

# Parent Education for Parents who have Cognitive Limitations - Phase II Final Report

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5R44HD047050-03

Project Period: 05/01/2006 - 04/01/2009

## Overview of Project Tasks

Parents who have intellectual disabilities often have a number of professionals in their lives who provide support, but the task of these professionals is made more difficult by three major factors: (1) uncertainty about how to identify parents who have ID, (2) limited knowledge and understanding about how to best support parents who have ID, and (3) the lack of relevant, easy-to-use training materials geared to the learning needs of this group of parents. Staff of child welfare agencies, public health organizations, and early intervention programs, such as Healthy Start, need materials they can use to support parents through the challenging preschool years and beyond.

The central aim of this project was to create a media-based parenting program for parents with preschool-aged children who have ID, and the professionals who support them. In Phase I, we completed our two primary goals. First, we developed a parent training program, My Bedtime Routine for parent mentors to use with parents who have ID. Second, we conducted a feasibility evaluation of the program with 15 parent/parent mentor dyads. The result of this evaluation was positive and encouraging. Parent participants established bedtime routines or improved their already-established routines. Parents reported having less stress and more fun with their children at bedtime. The program also led to an improved relationship between parents and the mentors supporting them. Improvements were seen in the quantity and quality of mentor-provided support, which is a leading predictor of more positive parenting in households headed by a parent or parents who have ID. Consumer satisfaction results showed that parents and mentors were enthusiastic about the usefulness and quality of the materials and would recommend them to other families and colleagues. We also conducted a program review with positive ratings from with two outside panels: (a) social service professionals and (b) at-risk parents.

The primary goals of Phase II were to continue development of the theory-based intervention, and to conduct an evaluation with parents who have ID and their support professionals. The Phase II Project had the following aims:

1. Creation of program content objectives with input from expert professional key informants.
2. Development and production, with guidance from Project Consultants, of five parenting modules (Ready for School, Ready to Read, Ready to Play, Ready to Get Along, and Ready for Bed) and a companion training module for support professionals. Each module is accompanied by a deck of interactive cards for the parent and child (for example, cards to lay out a morning routine), a video for the parent and child to watch together, and a separate "sing-along" CD with all of the songs from the program. The interactive and video materials were developed from feedback from expert key informant researchers and practitioners in the field, parents who have ID and their preschool-aged children, and social service professionals who work with parents who have ID.
3. Conducting a formal evaluation of the program with 30 pairs of parents and support people in their lives, "mentors," to assess the efficacy of the program in:
  - ∴ Increasing professionals' knowledge, skills and confidence related to working with parents who have ID
  - ∴ Increasing the quantity of support offered by professionals to the targeted parents
  - ∴ Improving the quality of the relationship between professionals and targeted parents
  - ∴ Improving parents' skills in the program topic areas

As described below, all of the Phase II tasks were successfully completed.

## Task 1: Develop content objectives with input from expert professional key informants.

- ∴ a. Interviews with expert key informants. Formative development included extensive interviews with experts and key informants. During Phase I, Dr. Jones developed relationships with leading researchers in the field. As a result, during Phase II, Dr. Jones was invited to attend a summit of experts and practitioners who support parents with intellectual disabilities, and present on this NIH-funded project. The summit, called A Chance to Parent, was held in September, 2007. During the summit, Dr. Jones interviewed Drs. Virginia Cruz, Susan Jones and Maurice Feldman, among other researchers and practitioners doing work in this area, and a panel of five parents who have intellectual disabilities. During her interviews, Dr. Jones inquired about what kind of content they saw as most needed in a parenting program for mentor/parent pairs, and what sort of format would be most usable in the field. Additional Key Informant interviews were held

after the summit with Cathy Haarstad Expert Key-informant interviews shed light on the needs of parents and mentors and underlined the urgent need for this program.

