he was—not above his level.”
- “It helped me see the natural progression of abilities for my child.”
- “It let me rank the most important skill areas to focus on for my child.”
- “My child’s IEP had no social goals, and I used this as a tool at the meeting to get the team to look at social skills.”
- “It allowed me a place and a time to assess my own child’s ability in specific terms.”
- “The positive slant throughout and especially in Part 3 was very helpful.”

Parents also had the opportunity to comment on negative features of *HomeTalk*. Nine of the 19 parents did not identify major weaknesses or problems. Others commented that: the section designed to gather medical information was complex and hard to complete; working on Part 4 (establishing educational goals) was like “re-writing the IEP”; and that the teachers would not use all of the information contained in the instrument. These parents also made specific suggestions for improving the assessment tool, and many of these ideas were incorporated in subsequent revisions. As part of the review, parents completed a rating scale in which they judged specific characteristics of *HomeTalk*, including its organization, length, level of difficulty, professionalism, relevance of test items, and design. The vast majority of responses were positive on each of these characteristics.

The feedback from professionals focused on overall presentation, relevance of questions and items to students with deafblindness, usefulness of the instrument, and potential for the instrument to increase the involvement of parents and care providers in the evaluation process. Professionals were also asked to make very specific and detailed comments on questions, instructions, and layout. Their comments were also reviewed for incorporation into revisions of *HomeTalk*.

B. Objective 2-- Enhance ability of family members to embed effective intervention into the daily activities of their children.

Assessment findings and observations should be linked directly to intervention priorities, goals, activities, and contexts for individual children who are deaf-blind. Intervention should be a logical extension of assessment. For example, in promoting a child's ability to prepare a simple snack, we may have a "curriculum" of goals that incorporate a variety of communicative, cognitive and social skills related to participating in this activity successfully. Such goals might include, for example: (1) opening cupboard doors and kitchen drawers and searching for required food items and utensils; (2) communicating need for assistance in opening a jar; (3) using a knife to spread peanut butter; (4) using a container such as a tray to stack dishes when finished and transport them to the sink.

A major objective of this project was to develop an instrument that could directly link assessment results to educational planning, including identification of appropriate goals and consideration of relevant intervention activities and strategies addressing those goals. The intent was to increase the involvement of parents in determining short-term and long-term educational goals for their children.

Activity 2.1 Collect intervention data, goals and contexts. From the onset of the project, the assessment protocol was conceived as linking assessment to intervention. Thus, even during the first year of the project when focus groups were convened, considerable discussion centered on parents' involvement in intervention design and implementation. In the three focus groups, parents discussed the goals and contexts of daily activities at home and in the community that were most important to them and their perception of the quality of their child's life experiences. Discussion embraced the opportunities that activities provided for demonstrating needed skills and how readily parents felt an activity could be adapted in order to promote child progress. Discussion also included how to monitor a

child's progress in the midst of conducting a typical activity.

Activity 2.2 Develop strategy to link assessment results to interventions as part of the assessment protocol. The data collected through the focus groups were then used to consider a strategy to link assessment results to family-driven intervention goals and activities. Based upon parents' comments and reactions, it was determined that the *HomeTalk* instrument should clearly show how assessment results could lead to consideration of appropriate educational goals. Several specific issues were identified in these focus groups, including: identifying communication goals as most important for children who are deafblind; considering how to make educational goals and interventions consistent between school and home; addressing needs of children aging out of one school and entering another school; and targeting the home and community as instructional environments.

In Part 3 of *HomeTalk: A Family Assessment of Children who are Deafblind*, parents rated the competencies of their children in several skill domains, including social interaction, problem solving, environmental exploration, and basic learning skills. Within each domain were several subdomains, each containing statements of questions about a child's specific competencies (see Appendix A). Parents rated the degree to which their children could succeed in each task or situation (total assistance needed, much assistance, moderate assistance, some assistance, no assistance). These ratings were numerical (1 to 5, respectively). At the end of each subdomain section, parents added up their rankings. For each skill area, two different sets of educational goals were generated to correspond to total scores above the 50% mark and below the 50% mark; it was recognized that children who are deafblind are extremely heterogeneous in their degrees of competencies.

The listing of educational goals and activities in Part 4 of the instrument was included in the assessment protocol to: (a) emphasize the natural and important connection between assessment and intervention, and (b) to help parents begin to consider goals that

might not necessarily be listed in the intervention sets, but which might be especially important to consider. In subsequent versions of *HomeTalk*, Part 4 was reconceptualized as a “parent-professional worksheet.” From feedback obtained during the field-testing, it became evident that Part 4 was very complex for many parents to do alone. Part 4 was subsequently revised to encourage parent-initiated collaboration in identification of educational goals and activities.

Within Part 4, several learning and intervention situations were described to: (1) help parents recognize typical events and activities as being important opportunities to enhance specific skills; (2) directly relate results of assessment to appropriate objectives/activities to be considered; (3) show how to create environments and opportunities for children where few might exist to enhance identified skills; and (4) exemplify how to monitor child progress.

Activity 2.3 Field test intervention materials. The same 19 parents and care providers who field-tested assessment materials also reviewed the intervention component of the protocol. These parents and care providers were asked to generate educational goals and activities for their own children after they had gone through previous parts in which they assessed their children’s competencies. The section on intervention goals and activities (Part 4) was then revised in response to field testers’ evaluation data and comments. Feedback was also obtained from Parent Consultants of the project, as well as members of the Advisory Board.

