UNDERSTANDING THE NEEDS OF CHILDREN WITH DISABILITIES IN THE FOSTER CARE SYSTEM

Prepared by:

INDIANA PROTECTION AND ADVOCACY SERVICES
IPAS

The Protection and Advocacy System for Indiana
Member: National Disability Rights Network

Table of Contents

Learning Objectives 3
Children with disabilities in foster care 4
Introduction 4
What is the relationship between children with disabilities and children who are abused and neglected? 5
What is a disability? What are the characteristics of disabilities? 6
Why are these children at so much risk? 7
Impact on the family 8
Rights and responsibilities 10
Common barriers and solutions you may encounter 18
When a parent has a disability 22
Summary 23
Available Resources 25
Contents of Appendices 28

Indiana Protection and Advocacy Services Commission
Mission Statement: To protect and promote the rights of individuals with disabilities, through empowerment and advocacy

This document is the result of a collaborative effort between Indiana Protection and Advocacy Services Commission (IPAS) and Indiana State Office of GAL/CASA, Indiana Supreme Court, Division of State Court Administration.

IPAS was created in 1977 by state law (IC. 12-28-1-6 as amended) to protect and advocate the rights of people with disabilities and is Indiana's federally designated Protection and Advocacy (P&A) system and Client Assistance Program.

Indiana Protection and Advocacy Services Commission
Voice: 317-722-5555 or 800-622-4845
TTY: 317-722-5563 or 800-838-1131
Fax: 317-722-5564

This publication was made possible by funding support from the Administration on Developmental Disabilities, Administration for Children and Families, the Health Resources and Service Administration, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, within the U.S. Department of Health and Human Services.

These contents are solely the responsibility of the grantee and do not necessarily represent the official views of any federal or state agency.

While this publication is intended to provide basic information, it is not legal advice. While attempts were made to ensure its accuracy, the reader should direct their questions concerning their specific situations to the legal aid society or private attorney of their choice.

February 2010

LEARNING OBJECTIVES

- Understand the prevalence of children with a disability(ies) in the child welfare system
- Explain the relationship between having a disability and maltreatment of children
- List factors that place children with disabilities at a greater risk for abuse and neglect
- Describe common family stresses related to having a child with a disability
- Recognize possible barriers to accessing resources that can be encountered and describe potential solutions
- Be aware of community resources for assisting families of children with disabilities
- Understand that there are laws and other civil rights that pertain to issues regarding children with disabilities

CHILDREN WITH DISABILITIES IN FOSTER CARE

Introduction

Having a disability is a natural part of the human experience. Having a disability does not diminish the right of a child or adult to exert control and choice over their own lives, to live independently and to fully participate in and contribute to their communities. GAL/CASA volunteers, family members, foster parents, guardians, caretakers, friends and members of the community can play an important role in enhancing the life of a child with disabilities, especially when they are provided the necessary community services, individualized supports and other forms of assistance.

While there have not been systematic national studies of the prevalence of disability among children in foster care, individual studies in various states and localities have highlighted a range of potential challenges. Children who enter foster care with special needs have a higher likelihood than children in the general population of chronic medical problems, lifelong psychiatric and behavioral issues, as well as permanent physical, cognitive and developmental disabilities. Whether they experience maltreatment that *results* in disabilities, or are victims of maltreatment *because* of their disabilities, children who enter foster care with special needs, on average, already have experienced more than 14 different environmental, social, biological and psychological risk factors before coming into care. These children have been exposed to conditions that undermine their chance for healthy development.[1]

- 80 percent are prenatally exposed to substances
- 50-80 percent have mental and behavioral health problems
- 40 percent are born at a low birth weight or premature
- 30-80 percent have at least one chronic medical condition (e.g. asthma, HIV, TB)
- 30-60 percent have developmental delays
- 30-50 percent have dental decay
- 30-40 percent receive special education services
- 25 percent have three or more chronic health problems[2]

Children with these types of special needs experience disproportionately poorer foster care outcomes. When compared to children and youth without disabilities, those with disabilities in foster care:

- Have lower rates of achieving permanency, including lower probability of reunification with their birth families, guardianship with relatives or adoption and higher rates of re-entry into care

- Experience more placement instability
- Have longer lengths of stay (in foster care)
- Have poorer educational experiences and outcomes, including higher rates of grade retention, dropping out, suspension and expulsion, placement in more restrictive classrooms and lower rates of receiving help with school work from caregivers, receiving a high school diploma or participating in postsecondary education
- Are more likely to be on psychotropic medications
- Are less safe, and more likely to be maltreated
- Are more likely to be institutionalized
- Have fewer opportunities for positive adult functioning, including higher rates of homelessness, substance abuse, unemployment, receiving public assistance and criminal justice involvement [3]