Dr. Maurice Feldman is a scientist-practitioner with expertise in child maltreatment, parenting, behavior disorders, autism and developmental disabilities. He is a leading expert in parenting by persons with intellectual disabilities, having designed and scientifically validated a parent education program emulated worldwide. Currently, he is co-Principal Investigator (with Frances Owen) of the Human Rights Training Project for Persons with intellectual disabilities. He has published extensively in peer-review journals and books, and has given numerous addresses and workshops. Dr. Feldman has developed some health and safety programs for parents who have ID. In our discussions, Dr. Feldman emphasized the need for developing a flexible, competence-based intervention that includes assessment in key parenting areas. Parent mentors (PM) need training in how to work effectively with parents who have ID. Helpful PM qualities include: nonjudgmental communication, empathetic, and the ability to offer competency-enhancing support. Dr. Feldman noted that his programs have led to successful improvement in parenting behaviors among parents who have ID. Materials should be simple and include examples of "right" and "wrong" ways. Inclusion of an accompanying audio tape reinforces newly learned skills. Dr. Feldman noted that parents need resources that do not require reading but provide support in setting up household routines, and fostering school readiness skills in their children.

Dr. Virginia Cruz and Susan Jones met with Dr. Jones to talk about the needs of parents who have ID and the social service professionals who support them. Dr. Cruz is the Chair of the Social Work Department at Metropolitan State College of Denver, CO. She is the Executive Producer of the video, "A Fair Chance," which profiles the strengths and limitations of six parents who have intellectual disabilities. Susan Jones is Positive Parenting Coordinator at The United Arc. Dr. Cruz and Ms. Jones noted that an effective program is one that does not overwhelm families, and focuses on one skill at a time. Social service professionals need guidance in how to build appropriate goals for parents with specific achievable action steps. Visual tools that present choices and options are needed. Color coding by lesson is helpful as is assistance in building a sustainable natural support network. The program should be preventative, rather than crisis-driven and must be flexible to meet the varying needs of professionals and families. The most important features of a program would include training for the mentor in: identification of parents who have ID, how to provide effective in-home service and support, including tips in working effectively with parents who have ID, in-home assessments for targeted parenting areas, a focus on including the whole family in the training, and skill-building for parents that is repetitive; uses demonstration and includes resources that require little/no reading. The parenting materials should be attractive, engaging, and user-friendly.

Cathy Haarstad. Cathy has a master's degree in special education. She has over 30 years of experience in education and service. Cathy has served as a special education teacher working with minority populations, a support provider for adults with developmental disabilities and a family support specialist. Ms. Haarstad directs projects of national significance in family support and transportation and serves on several statewide advisory committees. She is an adjunct faculty member at MSU, teaching both on campus and online courses in special education. Our discussions with Cathy gave us information about the experience of the social service professional in the field, working on a daily basis with parents who have ID. Cathy noted that many professionals are unaware of how to identify parents with ID and how best to support their parenting. Materials that are appropriate for parents are scarce and mostly focus on health and safety. In Cathy's experience, parents who have ID tend to provide either too much or too little supervision. Parents need "just in time" information and repetition of a skill in multiple environments, situations to help generalize the skill. Ideal programs would include lots of in-home activities; in-home visits at least once a week, help in building a natural support system, and comprehensive services to support the whole family. Professionals working with parents need to know how to establish rapport with parents, are approachable and warm, but not naïve. They will have received training in how to work with this population and are capable of individualizing supports for parents and knowledgeable about adult learning principles. What is not helpful is quizzing parents, splitting family services up between uncoordinated agencies, unrealistic expectations, disrespectful communication, and the inability to follow the parents' pace in training.