Objective 3-- Enhance the transition of children from home-based to school-based intervention to promote consistency and continuity in the planning and implementation of intervention activities and collaboration between parents and teachers.

Most students face major disruptions in terms of continuity as they transition from one program to another, move from one grade to the next, or enter one educational system, then another. Often each succeeding teacher starts the process over again, designing

programs that may have little relationship to previous program goals. This project was designed to help resolve these problems by developing tools to support an enhanced role for parents in overseeing the transition process. Parents and caregivers are in the unique position of being long-term evaluators of their children, as well as the most consistent interventionists. They are usually the only constants in the lives of their children and as such are in the best position to oversee their transitions from one service program to another.

Activity 3.1 Use *HomeTalk* to help parents and educational teams consider transition needs, barriers and successes. After the field-testing and reviews of Professional Consultants, Parent Consultants, and Advisory Board Members, *HomeTalk* underwent major revision into the format that eventually led to the development of the final product (see Appendix A). The revised instrument underwent a field-trial process in which parents utilized *HomeTalk* as a member of an educational team. A request went out through NFADB asking for parents whose children were currently being evaluated by their schools, or who were scheduled to be evaluated, to utilize *HomeTalk* as part of the teaming process. In addition, several project directors or project consultants from various state deafblind projects assisted by contacting families to solicit their interest in participating in the *Bringing It All Back Home* project. One of the Project Co-Directors, Harvey Mar, had also been working directly with families of children with deafblindness in the state of Minnesota through the Greater Minnesota Assessment Service, Health & Wellness Program of Regions Hospital, St. Paul and the Minnesota Deafblind Technical Assistance Project. During the fourth year of the project (2001-02), a total of 8 families participated in this field-trial process.

The purpose of this field-trial process was somewhat different from field-testing. The main purpose of field-testing was to revise the instrument, itself. The purpose of the field trial, on the other hand, was to examine the extent to which the use of *HomeTalk* actually led to the intended goals: increased involvement on the parts of family members in

the evaluation process; assistance with transitions issues; and promote the families' sense of self-determination. Families who participated were asked by e-mail or questionnaire or interview to comment on these specific aspects of their experience using *HomeTalk* during an actual evaluation process. Comments included the following:

- The tool has fabulous potential to help parents introduce their complex child to new team members.”
- “It is an easy way to introduce C__ to new teachers who don’t know about him.”
- “Useful in describing my child with greater detail than I would have otherwise. Helped me to remember what to comment on.”
- “This is an important goal-setting tool that helps parents and team members of an IEP team can use. Parents can play a more active roll with their child’s education by setting goals themselves with the help of their child’s IEP team.”
- “The most important thing is being able to set goals for your child using *HomeTalk* with others who are part of your child’s educational team.”
- “It helps you think about goals for continuing growth of your child.”
- “It gave me the specific suggestions that I had brought to the IEP meeting, which I used from *HomeTalk*. It gave me more confidence to tell the 17 people at the IEP meeting what my daughter needs.”
- “It brings what teachers do in writing IEP goals home to the parent. I found myself taking a good look at how school and home can help my child,”

Although these do not represent formal data, the comments and reactions of 8 parents who used *HomeTalk* as members of educational evaluation teams were, on the whole, very positive.

V. Dissemination

The major final product was a bound assessment-to-intervention protocol, *HomeTalk: A Family Assessment of Children who are Deafblind*. The instrument was 42

pages long. The project identified a professional consultant to design the layout of the final product. As the instrument was revised following reviews and field-testing, layout versions of the product also changed. One of the goals of this project was to make the instrument accessible to any and all parents and care givers, educational consultants, special education personnel, and other professionals who would make use of the instrument.

The initial printing of 1,000 bound English-language copies was completed at the end of the fourth project year. The availability of the resource was announced in several ways:

- NFADB newsletter
- Deaf-Blind Perspectives
- Letter to each state deafblind project
- OHSU website
- DB-LINK listserv
- TASH national conference poster presentation, 2003
- Project Directors' Meeting topical sessions, 2000-2002

This project collaborated with DB-LINK (National Information Clearinghouse on Children who are Deafblind) to disseminate the printed assessment protocol. DB-LINK announced the availability of the resource and responded to questions and requests for copies. The first 1,000 copies have already been disseminated, and a second 1,000 copies were printed by the project and sent to DB-LINK for distribution. Each state/regional deafblind project funded by the United States Department of Education was also sent two copies, along with information about ordering additional copies. DB-LINK has also considered other formats for dissemination of this instrument, including electronic transmission (PDF file through its website). *HomeTalk* may now be downloaded in either English or Spanish and in Word or PDF formats from the following link:

http://www.ohsu.edu/oidd/d21/our_pro/hometalk.html

It is expected that the use of these materials will enhance the satisfaction of parents with the evaluation and education of their children and with the transitions of their children from one classroom or program to another. In addition, it is expected that teachers' satisfaction with their ability to provide services to families who have used these strategies and materials will be enhanced. Children whose school experiences are reinforced by effective intervention at home during these formative school years will be well on their way to successful transitions to middle and high school. This project expects that these materials will continue to be of direct benefit to children with deaf-blindness ages 3-12 and older, and their families and service providers, regardless of their racial, ethnic, or cultural heritage.