



**SERVING CHILDREN
WITH DISABILITIES**

*A Video Series for Child
Welfare Workers*

Supporting Families with Children with Disabilities





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A Video Series for Child Welfare Workers

Overview of the Video Series

Serving Children with Disabilities, *A Video Series for Child Welfare Workers*, was developed by the Georgetown University Child Development Center, through a grant from the U.S. Department of Education's Office of Special Education Programs (OSEP). This program is designed to help child welfare workers and other professionals who provide support to families with young children (ages birth–8 years) served by the social service system. The videos and training will help staff to:

- Identify various disabilities found in young children and the characteristics associated with them;
- Develop skills needed to identify young children who may have disabilities;
- Recognize the extra stress families face as they raise a child who has special needs;
- Identify strategies for assisting families in the care of their child with a disability;
- Identify the components of IDEA and the services available through it;
- Assist families to obtain the services their children need; and
- Assist families to recognize and use their own resources and supports as well as those in their communities.

Audience

This video series is designed for use by child welfare personnel working in child protective services, family preservation programs, foster care, and adoption services. Other service providers who work with children in the social service system, such as legal advocates, health professionals, and childcare providers will also find this video series helpful. Professionals may find it helpful to use one or more of the videos with parents of children who have special needs.

Description of the Videos

Developmental Disabilities (21 minutes). This video provides child welfare personnel with information about various developmental disabilities and helps them recognize signs of disabilities in the young children they serve. It illustrates key developmental milestones children achieve as they grow and develop. It also describes atypical behaviors that may indicate the possibility of a developmental disability. In addition, biological and social factors that may increase a child's risk for developmental disability are described.



Supporting Families with Children with Disabilities (22 minutes). This video focuses on the impact raising a child with disabilities can have on family life. It highlights the issues families find important in obtaining and coordinating care for their child and suggests strategies child welfare workers can use to work with families to reduce stress and build on families' strengths.

Accessing Services Through IDEA (23 minutes). This video describes the services and supports available to children from birth through 21 years through the Individuals with Disabilities Education Act (IDEA). By understanding this legislation, child welfare workers can help families obtain needed services for their children, understand available supports, and transition smoothly from one service system to another as their child grows.

Children with Disabilities in the Social Service System

It is estimated that one out of 10 children nationwide has some kind of physical, mental, emotional, or developmental disability and that half of the children within our country's social service system (child protection, family preservation, juvenile justice, foster care, and adoption) have some problem that affects their development (U.S. Department of Education, 1998). Estimates indicate that approximately 50 percent of the 50,000 children available for adoption in the U.S. and 50 percent of all foster children have developmental delays (Jaudes & Shapiro, 1999; Takayama, Wolf, & Coulter, 1998). In addition, an estimated 30 to 70 percent of children in out-of-home placements such as foster care have emotional problems.

Child welfare workers have regular and frequent contact with a population of children at high risk of developmental disabilities. Many of these children do not receive regular or adequate medical care and assessment. Until they reach the age of mandatory public school attendance, the child welfare worker may be the only social service professional to have contact with them (Hughes & Rycus, 1998).

Child welfare workers are in key positions to recognize the warning signs of developmental delays, to refer children for evaluation, and to help families access services to which their children are entitled. In order to fulfill their role child welfare workers need knowledge of a variety of areas including child development, developmental disabilities, indications of possible disabilities, referral mechanisms, and the impact of disabilities on family interaction. They also need to develop working relationships with agencies that provide early intervention and special education services. The National Symposium on Abuse and Neglect of Children with Disabilities (1995) recommended that child welfare personnel have training that focuses on issues surrounding disabilities.

This video series will provide information about:

- The developmental milestones children achieve as they grow and develop;
- The characteristics of a variety of developmental disabilities;
- Red flags that signal the need for a developmental assessment;
- The services available to children and families through the Individuals for Disabilities Education Act (IDEA);
- The impact of various disabilities on families;
- Strategies for working in partnership with families; and
- The key role child welfare workers play in helping families access services and supports.



Underlying Philosophy of the Series

The underlying philosophy of this video series is the belief that children should be viewed within the context of the family rather than in isolation. Based on this guiding philosophy the following principles are reflected throughout this video series.

- **Support should be offered within the context of the family and the community in which they live**, rather than to the child in isolation. Family constellations differ, and their racial, ethnic, cultural, and socioeconomic diversity deserves to be honored. Families are the constants in the lives of children and, as such, they should be seen as the experts regarding their children. The most successful support results from the collaboration of service providers and families throughout planning and service delivery.
- **The child's development influences family interactions.** Like all professionals, child welfare workers need to recognize the signs of developmental problems since these problems can have a strong impact on family interactions.
- **Services should be provided in the community.** Services for children identified as needing early intervention or special education services, should be located in the community, whenever possible. Services should be provided in a culturally competent, family-centered, and coordinated manner.
- **A strength-based approach is pivotal.** This approach focuses on the strengths of children and families and moves away from a problem-focused service delivery approach. A strength-based approach focuses on identifying and maximizing the resources of families and includes mobilizing the community, as well as other service sectors.