Delphia Perezselsky. Delphia is a Healthy Start worker. The mission of the National Healthy Start Association is to promote the development of community-based maternal and child health programs, particularly those addressing the issues of infant mortality, low birth weight and racial disparities in perinatal outcomes. Delphia actively works with parents who have ID with preschoolers. She noted that organizational skills are probably one of their biggest barriers to having a safe, livable environment in homes headed by parents who have ID. That carries into their housekeeping, mealtime routines, all of their routines. Much of Delphia's work involves providing structure for the parents where they have deficits. Engaging, interactive materials that structure activity (such as a bedtime routines chart) will help them sustain the activity over time. Parents who have ID have difficulty with written material so it is important that learning materials require only minimal reading. Delphia concurred with the other key informants, that, since professionals have little time to spend with parents, it's very important to help them develop natural supports. Materials for parents should be very concrete, user friendly, and something parents will feel nurtured by (because they've had to live with barriers and biases against them all their lives). Parents are very concerned that their children will be taken from them, so they tend to try to hide their challenges.

Parent Panel. Parents in the panel unanimously agreed that families that have the most success have good supports (social service and natural supports). Moms in panel had trouble getting social service supports and were persistent in pursuing them. The majority of support for these parents came from their families.

When asked about the types of support that are most helpful, parents responded with the following:

- Show me by example
- Let me make mistakes
- Be there for me when help is needed
- Listen when I need someone to talk to

- Give advice only when I ask for it

The types of support that are least helpful include:

- Taking over: "it's hard to make people understand that I can be a good parent"
- Hovering - "mom was always basically two feet from me and my worker"
- Supports that are difficult to access (e.g., location difficult or person unavailable when needed)
- People who assume that they will not be adequate parents

## Task 2. Development and production, with guidance from Project Consultants, of five parenting modules (Ready for School, Ready to Read, Ready to Play, Ready to Get Along, and Ready for Bed) and a companion training module for support professionals.

### Collaboration with Consultants

We worked with our consultants, Polly Snodgrass and Marilyn Espe-Scherwindt throughout the development period. When development began, we interviewed both of them to learn more about their perceptions of what is needed to effectively support parents who have ID. In addition, our consultants also gave us ongoing feedback on our scripts and materials as they were developed. Polly Snodgrass, RN, is a graduate of the Jefferson Medical College Hospital School of Nursing in Philadelphia, PA. She has a long history of leadership and success in bringing together resources to serve children and families at risk. Ms. Snodgrass pioneered a family-directed, family-centered approach to supporting young children in families headed by parents with disabilities, and served as its director for 11 years. Marilyn Espe-Scherwindt is Director of Family Child Learning Center (FCLC), a research and training program located in Tallmadge, Ohio that is committed to developing, evaluating and disseminating innovative services for families. Ms. Espe-Scherwindt has a Ph.D. in Educational Policy and Leadership from Ohio State University and has been a researcher and practitioner concerned with the needs of parents who have ID for over two decades.

### Theoretical Framework

Program development was grounded in sociocultural and social cognitive theory. Vygotsky (1978) maintained the child follows the adult's example and gradually develops the ability to do certain tasks without help or assistance. The difference between what a child can do with help and what he or she can do without guidance the "zone of proximal development" (ZPD) (Vygotsky, 1978; Berk, 2004). According to Vygotsky, cooperative between children and more knowledgeable members of their society are necessary for children to acquire the ways of thinking and behaving that make up a community's culture. These dialogues occur as adults and children spend time together ? in everyday situations such as household chores, mealtimes, play, story book reading, outings in the community, and children's efforts to acquire all sorts of skills. Although interactions that arise between adults and children may seem mundane and inconsequential at first glance, sociocultural theory emphasizes that they are powerful sources of children's learning. According to Laura Berk (2004) "children are active agents, contributing to the creation of their own thought processes by collaborating with more experienced cultural members in meaningful activities. The combination of child and adult leads to the communication between them? the child appropriates or "adopts" tools of the mind."

