

Recommended Knowledge and Skills for State Deaf-Blind Project Family Engagement Coordinators

This document outlines recommended knowledge and skills for individuals who serve in the role of Family Engagement Coordinator for state deaf-blind projects. The primary purpose of having a set of agreed-upon knowledge and skills is to serve as a guide for identifying and designing training opportunities.

The term Family Engagement Coordinator (FEC), rather than the more traditional term “family specialist,” is used to highlight the uniqueness of this role as it relates to promoting family engagement, defined as “the systematic inclusion of families in activities and programs that promote children’s development, learning, and wellness, including in the planning, development, and evaluation of such activities, programs, and systems.”¹

Because deaf-blindness is rare and very few practitioners understand its implications, state deaf-blind project family engagement coordinators require a skill and knowledge base that covers deaf-blindness, technical assistance strategies, and the needs of families of children who experience this extremely complex disability.

When reviewing the knowledge and skills that follow, it is important to keep in mind that they are intended to serve as a “gold standard” to inform training. It is very unlikely—and not expected—that any one FEC would possess all of the knowledge and skills. FECs come to their positions with varying levels of education and professional experience. In addition, the resources that state deaf-blind projects have to support an FEC vary widely. Most can only afford one part-time (often for just a few hours per week), and some cannot afford one at all. As a result, the roles and responsibilities of an FEC at a given state project will differ depending on their current experience and training, the number of hours they work, and the needs and resources of the project.

¹ U.S. Department of Health and Human Services, & U.S. Department of Education. (2016, May). *Policy statement on family engagement from the early years to the early grades*. Retrieved from <http://www2.ed.gov/about/inits/ed/earlylearning/files/policy-statement-on-family-engagement.pdf>

The content for this publication was derived from an unpublished document about the role of family specialists compiled at a 2003 workshop, state deaf-blind project job descriptions, input from family specialists, and relevant literature on best practices related to technical assistance and working with families. Workgroup members who developed the document are listed at the end. The knowledge and skills were revised based on feedback via a) an in-depth discussion with five state deaf-blind project directors and coordinators who were not involved in the development of the guide and b) a survey disseminated to all state deaf-blind projects (completed by 23 respondents representing 18 states).

Educational and Developmental Needs of Children Who Are Deaf-Blind

Knowledge

- Common causes of deaf-blindness
- The complex and unique effects of combined vision and hearing loss on communication, learning, and access to people and the environment
- The diversity of the population of individuals who are deaf-blind (e.g., different etiologies, range of cognitive abilities, presence of additional physical challenges, varying degrees of vision and hearing loss)
- The impact of deaf-blindness on opportunities for incidental learning (i.e., many children who are deaf-blind must be taught what others learn through observing, hearing, exploring, and interacting with others)
- Stages of communication development and the importance of specifically teaching early communication skills (e.g., intentional communication, symbolic communication)
- The importance of identifying and teaching to a child's sensory preferences (e.g., residual hearing or vision, smell, touch)
- The importance of touch in development
- The range of communication methods and devices used by children who are deaf-blind
- Basic awareness of the role assessment plays in educational decision making
- The impact of deaf-blindness on the family (including siblings)

Accessing and Influencing Services and Systems

Knowledge

- Basic knowledge of IDEA and state education regulations and guidelines

- How the IEP process works
- Processes and resources that families can use to prevent and address conflict in early intervention and educational settings
- The difference between the role of an FEC and the role of a parent center family liaison, and the importance of not duplicating services provided by parent centers
- Community, state, and national resources useful to families of children who experience deaf-blindness and how to refer families to these resources:
 - Deaf-Blind Technical Assistance Network (funded by the U.S. Department of Education)
 - National Family Association for Deaf-Blind
 - CHARGE Syndrome Foundation
 - Other organizations that serve individuals who are deaf-blind
 - Parent training centers
 - Family organizations and services
 - Disability services
 - Health and human services agencies

Skills

- Empower families by helping them access resources at local, state, and national levels
- Model and teach teaming and communication strategies that enhance family–professional partnerships
- Collaborate with other family support providers in your state (especially providers at your state’s parent center) and nationally to share knowledge and skills regarding family engagement, resources, and practices
- Engage and connect families by developing peer-to-peer support networks and other networking opportunities
- Identify information and training opportunities to provide to families and to advance your own professional development (e.g., related to evidence-based practices in deaf-blindness; educational and family engagement systems; local, state, and national resources)
- Engage in and model coping and self-care strategies

Consultation, Training, and Technical Assistance

Knowledge

- Family dynamics and how they impact the provision of TA
- The impact of family socioeconomic factors on the provision of TA
- Knowledge and skills that families need to be effective group participants
- Distance communication technologies and strategies and how they can be used to engage families
- Cultural differences and the impact they have on communication with and provision of TA to families
- Adult learning and training principles

Skills

- Use strategic outreach activities to initiate and maintain contact with all families of children in the state
- Use distance communication technology (e.g., social media, web conferencing, telephone) to engage families
- Assist in assessing families' strengths and needs using a variety of methods
- Assist in developing, delivering, and evaluating training and TA for families
- Inform families about their role in supporting their child in the home, school, and community (e.g., how to evaluate and address their child's needs)
- Use effective consultation and mentoring strategies to assist families in learning about and accessing resources for their child's program development planning process (e.g., person-centered planning and transition planning)
- Assist in developing, conducting, and evaluating group family engagement activities
- Use effective organizational skills to prioritize and manage one's own workload
- Use effective communication skills to support and empower families as they navigate educational, medical, and other service systems
- Maintain complete records of services provided to and engagement with family members (and others) as required by the deaf-blind project for evaluation purposes
- Use teaming and collaboration skills to participate effectively as a state deaf-blind project team member
- Use teaming and collaboration skills to participate effectively as a member of the deaf-blind project management team and in advisory committee and other strategic planning meetings

- Use teaming and collaboration skills to participate in the FEC community peer-to-peer learning and other activities
- Adapt informational materials into family-friendly documents and formats
- Facilitate family participation in conferences and other training events (i.e., help them identify relevant opportunities, obtain funding to attend, and subsequently share what they've learned with other families)

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National Center on Deaf-Blindness, 2017

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The contents of this factsheet were developed under a grant from the U.S. Department of Education #H326T130013. However, those contents do not necessarily represent the policy of The Research Institute, nor the US Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Jo Ann McCann.