Use of the Video Series

The three videos in this series are designed to be used in training programs for social workers, child welfare personnel, and other professionals working with young children. They can be used:

- For inservice training for child welfare and social service personnel;
- During orientation for newly hired social service personnel;
- Within training programs for foster and adoptive families;
- As a component of a university-based social work curriculum;
- For continuing education purposes; and
- As a self-study course.

A program of staff education that focuses on child development and disabilities can be created with continuing education units (CEUs) awarded at the end of the course. To facilitate awarding of CEUs, the program objectives and a pre/post test for each video are included in the handbooks. Discussion questions also are included. Related activities are included to help further the learning experience.





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SUPPORTING FAMILIES WITH
CHILDREN WITH DISABILITIES



Introduction

Objectives for the Video: Supporting Families with Children with Disabilities

As a result of viewing this video, individuals will be able to:

- Recognize the impact a child with disabilities can have on a family;
- Discuss with families the developmental needs of their children;
- Help families identify strategies that may decrease stress;
- Demonstrate strategies to promote appropriate behavior, methods of communication, and mastery of the activities of daily living;
- Help families recognize their strengths; and
- Assist families to identify community based resources.

This handbook also provides materials on accessing appropriate services, barriers to obtaining those services and advocacy information for families. As with the videos and other materials in this program the term families will be used to refer to the broad range of family constellations such as birth families, foster families, adoptive families, extended families, etc. who child welfare personnel support.



SUPPORTING FAMILIES WITH
CHILDREN WITH DISABILITIES



Part One

The Impact of a Child's Disability on a Family

At times, all families experience difficulties balancing the demands made on them. The need for money to pay for a place to live, the demands of jobs, supports required by individual family members, and issues related to relatives can stretch the fabric of a family. The stress can be even greater if the family has one or more children who have disabilities.

It is estimated that over half of the children in the child welfare and social service systems of the U.S. have special needs such as learning disabilities, physical impairments, chronic illnesses, or mental health problems (Jaudes & Shapiro, 1999; Takjyama, Wolf, & Coulter, 1998; National Adoption Information Clearinghouse, 1995). Families with children who have disabilities have related that they:

- Mourn what their child may not be able to attain;
- Have become a more tight knit family;
- Didn't anticipate the impact the disability has on the family, for example, when a child is unable to communicate;
- Have to alter their expectations of what they can do together as a family, for example, on routine outings, vacations, and trips;
- Manage well until an unexpected crisis arises;
- Frequently incur high costs related to the care for their child with special needs;
- Often have to take time off from work to respond to their child's needs resulting in loss of pay and, sometimes friction with their employer;
- Become socially isolated from family or community, for example, because of others' misconceptions about disability or reluctance to include the family in activities;
- Underestimate societal attitudes towards disability;
- Need to advocate for their child in order to obtain the appropriate services and supports;
- Need to give special attention to their other children to help them understand their siblings disability as well as their own needs; and
- Feel stretched and at times overwhelmed by the competing demands on their time and energy by family members and their jobs.

Disability and its causes are perceived very differently among different socioeconomic, ethnic, racial and organizational cultures. These perceptions can put extraordinary stress on the whole family or a particular member. The disability may be attributed to something the mother did, to a curse on the family, to the sins of the father, or to fate. Extended family or community practices can shun the family so others may not be "contaminated" by the disability, they may insist a child be hidden away, or given certain remedies to "cure" the child. Members within the same nuclear family may differ greatly on both their assignment of responsibility for the disability and how to respond to it.

In addition to stress arising from the child's disability, families can also be negatively affected by the systems that are created to assist them. Multiple providers and systems can be confusing to families. Having different people in the home can disrupt privacy and family routines. A family's concept of nurturing and protecting their child may be at odds with a professional's focus on promoting the child's independence or skill acquisition. Families may be overwhelmed by professional expectations. Siblings may need care while a family seeks services for their child with disabilities.



According to the National Clearinghouse on Child Abuse and Neglect Information (2000), children with disabilities are at higher risk for abuse and neglect than children without disabilities. The likelihood for neglect and abuse increases if families do not have the emotional, physical, or financial resources to meet increased caregiving needs. The factors that place the children at higher risk include factors that place all children at risk of maltreatment in addition to other risk factors that are more directly related to disabilities. These include:

- Societal attitudes about disabilities;
- Peoples' reactions to, and interactions with, children with disabilities (including family members and non-family caregivers);
- Factors related to the disability itself, such as increased caregiving demands; and
- Program policies and procedures governing the care of children by others.