Our goal was to train social service professionals to develop cooperative dialogues with parents just as we want the parents to do with their own children. The PM's task is to provide parents with experiences in their "zone" (activities that challenge them but can be accomplished with sensitive guidance) while continually assessing their progress. Mentors can create the "zone" by keeping the task proximal ? slightly above the parents' level of independent functioning. Another idea central to develop of the materials was scaffolding. In scaffolding, the learner is viewed as a building ? actively under construction (Berk, 2004). The teacher provides a dynamic, flexible scaffold ? or framework ? that assists the learner in mastering new competencies. To promote development, the adult varies his or her assistance to fit the learner's changing level of performance, with the goal of keeping the learner in the "zone." This is usually done in two ways: (1) By adjusting the task so the demands on the learner at any given moment are appropriately challenging, and (2) tailoring the degree of intervention to the learner's needs.

Bandura (1977) postulated that enhanced self-efficacy influences behavior by increasing the attempts to perform a task, the level of persistence despite encountering difficulties, and the degree of success of performing the task. Whether it is confusing information, lack of appropriate services, prejudice, economic strain, or difficulty navigating "the system," parents who have ID face multiple barriers in their parenting. There is evidence that improving parenting skills may increase efficacy in parenting (Haine et al., 2000). Mobilizing parents with increased self-efficacy may increase their motivation to engage in parenting practices associated with children's healthy adjustment, despite encountering barriers like confusing information, lack of services, and limited options (Coleman & Karraker, 2000). Sunny Side of the Street will help build parent efficacy by providing targeted skill-based training that gives the opportunity to practice and master one skill before taking on new challenges. Support materials for the parent mentor will emphasize the importance of building on parent's strengths (Wisconsin Council on Developmental Disabilities, 2004). By building on a series of small success, it is expected that parents' expectation of successful outcomes will increase and this will build motivation for sustained engagement to deal with the ongoing, challenging tasks of parenting (Dumka et al., 1996). In social cognitive theory, vicarious reinforcement is another important component: Parents who observe other parents successfully dealing with issues related to children will feel more confident in their abilities to successfully deal with the issues themselves. Finally, observational learning (i.e., acquiring behavior patterns and cognitive skills by observing the performance of others) (Bandura, 1986) is an important element of social cognitive theory.

Demonstration-based video, a central feature of the program, promotes vicarious reinforcement and observational learning and is an ideal medium for incorporating effective teaching strategies for parents with learning difficulties. (Krantz, MacDuff, Wadstrom, & McClannahan, 1991). Properly designed, video allows the viewer to experience realistic simulations of life events, view abstract concepts in practical concrete contexts, and by using situations and individuals that fit viewer characteristics, the program can be targeted to the interests and goals of parents who have ID, thereby increasing the relevance of the material. In addition to its attention-gaining and vicarious identification features (Dowrick (1991), video can assist in the promotion of behavior change (Gordon, 2000; Fletcher, 1989; Webster-Stratton, Hollingsworth, & Kolpacoaff, 1989; Harwood & Weissberg, 1987; Olson & Bruner, 1974). As noted previously, adults who have ID benefit from video-based educational interventions rather than typical parent education materials that make use of the spoken word, a less-effective medium for people who do not have sophisticated auditory skills (Sweet, 1990).

### Content Development

Program development involved meetings between the principal investigator, the program director and the scriptwriter. Input was given by consultants and key informants during key periods of development. In developing the content, we understood that it is important to create a program that was engaging and attractive to parents and their children and to the professionals who work with families. Given the scarcity of parenting materials available for this population, most Parent Mentors were developing materials on their own, or adapting existing materials. Each of these approaches left parents with learning materials that were typically unattractive, black and white with low engagement value. After our extensive conversations with researchers, professionals and parents who have ID, we decided that the program for parent and child would be colorful and musically-based. A musical approach would allow for repetition of key ideas and skills without being condescending. Moreover, we could create video sequences and interactive materials that parents and children could use together. Music also provides a structure for the parent/child activities.

As noted previously, the materials we produced for this project include a rich collection of music, interactive card games, video sequences, color pictures, and positive models for families; and a handbook and online training program for social service provider's professional development information on parents with cognitive limitations. These materials were developed to be easily integrated with each other.

