**“Wow, That Sounds Familiar”**

**Parent-Child Playgroups to Train, Support, & Build Connections**

By Julie Maier, CDBS Educational Specialist

**Background:** From September 2013-June 2016 the Northern California CDBS staff participated in a collaborative effort with the early intervention staff at the Center for Early Intervention on Deafness (CEID) in Berkeley, California to lead structured playgroups for children who are deafblind and their parents. These playgroup meetings were designed to not only to promote interactive connections between the children, but also to provide parents with information, coaching, and support related to the unique needs of their children. Unlike more traditional training or parent group meetings, the children also attended these playgroup meetings so that CEID and CDBS staff could provide in-the-moment coaching and suggestions.

The CEID early intervention staff was awarded a two-year Early Start grant from the state of California that covered all necessary costs for this project including providing transportation assistance to attend meetings, the materials for art projects and take-home projects, and one support staff from CEID to assist during playgroup. CEID provided time for the early intervention specialist to prepare for and facilitate group meetings and CDBS staff prepared written resources and articles and attended at least one session per month. In the final year the CDBS staff began to prepare for and facilitate meetings due to staff changes at CEID.
The group met twice each month for two hours of play, training, and shared conversations in classrooms at CEID, as well as community locations such as an accessible park playground, a local farm, a children’s museum, a pumpkin patch, and therapeutic horse riding facility. Initially, the meetings started out with a more structured and recognizable training format which included some icebreaker time to chat as families arrived, presentation of new information related to deafblindness by CDBS and CEID staff followed by a facilitated short discussion, and then opportunities to practice the new skills and strategies that had been presented earlier in parent-child activities such as art activities or explorative play. However in the final year, once the families had formed close relationships with each other and staff, the meetings and dynamic evolved into a more naturalistic, friendly support group format in which close and supportive friendships developed through shared discussions and experiences. Parents began to suggest topics for discussion and, in some cases, lead the discussions, which broadened from typical deafblind topics to include topics of advocacy, family leadership, and self-care for parents and care providers.

Rationale for playgroup  This idea for this group developed when a deaf/hard of hearing early interventionist noticed a particular need when working with families of infants and toddlers with deafblindness. This was a small and unique population and the families’ needs extended beyond separate intervention from a vision specialist and deaf/hard of hearing specialist. Providing early intervention and support to families of infants and young children who are deafblind is critically important. These children and their families require the expertise of early interventionists, including both hearing and vision specialists and educators specializing in the field of deafblindness, as well as adults and community members who are deafblind and can provide insights into living with deafblindness. One of the greatest challenges in the field of education for young children with deafblindness is reaching families to provide information specific to deafblindness in a way that is respectful of and accessible to the needs of families. We had hoped creating a shared place and specific meeting times each month would allow some of these families with that access to information and the opportunity to meet and share with other families and educators in the field.

Participants:  Recruitment fliers were sent to several agencies providing services to infants, toddlers and young children with deafblindness in the San Francisco Bay Area. Initially six families attended the meetings,
including three children with CHARGE syndrome, and four families continued to attend throughout the 3-year period. The youngest child joined us at 6 months and the oldest was close to 5 years old at the time. One father and four mothers consistently attended the playgroup. Although we hoped 8-10 families would join the group we realized that it was just not possible for some interested families to make this commitment given their many work and family obligations and other scheduling and transportation constraints. We were able to individualize the information and strategies we presented and shared because the group was a manageable size and because of the consistency of attendance by several families.

A typical playgroup meeting looked like this:

- **Arrival** and casual checking in.

- **Greetings circle** that included using children’s photos mounted in tactile photo frames that each family made and a greetings song done at the children’s pace.

- While children were held in parents’ laps, lay or played on a blanket with toys the CEID and CDBS staff led an **interactive discussion about that week’s topic**. Strategies were shared, stories were told, and questions were asked.

- Everyone joined an **interactive partner activity between children and their parent(s)** at the table or on the rug, such as a hands-on art project, sensory project, or creating experience books. Most weeks we also began to spend time with the service dog from CEID, which was a favorite activity for some children. During the group activity the discussion on the week’s topic and other concerns continued as CEID and CDBS staff modeled strategies and techniques, such hand-under-hand support, follow the child, use of touch or object cues, encouraging use of the child’s functional vision, etc.

- **Goodbye circle and song** and then staff gave parents a **take-home packet with more information, ideas and materials**. Each packet included information about the week’s topic and announcements of upcoming playgroup events and other fun family events happening in the local area, a short article about the topic for parents who wanted to learn more, and a ”homework” assignment which was a suggested activity for the parents to do together with their child to practice the skills and concepts we had discussed that week (e.g., assemble a story bag with tactile objects for a favorite bedtime story, make scented bubble bath soap, select object cues for several daily home routines).

- During the second and third years we began to meet in community settings for **field trips** once every month or two and also invited guest speakers to come to our some of our meetings (e.g., adults with deafblindness, parents of older children with deafblindness) based on feedback provided by the parents at the end of the first year.