Since children with disabilities served by child welfare personnel are at elevated risk, it is essential that staff be prepared to recognize when a child may have a disability and to support families as they identify and access services. Even when an evaluation is completed and eligibility for services is determined, it can be no small task to find appropriate services with no waiting lists, at sites within the family's community, etc. With the proper understanding and supports from child welfare workers, families can find resources that give them and their children the support they need. They will also develop strategies to face stress, bond as a family, and remain productive members of their communities.

Strategies Focused on the Child with Disabilities

In addition to assisting families to obtain appropriate developmental services, child welfare workers can help families develop practical, and effective strategies to enhance their child's development. Child welfare workers are in a position to work with families to develop a realistic perception of their situation, to reduce problems, and improve family interaction in three important areas: *behavior*, *communication*, and *activities of daily living*. Children in the child welfare system often change placement. Children are moved from their birth family to foster families back to their birth families or onto different foster families or an adoptive family. Child welfare workers are in a position to share with these various families management strategies that have been found to be helpful and developmentally appropriate. Children who receive consistent messages, strategies, and techniques are more likely to be successful.

Behavior

A child's challenging behavior may be related to the child's disability. For example, lack of impulse control, hyperactivity, distractibility, and/or emotional outbursts are often characteristics of an attention deficit disorder. Crying or whining may be a way for a child with a language impairment who uses few words to communicate.

Child welfare workers can help families:

- **Understand the disability.** Ask professionals and families who have children with similar disabilities to talk to the family about the nature of the disability, its ramifications in everyday life, and ways for the child and family to meet the challenge of living with it. It is especially effective when families come from similar backgrounds or can bridge cultural attitudes such as country of origin and mainstream American culture.



- **Identify the strengths of the child.** Recognize the skills and characteristics of the child, and use them as building blocks to improve behavior.
- **Set realistic expectations that allow the child to succeed.** Help families set realistic expectations for their child. When a child succeeds his or her self-esteem is enhanced and the child is motivated to repeat positive behavior.
- **Convey expectations in simple language.** Coach families to tell their child their expectations in plain, simple words. Break down directions into simple steps, steps that the child easily understands. Only if a child really understands can he or she comply.
- **Recognize that expectations change as a child changes families.** A child in foster care, especially one who has had several placements, may well be confused about what is expected in his or her current placement. Help families clarify current (versus prior) expectations.
- **Simplify the child's environment.** Help families find ways to enhance their organization to reduce unnecessary chaos around the child. Children of all abilities do better when their environment is not confusing.
- **Understand that inappropriate behavior may stem from difficulty communicating.** Often children with disabilities cannot articulate their frustrations. Difficult behavior can result. Encourage parents to look for the source of their child's frustration. Perhaps their child needs to communicate in ways other than words.
- **Establish and maintain routines.** Many children with disabilities function best within structure and a regular routine. Help families establish and maintain simple, understandable routines. Routines reinforce expectations.
- **Act** as a bridge between the foster family and the birth family to insure that both families are following the same behavior management approach.

Communication

Some children have delayed receptive language. This means they have difficulty understanding directions and making sense of what is said to them. If they have a language processing problem, they may hear the words but have difficulty understanding the meaning of what is said to them. Other children may have difficulty with expressive language—they cannot find the words to tell others what is bothering them or what they are thinking about.

Most children, however, can be helped to learn to communicate their needs. Children with severe communication disorders may need to have access to alternative forms of communication such as sign language, picture boards, or computerized communication systems.

Child welfare workers, families and the professional service providers will need to collaborate to develop successful communication strategies. The strategies must take into consideration the families dominant language as well as cultural norms that may impact communication. Some suggestions for family members:

- **Say what they are doing.** Family members can be encouraged to explain what they are doing, even to the youngest children. Talking to children, even to babies, is the way most children learn language. Emphasis simple nouns and action words. Providing verbal labels links words to common objects.