At the program's core are a series of 10-minute videos that employ simple naturalistic models and systematic curricular approaches to provide instruction on five basic parenting competencies: (1) Ready to Read (how parents can foster children's emergent literacy skills), (2) Ready for School (school readiness skills, including a morning routine), (3) Ready to Get Along (manners, encouragement and sharing affection), (4) Ready to Play (how to play with children in a way that builds the relationship and fosters cognitive development), (5) Ready for Bed (bedtime routines). Each topic area contains four instructional components: (1) Video training for parents, (2) a sing-along CD for the parent and child, (3) parent/child interactive materials for each module that scaffold the learning for parents, and (4) training specific to each topic for the parent mentor. A separate mentor-training module would contain video-based and printable research-informed ideas and tips for working with parents who have ID. Traditional songs and original songs written by our development specialist, Jessie Marquez, would be included. The songs were chosen to complement the learning material, to extend and structure material for parents and children.

### Video episodes

Each short video segment opens with a family home scene. An interaction between a parent and child sets up a familiar problem commonly experienced by most families: the stress of leaving the house in the morning and getting to school on time; a disagreement about making a request or using manners; a difference of opinion about playtime or a household routine; a conflict about bedtime or what book to read. In the second scene of each video, the family arrives at the Sunny Side School. Miss Jessie, the teacher, asks them about how things are going, the parent shares the morning's problem with Miss Jessie. She invites the parent to join the class because, "We are going to be talking about that very thing today." The parent stays and joins in the circle. Everyone talks, listens, learns songs and shares ideas from their own homes. Miss Jessie teaches a game, reads a book or tells a story. This unites the class to learn the lesson and return home to practice what they have learned. Both parents and children learn ways to create happier, healthier relationships and routines.

### CD with songs and stories

The CD includes 14 songs and two narrated stories. Six of the songs on the CD are traditional children's songs commonly sung in pre-schools. These traditional songs give children familiarity with music they will encounter in school. The other nine songs are original to the Sunny Side program. Including original songs gave the development team an opportunity to shape messages that support the core ideas of social and emotional learning themes. In Ready for School the songs are This is the Way (we wash our face. . .), I'm Going to Eat, and What will I Wear Today. Learning and singing these songs help families build strong, healthy morning routines. In Ready to Read, the songs In My Cozy Nook and Don Gato support early literacy skills. The Don Gato song is an old song from Mexico (translated into English) with many fun verses about a cat who falls in love, dies for love, and comes back to life for love. Most of the children who acted in the video, and children who heard the songs during the evaluation study, identified Don Gato as their favorite song. The Don Gato story is also told using sequenced illustrations in the Practice and Play card deck. Families can sing the song, lay down the cards and have fun developing early the literacy. In My Cozy Nook, scaffolds dialogic reading with parents and children. In Ready to Get Along the songs Courtesy Cap and You are a Ray of Sunshine teach the concept of using courtesy and manners and give parents and children words for expressing love and affection. Ready to Play includes traditional songs, Say, Say oh Playmate and Follow the Leader, and an original song, It's Playtime. These songs celebrate the friendships of those we play with. Ready for Bed includes an original song, Bedtime Song, which describes all the steps in a bedtime routine. Families can match the words of the song to the Practice and Play cards and make up their own bedtime routines.

## Practice and Play Cards

The deck of 52 large-format, full-color cards are richly illustrated and are dividable into five color-coded sub-decks, one for each of the five topic areas. Each card's face presents a picture of a teachable concept with a simple word below describing what is happening in the picture. For example, one card shows a picture of two girls sharing toys as they play. The word on the bottom of the card is "Share." On the back of each card is a grid of nine or 12 pictorial elements used throughout each sub-deck. One of those elements in the grid can be found on the face of the card. Parents and children can play a game where they find the picture on the back of the card that matches the pictorial element "hidden" on the face of the card. There are several other ways parents and children can play with the cards; many of these ways are modeled in the videos. Families can lay out the steps of their morning and bedtime routines with the Ready for School and Ready for Bed sub-decks; they can layout the Don Gato cards to the verses of the Don Gato song; they can play Follow the Leader with the Ready to Play sub-deck; they can talk about manners, etiquette, and their feelings for each other with the Ready to Get Along sub-deck.