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**Julie, Hanks’ mom, shared,** “Initially, I didn’t know what to expect from the deafblind playgroup at CEID. I was hoping it would give me some “Mommy and Hank” time. It has certainly done that and more. It has become a small social network and support group as well a resource for invaluable information and techniques that can help my son now and in the future. Also, Hank’s favorite part is spending time with Nan, the service dog at CEID. It’s so wonderful to see him smile around Nan. I also enjoy our field trips exploring the amenities throughout the Bay Area that are available and accessible to Hank. I’m very grateful for the playgroup and look forward to it every couple of weeks.”.
Outcomes we anticipated
Our goal was to provide family-centered training and support that would promote more knowledge, skills, and confidence about deafblindness and essential key understandings about deafblind learning and communication and related intervention practices. Some specific goals we anticipated: increased knowledge of the range of the impact of deaf-blindness on communication and social, emotional, and cognitive development; increased use of the skills and strategies demonstrated and suggested by facilitators; increased confidence in sharing information about deaf-blindness with others; increased knowledge of local resources and support services; and the opportunity for interventionists to provide individualized coaching and support to families.

Through the collaborative involvement between CEID staff and CDBS staff parents received training on many relevant topics including: various forms of communication and language techniques including name signs and tactile and co-active signing; methods for maximizing visual and auditory abilities; establishing and following structured routines; using play to promote interactions; sensory processing interventions; instructional strategies such as hand-under-hand support and “follow the child”; literacy and creating experience books; how to provide multisensory input; promoting interdependence; and the role of an intervener among many other things.

What we learned
It became apparent near the end of our second year of our playgroup meetings that our training and coaching roles had changed and we were now primarily facilitating the sharing of knowledge, experiences, resources, and support among the parents. Through the time we spent with these parents and their children we learned some remarkable things about families raising children with deafblindness and complex needs.

We learned that...
• Knowledgeable, informed parents are POWERFUL parents.
• Parents were eager to receive information and did use the practices we demonstrated.

Shilo, Mackenzie’s mom, told us, “We have learned from the playgroup that with a child with special needs you need to think outside of the box to do normal everyday things. Get creative and have fun! We have had so much fun going on field trips to the petting zoo and the local park. It helped teach us how to get Mackenzie more involved in each experience. During the holiday’s class we learned about how to get your relatives to interact with our child. Family is very important to us and we want everyone to connect with Mackenzie. The tips we learned in class have made our family closer. Our most memorable class was when we had a guest speaker, Ms. Haben Girma. She gave us hope that Mackenzie can do or be anything that she wants to do in life. Mackenzie is already an independent little girl and I look forward to where she will go. We give credit to the training we have received from the deaf-blind playgroup for her development. We look forward to going to the playgroup to see what tricks of the trade we will learn next. The bonds that we have developed with the other parents are great. We know that we have someone to bounce ideas off of and that they would be there to listen to us and understand where we are coming from.”
Parents had a great deal to share about their child and their family’s story with the playgroup facilitators and each other and seemed to bond over their common experiences and challenges.

The parents appeared to appreciate and value what other parents had to share and recognized each other as another important source for support and resources.

Informed and supported parents advocate more. As the months passed the parents first asked for additional information about their children and their unique support needs, and then for resources that would allow them to advocate more effectively for their children with local support & funding agencies and educational programs.

A final unexpected outcome was these parents have agreed to accept the role as family support providers for CDBS and will share their knowledge and skills about deafblindness, leadership and advocacy with other families looking for answers, support, and resources.

Our formal playgroup meetings culminated in a final gathering and party in June 2016, which was bittersweet. Over the years the families and CEID and CDBS facilitators have supported each other through their children’s illnesses and medical crises and transitions to preschool and kindergarten. Together we celebrated the children’s

And this leads to one of the most important things about the playgroup: **support from other parents.** Having a special needs child with multiple disabilities and medical needs is hard. I love my daughter with all my heart, but there are times when it feels overwhelming. Being able to talk with other parents and share both the pain and joy of raising our children is incredibly helpful to me. Plus we have fun with new friends! The deaf-blind playgroup has truly helped my daughter and me. From learning, playing, and developing, Isabel and I have grown a lot from being a part of this group.”
birthdays and new developmental milestones. We encouraged and cheered each parent’s advocacy efforts at IFSP & IEP meetings and listened when someone needed to “just vent”. Because of the relationships that formed over the past three years the families and CDBS staff continue to meet monthly for some pre-planned social events like celebrating one of the children’s birthdays or spending the afternoon together in a local park. The initial funding for this playgroup helped launch it, but this type of parent/family group really just needs a consistent place to meet, dedicated staff to join, train, and learn from families, and local connections to locate families who might be interested in this type of training and network building.

Participation in these parent-child playgroups has truly been one of the most humbling and profound experiences of my professional career. I was reminded once again of the rewards of sustained and equitable connections between families and professionals. I am very grateful for invaluable lessons I learned about the strength, resiliency, and character of families raising children with complex medical and educational needs.

*The author would like to offer genuine appreciation to Kimberly Leong, former early intervention provider at the Center for Early Intervention on Deafness, for her work in pursuing and writing the grant that launched this playgroup, for inviting CDBS staff to partner with her, and for her remarkable leadership facilitating this playgroup. We are also extremely grateful for our continued rich collaborative relationship with the Center for Early Intervention on Deafness while implementing these playgroup meetings and their ongoing support of our outreach efforts to families.

**If you would like to contact Julie Maier to discuss starting your own local parent-child playgroup please send her an email at: jmaier@sfsu.edu

![Images of families enjoying outdoor activities]