- **Respond to the child's attempt to communicate.** Remind families to respond to their child's attempt to communicate. An infant smiling, a toddler pulling on your pantleg are communicative attempts. Remind families to smile back, talk to the infant, and ask the toddler what he needs.
- **Stoop down to the child's level** to address them directly in order to help them maintain attention.
- **Get the child's attention each time.** Make sure that the child knows that he or she is being addressed, and then have conversations about things that are important to that child.
- **Break down information into small parts.** Simplify. Clarify. Separate information into small units. Directions, especially, should be clear. Break down multiple step directions into each step so the child doesn't have to hold onto too much information for too long.
- **Give the child a chance to process what is being said.** Slow down. Allow spaces between questions or statements. Give time for the child to think about what is said and then respond appropriately.
- **Combine words with gestures.** Remind families to reinforce verbalizations with gestures, signs, pictures. Some children will respond more quickly and more appropriately with multiple communication styles.
- **Get speech therapy.** Some children will need the assistance of a speech and language pathologist. Intervention with a speech/language pathologist can be very helpful. Strategies can be presented to the family by the specialist so that they can be incorporated into activities throughout the day.
- **Establish alternative communication systems** for children with severe disabilities that match the child's needs and the family's routines. Using gestures or sign language or picture boards could enhance a child's communication and decrease frustration that occurs when a child cannot get his or her point across.

Activities of Daily Living

Children feel successful when they learn to take care of themselves. This not only gives them a sense of independence but it also allows family members to focus on other aspects of family life.

Child welfare workers can help families collaborate with teachers, other professionals, and other family members to help their child master basic self-care skills. For example, child welfare workers can encourage families to:

- **Ask their child's teachers** to help the child learn self-care. Teachers can help a child work on skills such as self-feeding during snack time, brushing teeth after snack, and putting on a sweater or coat to go outside.
- **Get specific self-help skills written into the IEP.** For children with severe disabilities, functional, everyday skills can be addressed through the Individualized Education Program (IEP). These goals will be part of the educational program for the year and can be worked on and reinforced by all service providers. This is especially helpful for young children with significant delays and disabilities.



- **Work with families and professionals as a team on daily living skills.** Sharing approaches and progress on a regular basis on specific self-help skills will assist family members to reinforce successful activities with the child enhancing learning and generalization of the skill.
- **Break tasks down into manageable steps.** Every task has multiple components. Chances for success increase as a child deals with one component at a time. If family members and others involved with the child all attempt to do this, the chances of a child's success increase.
- **Decide which steps of any activity the child is expected to do.** Make those steps clear to the child and make those steps achievable.
- **Give just the right amount of help.** Teachers and other service providers will be helpful to families in determining how much help a child needs for a specific task.
- **Incorporate activities of daily living into the family's routine.** As a child becomes familiar with routines, the struggles between adults and children can lessen. Also, as children learn to anticipate activities, they become more independent. Most learning occurs within the context of when and where the skill is needed.
- **Set expectations for both work and play that the whole family shares** and stick to them.



SUPPORTING FAMILIES WITH
CHILDREN WITH DISABILITIES



Part Two

Children with Disabilities as Part of the Family and Community

Children with disabilities who qualify can receive services and supports for early intervention and special education under federal legislation, the Individuals with Disabilities Education Act (IDEA). Child welfare workers can help ensure that the child is receiving the appropriate services and supports he/she is eligible for under this legislation. IDEA encourages service providers to collaborate with families to make sure that the Individualized Education Program or Individualized Family Service Plan reflects the vision the family has for their child.

In addition, families need strategies that will help them address the demands of raising a family. Where necessary, child welfare workers can guide families towards strategies that promote family interaction, increase support from their family network, and access help from the community.

Promoting Family Interaction

Families can benefit from strategies that help them work and play as a family. Child welfare workers provide services to families who are often under a great deal of stress. The families may be challenged by multiple demands and needs. As a result they may not interact as a family unit very often. Child welfare workers can be supportive of the whole family by broadening the focus to include siblings and extended families. They can encourage the family to:

- **Pick activities that the child and family find meaningful.** Encourage families to select activities based on what the child considers to be meaningful—activities that the child cares about. This will increase the likelihood that he or she will want to participate appropriately.

Donny loves the hustle and bustle of the shopping mall. When his mother and her sister go to the mall, it's also Donny's time to use the walker more.

- **Create opportunities for family members to include the child in their scheduled routines.**

The whole Murphy family cooks together on Saturdays. Darren's job is to stir while his brothers chop.

- **Be specific with friends and relatives about skills the child is practicing.**

When Robert takes Sean to his aunt for babysitting, he tells her they are working on communicating by pointing to identify objects in his environment. She decides to read to him and helps him point to the animals in the story.