## Parent Mentor Training

The information we received from our Consultants and Key Informants echoed evidence in the field: Although social service professionals are currently working with parents who have ID, most are ill-equipped in three respects: (1) Difficulty in identifying parents with ID, (1) lack of understanding and knowledge in how to work with this population and (2) a scarcity of appropriate training materials. A Parent Mentor can be a social service professional or other individual in the natural environment (e.g., family members, friends, or other individuals who are in the parent's natural setting). Designing the program to be used with a mentor promotes the transfer of skills from model to practice and, at the same time, creates a mechanism of support for the parent. Since the relationships between each professional and parent varies in the role requirements, level of direction, etc., the program would have a flexible design allowing the parent mentor to decide how to use the material with the parent (e.g., in-home, in the office) and how much to use with the parent (modules can be used individually, depending on the parent's needs). The mentor component of the curriculum includes Mentor Training with general and specific information about best practices in effectively working with parents who have ID:

- Identifying parents with ID
- Understanding and knowledge in how to work with this population
- Knowledge and skills in supporting parents' effort at home

The "Side-by-Side Training Guide" includes training in skills needed to best support parents with ID in each of the topic areas. This 55-page handbook was designed to be used by PMs side-by-side with parents. The handbook includes full-color layouts (photos, icons, and graphics) that are taken from material presented in the video episodes and the card deck. These layouts are highly pictorial with only a few sentences of explanation. PMs and parents can sit together reviewing the side-by-side pages, recalling the content from the video and cards while sharing information about how the supported family is doing in implementing the various parenting skills. Also included for parents in the side-by-side pages are pictorial "fridge" charts that help parents track their use of highlighted parenting skills, and a colorful page showing the card faces from the episode. The guide would contain suggestions for a variety of ways the program can be used by the mentors, including ideas for using the material in the home or in the office; parent skill-building techniques, strategies for in-person instruction and home practice ideas that will help parents apply the new skills they have learned in the home setting. Other elements especially for mentors in each handbook chapter include:

- An overview of the objectives and materials for each topic/chapter
- A spotlight on child development for children in the specific topic area
- Parent support strategies in the topic area
- "Trouble shooting" for possible challenges parents might have with specific parenting skills and what mentors can do to support parents
- Five in-home assessments that relate to the skills highlighted in the parenting materials. Social service providers can use the assessments to identify family's areas of strength and areas for growth, track family progress and maintain records of parents' skill development

## Online training for Social Service Providers

All the materials described above were also packaged as an online professional development program for social service providers. The production team loaded the digital assets into IRIS Media's online platform, IRIS Ed Online and included three additional components: a video overview of how to recognize a parent who might have a cognitive challenge; an online journal function so participants can write about the families they serve; and a knowledge check for each module. The online program is sponsored by the National Association of Social Workers for professional development credit.

## Formative Review

After the songs and interactive materials were sufficiently developed, content specialist, Jessie Marquez and the Principal Investigator attended two events to get families' feedback about the songs and materials. The first event, "Family Night," was a gathering of families headed by one or more parents who had ID at Pearl Buck Center in Eugene, Oregon. The mission of Pearl Buck Center Incorporated is to create opportunities and provide support to individuals with developmental disabilities and others at risk, their children and families, to promote their independence and active participation in the community. The Pearl Buck Center has a unique program designed for families headed by parents who have ID. Twelve adults and 10 children, aged one through eight attended. The goal of the 'Family Night' presentation was to gauge families' interest in the materials being developed for the Sunny Side curriculum. Jessie Marquez presented content-rich songs to the group as well as large-format books for "reading" pictures. Each song was introduced with a short interactive discussion of the topic (morning routines, looking at books, play time, getting along and bedtime routines). Children in the group were highly engaged in the activities. While parents tended to be reserved during the short discussions, they encouraged their children to participate and joined in when the group sang. The second event was held with a parent/child group at the Arc of Lane County in Eugene, Oregon. Five parents and three children under the age of two attended. Again, the goal of this presentation was to gauge families' interest in the materials being developed for the Parent Education program. The children in this group were too young to actively participate in the discussions and singing, but the parents showed a great deal of interest and enthusiasm. They engaged in the interactive discussions and listened attentively to the songs.

### Consultant and Key Informant Feedback

The research team incorporated key informant feedback into the development of the scripts, text and graphic materials for each program topic. After feedback from the key informants was incorporated into the development of program materials, the revised materials were reviewed by the project's professional consultants, Marilyn Espe-Sherwindt, Ph.D., and Polly Snodgrass, RN. Dr. Espe-Sherwindt and Ms. Snodgrass reviewed the scripts, parent mentor's guide, and parent/child interactive materials and provide feedback on the program content, usability, appropriateness, and design. The Media Developer and the Instructional Designer completed development of the materials, e.g. scripts, mentor guide, child/parent instructional materials, and web assets.

### Usability Testing

A usability test was conducted in which six people engaged with the online program to detect user difficulties and to note questions that arise in the process of interacting with the program. Users took notes any time they encountered a barrier. This feedback was combined and changes in the program were made to improve its ease of use.

### Production of the Sunny Side of the Street Assets

The video production team included Nell Caraway, project manager, Adam Wendt, video director; Laura Strobel, line producer and video editor; Eva Osborne, casting director and production assistant; Chuck Looper, audio technician; Andy Pratt, camera operator; and Dirk Wallace, key grip and second camera. An additional production assistant was brought in to help with make-up and child care. In August 2007, Eva Osborne began casting the production. A call went out to talent agents, flyers were placed on bulletin boards in high (family) traffic areas, and word-of-mouth efforts were put in place. Over two weeks, Osborn recruited over 25 children ages, 4-8, to audition for the 10 children's roles. Children needed to be able to sing as well as act, so the children's audition included both a singing a speaking component. The auditions were recorded on video and they were then reviewed by the development and production team. Children's roles were cast by selecting a group that was balanced for gender and ethnicity. After the children were cast, parent roles were cast. Jessie Marquez made a preliminary CD of the 15 songs, and a copy of this scratch CD was sent home with each child so they could spend several weeks learning the songs they would be singing on the set. Laura Strobel, the line producer, scouted a classroom location that was large, flexible to schedule, and that included extra rooms to accommodate talent, crew and parents of the children when they were not on the set. Strobel settled on a dance studio with very large classrooms. It was rented for two and a half weeks. Additionally Strobel scouted and secured six family home locations. The talent and locations were confirmed and production was scheduled. Working with children requires working with their school schedules and working a shortened production day. Eight days of production were scheduled for the Sunny Side classroom scenes and an additional six days were scheduled for the home locations. Other days were scheduled to bring children into the sound studio for the songs on the CD and to cut program narration. When the assets were all produced, the project went into a 3-month post-production phase.

Post-production activities included video editing; graphic, special effect and titling design and implementation, sound track design with special effects and sound sweetening. Post-production was completed at IRIS Media's studio using an Avid non-linear video editing system and ProTools sound software, Adobe PhotoShop, Adobe Illustrator, Adobe AfterEffects, Ulimatte and Boris FX. Once all media production was completed, the program was reviewed and approved by members of the development team. The final program was mastered onto DVD and sufficient copies were duplicated for study purposes.