Increasing Support from the Family Network

All families have strengths. It may be difficult for a child welfare worker to recognize the strengths of the family as they meet under trying circumstances. It is important, however, for the child welfare worker to partner with the family to uncover their strengths. Families also have strategies and resources that already are available to them. Child welfare workers can help each family identify the resources it has within its own network. Professionals can encourage families to:

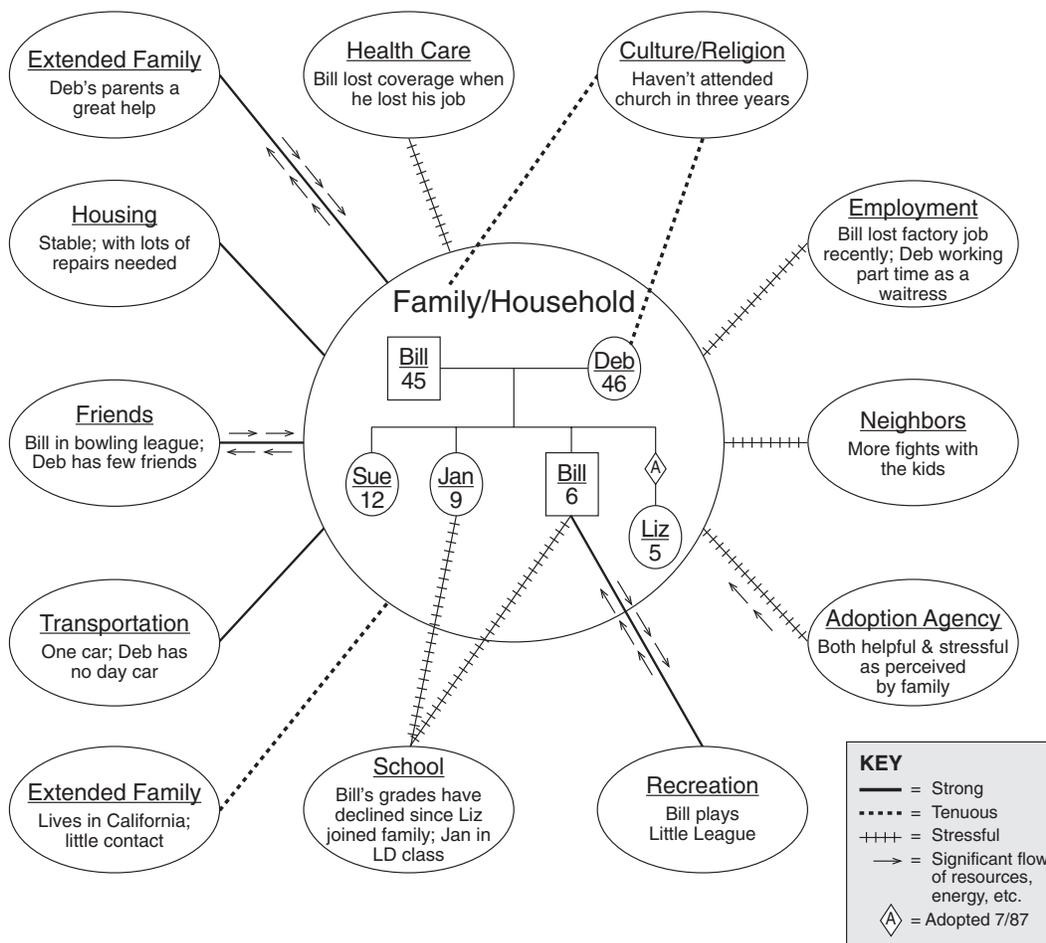
- **Do a strength-based assessment of their immediate and extended family.** Make a list of its strengths. Identify the family's values, its specific skills such as carpentry and child care capability as well as its own cultural resources that can be drawn on.
- **Identify the key things they need to succeed.** This could be as fundamental as getting transportation to a job interview, day care for their children so they can work, or emergency food rations to tide them over.



- Assist families with resources to help them be effective caregivers.** Raising a family is demanding work. Although usually not a priority, parents often need a break from the everyday demands. Helping them understand the need for and benefits of respite care and helping them obtain it is essential.

THE ECO-MAP

The Eco-Map diagrams a family's relationship with its environment. It can be used as a tool to help families identify sources of support in their community and areas of unmet needs and stress. For a family with a child with a disability the eco-map can show the relationships among various family members and community organizations. It may also show how different the relationships are from their expectations or how they have changed. (Sandmaier, 1988). Families are frequently unaware that outside interests, hobbies, and community and extended family supports have dwindled. In addition, eco-maps may help families discover that increased demands, such as medical and schooling needs of their child with a disability, have resulted in additional stress on the family. Eco-maps may prove helpful in discussing needed support and services.



Accessing Help from the Community

Just as the strengths of a child and family are the starting point for building supports and services for a child with disabilities, every community has resources that can support families.

Child welfare workers can be instrumental in helping families by encouraging them to:

- **Conduct a resource-based assessment of the community.** Families can identify resources within the community that they can draw on (respite care, church programs, community center activities, transportation, a local food pantry, the library, a recreation program).
- **Advocate for the child to take part in local programs as appropriate to the child's needs and level of functioning.** The following Inventory of Resources should be helpful to identify local, community based resources.