### Task 3. Conduct a formal evaluation of the program with 75 pairs of parents and support people in their lives, "mentors," to assess the efficacy of the program

The project evaluation focused on four major PM and parent outcomes: 1) increasing professionals' knowledge, skills and confidence related to working with parents with cognitive limitations, 2) increasing the quantity of support offered by professionals to the targeted parents, 3) improving the quality of the relationship between professionals and targeted parents, and 4) improving parents' skills in the targeted content areas. To accomplish this evaluation, we used a two-group pre-post panel design. The study took place eleven months with professionals in a variety of

organizations nationwide that deliver services to parents who have intellectual disabilities.

In designing an evaluation plan, we were faced with some complicated issues. While we wanted to carry out an evaluation that was as scientifically rigorous as possible, we recognized that in doing field research, especially with this population of parents, we had to make certain compromises. Because of their perception of bias in the system and related concerns regarding having their children removed from their home, parents who have ID are difficult to identify and recruit. To enhance our ability to recruit the number of subjects we needed, we had to widen our recruitment area. But if we recruit from a wide area, it is logistically impractical to do direct measures of outcomes in these families' homes. For a number of reasons, (see below) we also decided it was inadvisable to try to conduct phone-based assessments with parents. In the end, we chose a design and measurement strategy that, while not as powerful as it ideally might be, was as rigorous as we could achieve given the constraints of the study and challenges facing parents who have ID.

We are purposely limiting research demands on the parents for three major reasons. First, as mentioned above, this population tends to be suspicious and mistrustful of people examining their parenting skills. One of the parent participants in Phase I dropped out due to the fear that her involvement might lead to the removal of her children. We want to minimize attrition and stress on parents, and enhance our ability to recruit by eliminating, as much as possible, these kinds of concerns. Second, the intent of the program, in addition to improving parenting skills, is to enhance and improve the relationship between the professional and the parent; we are concerned that complicating that relationship by inserting a third person in the form of a research assistant might impede the establishment of rapport and trust between the professional and the parent. Finally, not requiring a face-to-face interview with the parent allows us to widen our recruitment area to the whole of the United States. Not requiring a phone interview allows us to include parents who might not otherwise be able to participate. Phone interviews are not a practical measurement technique with parents who have ID parents. Many find it difficult or impossible to answer Likert-type questions without having visual aids to assist them in understanding the scales. Families headed by parents who have ID also tend to have relatively chaotic home lives; attempting to set and keep an appointment for a phone interview would be challenging at best. At worst, requiring that level of participation would have the effect of eliminating higher-risk families, resulting in a sample that isn't truly representative of the population. High rates of attrition are common in studies with this population (around 50%). The home environment tends to be more chaotic and it is not unusual for parents to fail to be home during a PM visit. This was a particular concern given that our study was web-based. To maximize retention, we let PMs know that we were available to them for ongoing contact and consultation.

Professionals were recruited via flyers and announcements sent to state and local agencies providing services to people with developmental disabilities (e.g. local and state Arcs, service brokerages, not-for-profit private agencies) and organizations providing services to at-risk and low income families (e.g. Head Start and Healthy Start programs, state child protective agencies). Interested professionals were given a toll free number and email address to contact project staff. During a screening intake phone interview, project staff explained the project and obtained an audio-taped verbal consent. These professionals were then mailed a written study explanation and guidelines for identifying parents who have ID on their caseloads. Participating professionals approached targeted parents about participating in the study. If a parent agreed, project staff contacted the parent by phone to further explain the project and obtain audio-taped informed consent.

Parents were eligible if they met the eligibility requirements below. Eligibility requirements were determined by talking with other researchers and experts in the field to determine the most commonly used way to identify parents who have ID. Professionals were current employees or volunteers in agencies, and were providing direct services to parents. Professionals completed three assessments and were paid \$50 per assessment for a total of \$150. Parents were paid \$10 for each user satisfaction interview they completed with the PM, up to \$60 per parent if they used all six modules. We anticipated that at least 50% of the professionals would be female and that at least 50% of the participating families will be single-mother families.

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### **Related Principal Investigators**

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