INVENTORY OF RESOURCES

Inventory of Family and Friends:

- Do any of the child's family or friends have equipment that might be helpful to your child?
- Do they have access to recreation opportunities?
- Do your friends have skills your family needs, such as:
 - Professional training?
 - Advocacy skills?
- Are they willing to offer respite?
- Are they willing to make phone calls?
- Are they willing to baby sit?
- Are they able to help with transportation?
- Do they have other assets that might be helpful?

Inventory of Neighborhood Supports:

- Is there a local recreation center or program?
- Does the neighborhood school have an after school program?
- Are there activities at the local library that your child could take part in?
- Are there Boy Scout or Girl Scout troops nearby?
- Are there cultural organizations nearby that offer enrichment activities?

Inventory of Community Organizations:

- Are there any social clubs that offer the child or family positive things to do?
- Are there civic groups that could promote inclusive activities?
- Are there parent or family support groups such as ones geared towards adoption, foster care, or disabilities?
- Are there professional organizations in the community that might offer assistance to a child or family?
- Do the local churches have youth groups that may be of interest to the child?
- Are there charity organizations nearby that have programs to take part in or resources to share?
- Are there businesses that might offer a service needed by a family?



SUPPORTING FAMILIES WITH
CHILDREN WITH DISABILITIES



Part Three

Creating Supports

Once resources have been identified, some families can access them on their own. Other families, however, may need further assistance: a parent may not be able to make phone calls during working hours, there may be language or cultural barriers, service providers may not be responsive, there may be no advocacy experience in the family background, community resources may not have a tradition of working with a child with disabilities, or the family itself may have other stresses that are overwhelming the family's ability to access services. Many families will need assistance from several service systems: medical, mental health, education, social security, and other social services. These systems may not routinely work together and may need to be helped to do so by child welfare workers. The child welfare worker may be in the ideal position to bring teams of service providers together to plan appropriately and prevent redundancy. As advocates, child welfare workers may need to:

- **Educate families about the services and supports that can be secured for eligible children under IDEA.**
- **Link the family to a service or support.** Linking the family may mean making phone calls, arranging appointments, finding transportation, accompanying them to the site, and providing interpretation.
- **Promote equal access to services.** In some cases, a child may be placed on a waiting list, an agency may be short on staff, an organization may have no previous experience with children with disabilities, a service may no longer exist or a family may be turned away by a service provider. Child welfare workers can make sure resource providers understand the family's entitlement to services and their need to provide "reasonable accommodations" to allow children with disabilities to participate in services.
- **Support parental efforts to get appropriate services** including finding the appropriate providers, following through with referrals, and moving the application process forward.
- **Help families advocate for themselves.** Effective advocacy is a learned skill and is not common to all cultures. Families with children with disabilities may find advocacy exceptionally challenging as they try to attend to all their children's needs. Advocacy may help them obtain community-based resources increasing the possibility that their children may become part of their neighborhood.

Advocacy

Child welfare agencies regularly serve a large number of children with developmental disabilities. Most of these children enter the child welfare system as a result of abuse or neglect, or because they need temporary or permanent care. Because developmental disabilities have typically been perceived as secondary to the primary presenting problems of abuse and neglect, services for children with disabilities have not always been formally integrated into child welfare programs. When available, these services may be poorly planned or inconsistently applied, and delivery often depends upon the ingenuity and determination of the individual worker or agency. If we are to maintain children with disabilities in family and community settings, we must advocate for



and deliver supportive, developmental, and therapeutic services to these children and their biological, foster, and adoptive families (Hughes & Rycus, 1998).

Children with disabilities and their families may need additional advocacy as disabilities and its impact on families are not always easily recognized, or well understood either by family members or professionals. It may be necessary to coordinate a great number of services to support the child. Additionally organizations may need support and assistance to provide appropriate service to a child with a disability and their family. Child welfare workers may need to:

- **Share** information on a particular disability with local organizations to increase their awareness of the needs of members in their community.
- **Help** neighborhood resources find ways to include children with disabilities in their activities.
- **Identify** sources of information on specific disabilities so that family members can be better informed about their child.
- **Link** families with other families or with family organizations who will help them advocate for their child.
- **Attend** IFSP or IEP meetings with parents to make sure the plan developed for the child and family meets their needs and is in the least restrictive environment.
- **Assure** timely, quality interagency service coordination.

For family members, advocacy means doing whatever is necessary to make sure their child gets what he or she needs and what the family needs to support and care for their child. The most important thing a parent can do for their child is to participate: attend teacher conferences, parent meetings, school functions, go to IEP or IFSP meetings, give their ideas and suggestions, and negotiate a program that is truly individualized for their child.

Parenting a child with special health care needs is not easy. The 18,000 members of Family Voices, most of us parents of kids with disabilities or chronic conditions, want you to know you're not alone on this amazing journey. We're there, too. And we know that the sooner we parents become knowledgeable and strong advocates for our children, the smoother life becomes for our entire family (Family Voices Leadership Handbook, 1999).

Helping families advocate for themselves often means helping them become empowered. There are two strategies child welfare workers can use to help promote empowerment in the families they serve: gathering information and encouraging partnership building. Helping families gather information about their child, the child's disability, and services available to them increases the family's ability to convey their needs and discuss their child equally with professionals. Encouraging a partnership between the family and the services providers, other families, and parent organizations will build long lasting ties that families can count on over the years.

Information

Information about the child: Whether the family is a birth, foster, or adoptive parent, they know the special gifts of their child. The family is in the best position to keep that information front and center among friends and family, with professionals, and within the community. The family also understands the child's personality, likes and dislikes, what's routine, what's out of the ordinary, and what the child's typical behavior is.



- Trust the expertise of the family about their child and encourage them to remain focused on the child's positive points.

Information about disability: There is a lot of information written about disabilities. Help families increase their knowledge about their child's disability by encouraging them to talk to their pediatrician, teachers, caregivers, parent groups, or through resources at the library and on the Internet.

- Encourage families to ask questions any time, anywhere, of anybody. Remind them that it is their right to ask for clarification until they feel comfortable with the information.

Information about their rights: Families and children with disabilities have rights under IDEA: rights to records, to confidentiality, to services, and to learning in the least restrictive environment. Social workers, the early intervention program, other parents, and the special education department of the local school system can all help families understand their rights as well as what to do when they feel things are not going as they should.

- Families should be aware of the processes that support them when they feel that services are not as they expected, processes such as mediation and due process.

Partnership

Other families: Other parents and family members are guides who have traveled the road of parenting a child with a disability and who are willing to help other parents and family members with the experience they acquired on their journey. For some families it is difficult to talk to professionals about family life, but parents report that talking with other parents who have also felt inadequate, are always tired, and worry about the future can be extremely helpful. Not only is their attitude helpful, but their experience can save a family time looking for appropriate assistance. Parent to parent support programs can be found by calling parent organizations such as Family Voices or disability-related groups such as United Cerebral Palsy Association.

- Encourage families to reach out to another family with a child with a disability as soon they feel ready and comfortable.

Parent organizations: Parent organizations can be very helpful as they have worked to make changes in communities. They are willing to help other families chart a path in this new world and provide assistance with advocacy as needed.

- Support families in taking advantage of the power of parent organizations.

Professionals: Families of children with disabilities work with a lot of professionals. Establishing a strong relationship with them gains families additional advocates for their child's needs in a changing environment.

- Assisting families in developing partnerships between families and professionals will increase advocacy for the child.

Local and National Resources to Inform and Support Families

When a family is linked to other families, advocacy groups and organizations that are expert in their child's disability, they often find the camaraderie and knowledge that will help them



confront both the barriers they may face and their conflicted feelings.

- Other parents of children with disabilities can help them with practical suggestions from their own experience. As you work with them to identify resources, ask them if they know other families who have children with disabilities. If not, ask them if they would like to be connected with some.
- Local and national parent advocacy and information organizations such as the Parent Education and Advocacy Training Centers (PEATC), and NICHCY (The National Information Center for Children and Youth with Disabilities) are valuable resources for help with information, advocacy, and support.
- Formal organizations provide disability expertise. Organizations such as The Federation of Families for Children’s Mental Health, The Autism Society, the Arc, or the United Cerebral Palsy Association may help families advocate for services appropriate to their child.

Like all children, children with disabilities revel and grow through friendships formed in school and community activities. It’s important to facilitate the development of friendships and social skills through existing community organizations such as:

- Boys and Girls Clubs
- Community recreation centers
- Church-sponsored leagues or activities
- Boy and Girl Scouts, Cub Scouts, Brownies, Camp Fire Girls
- Big Brothers and Big Sisters

Some organizations embrace children with disabilities. Others may need help to find ways to include them in their activities. Sometimes it is as simple as introducing group leaders to the particular child or giving them a chance to ask questions and dispel misconceptions or having an extra pair of hands work with the group. Encourage families to seek opportunities that include their child in everyday life.

The Role of the Child Welfare Worker

The child welfare worker is in a unique position to diminish stress and support families by working with families to:

- **Find and coordinate** the services to which eligible children are entitled;
- **Develop** strategies that positively affect their child’s behavior, communication capability, and activities of daily living skills;
- **Identify** their child’s strengths, the assets they have already in their family, and the resources available to them in the community where they live;
- **Advocate** for their child and family within the social service system; and
- **Help** families recognize and find the local and national resources that are available to inform and support families of children with special needs.



Child welfare workers can help children and families get the services and supports to which they have a right and which can help their child reach his or her potential while giving the family the supports they need to be productive, contributing members of their neighborhoods and communities.



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SUPPORTING FAMILIES WITH
CHILDREN WITH DISABILITIES



Pre-Post Test, Discussion Questions & Activities

SUPPORTING FAMILIES WITH CHILDREN WITH DISABILITIES

PRE-POST TEST QUESTIONS

The Pre-Post Test Questions are provided for those individuals who require an objective measure of change following training. Many States that require CEUs also require that training programs conduct a pre-post test. These questions represent material presented in the video and manual. As with all trainings, instructors or trainers may find it necessary to substitute these questions for others to be aligned with individual training programs.

Please choose the BEST answer

1. Families who have children with disabilities relate the following
 - a. We have become closer as a family
 - b. We mourn what my child may not attain
 - c. We frequently have high costs related to care
 - d. All of the above
2. Children with disabilities are at an increased risk for abuse and neglect
 - a. True
 - b. False
3. Three developmental areas that child welfare workers can be of help to families are
 - a. Neurological, gross motor, problem solving
 - b. Gross motor, fine motor, perceptual motor
 - c. Behavior, communication, activities of daily living
 - d. Visual motor, cognition, school performance
4. One way a child welfare worker can help a family help their child with a disability be better behaved is to:
 - a. Help the family set realistic expectations for the child within the context of their family
 - b. Provide individual, daily psychotherapy
 - c. Get the doctor to prescribe medication
 - d. Tell the family not to make demands on the child
5. Which of the following could lead to inappropriate behavior in children with disabilities
 - a. Disobedience
 - b. Difficulty communicating
 - c. Difficulty walking
 - d. Being happy
6. The learning of activities of daily living can be incorporated into which document under IDEA
 - a. physical therapy treatment plan
 - b. transition plan
 - c. IEP
 - d. A physicians prescription

Continued

7. When a child receives services from a specialist such as a speech pathologist or physical therapist
 - a. Family members and other caregivers should set aside a special time each day to carry out the therapists recommendations
 - b. The therapist should identify the child's most immediate needs and focus on those skills
 - c. The therapist should consult with family members and other caregivers to identify beneficial activities that can be integrated into existing daily routines
 - d. The therapist should work only on the skills related to his/her discipline

8. One strategy a child welfare worker could use to help a family identify community based services and supports appropriate to meet their needs is
 - a. An interdisciplinary team
 - b. An eco-map
 - c. The internet
 - d. An extended family meeting

9. Children with disabilities should
 - a. Participate in special activities with other children with the same disability
 - b. Participate in school related activities only
 - c. Participate in community based activities with all types of children
 - d. Not participate in activities as they may get colds or other illnesses

10. Child welfare workers can help empower families by
 - a. Telling them what to do for their child
 - b. Making sure they follow the instructions from any service providers
 - c. Encouraging them to attend special parenting classes
 - d. Encouraging families to develop partnerships with service providers, other families, and pertinent organizations

SUPPORTING FAMILIES WITH CHILDREN WITH DISABILITIES

ANSWER KEY FOR PRE-POST TEST QUESTIONS

- | | |
|------|-------|
| 1. d | 6. c |
| 2. a | 7. c |
| 3. c | 8. b |
| 4. a | 9. c |
| 5. b | 10. d |

SUPPORTING FAMILIES WITH CHILDREN WITH DISABILITIES

DISCUSSION QUESTIONS

1. What influence do you think culture has on raising a child with a disability?
2. What factor do you think would place the greatest stress on a family with a child with developmental disability?
3. What role can the child welfare worker play in the IEP or IFSP process?
4. What strategies can the child welfare worker use to support families in caring for a child with a disability?
5. What role can the child welfare worker play to insure that a child with a disability is integrated into community based activities?

RELATED ACTIVITIES

1. Think about the children and families you serve, develop a tool that you feel would be helpful to you in gathering information about community based resources.
2. Spend a day with a family who has a child with a significant disability. Record all the activities that the family and child participate in. List the facilitators and barriers to each of the activities.
3. From the record you created above list five strategies or activities that you think could be helpful to the family to overcome the barriers.
4. Depending on the cultural/ethnic make-up of your community, discuss with a community leader some of the culturally based factors that may influence your interactions with families in the community. Ask the leader for some suggestions that may help you be more sensitive to culturally based attitudes and expectations.
5. Create a handout of community based resources that would be helpful to families with children with developmental disabilities at different ages: birth to three, three to six, six to ten.