One study suggests that 33 percent of children in foster care have a disability. Anecdotal information from caseworkers suggests the percentage is much higher.[4] Often, local and state child welfare agencies do not have data that can be pulled out, tracked and analyzed regarding children with disabilities within the foster care system. This information *may* be found in a child's case file but it is impossible to collect any statistical information that would indicate the disability status of children in foster care and the magnitude of the problem in a local community, state or the nation. Evidence suggests the special needs of these children are often not fully met in foster care systems across the country.

Activity: As a group, discuss *why* you think "children with disabilities experience disproportionately poorer foster care outcomes?"

What is the relationship between children with disabilities and children who are abused and neglected?

- We know that abuse and neglect can *cause disabilities*. The National Coalition on Abuse and Disabilities estimates that 18,000 children per year are permanently disabled by abuse and neglect or suffer mental retardation or sensory and motor impairments.

- Circumstantial factors such as chronic substance abuse or violence in families can substantially increase the risk of abuse and disability.

- We also know *having a disability* increases the risk of suffering abuse or neglect and/or exacerbating the disability. A national study sponsored by the National Center on Child Abuse and Neglect indicates that children with disabilities are abused at a rate 1.7 times that of children without disabilities.

- Children with disabilities are 3.76 times more likely to be neglected, 3.79 times more likely to be physically abused and 3.14 times more likely to be emotionally abused than children without disabilities.

- Children with disabilities tend to be abused and/or neglected at younger ages. This is in contrast to children without disabilities, who tended to be abused and/or neglected between the ages of five to nine years.

- Children with a behavior disorder have the highest incidence rate of abuse and/or neglect across all age ranges. Neglect was the most predominant form of maltreatment.

- While families often effectively manage the special needs of children with disabilities, the risk of abuse and/or neglect by other caregivers remains.[5]

In addition, many children with mental illness or developmental disabilities enter foster care not due to parental abuse or neglect but due to the family's *lack of understanding* of the child's disability or they are *unable to access the appropriate resources.* The Government Accounting Office has reported that in fiscal year 2001, "child welfare directors in 19 states and juvenile justice officials in 30 counties estimated that parents placed over 12,700 children into the child welfare system or juvenile justice systems so that these children could receive mental health services".[6]

What is a disability? What are the characteristics of disabilities?

A disability in a child is most generally determined by its impact on the different developmental domains:

- Communication skills
- Cognition and learning skills
- Social-emotional skills
- Motor skills
- Self-help or adaptive skills

There are many definitions of disabilities and the definitions change over time. Disabilities can range from the mild to severe in their effect. A given disability may affect a different child differently; most disabilities affect children in mild ways though. Two-thirds of children with disabilities have more than one disability. The most common disabilities among school-age children are speech and language disorders and learning disabilities.[7] Special needs, as used in this training module, refers to both children with disabilities and children with special healthcare needs.

Activity: Read Handout 1 - Is This A Child with a Disability? Think about a child you know. Follow the directions on the handout and complete the checklist. When completed, have a group discussion about what you learned and how it can be applied.

LEARN MORE

A Continuum of Disabilities appears in the Appendix B

A Glossary of Disabilities appears in Appendix B

Why are these children at so much risk?

Lack of appropriate placement: Fewer families are willing to foster youth with disabilities. Prospective foster parents may have a negative perception of youth with disabilities and feel overwhelmed by the idea of fostering a special needs child. Prospective foster parents may also feel they are not adequately trained and/or have knowledge of available supports and resources. Inappropriate placements can lead to compromised child well-being and more frequent disruptions when they do not work out. This is more likely to lead to institutionalization which has a prevalence of negative outcomes associated with this type of placement.

They are "multi-system" youth: Youth with disabilities in the foster care system come in contact with many systems throughout their lives. Like all youth, they interact with the **education** system. However, they also interact with the **child welfare** system, the **foster care** system, **dependency court** (juvenile) system, various **health** systems, perhaps various **mental health** systems, **social services** organizations and they have a higher chance of coming in contact with the **juvenile justice** system. For these young people, navigating the various systems, obtaining rightful services and fully understanding their place within them is daunting at best and can be impossible at worst.

Lower rate of achieving permanency: Despite systemic positive trends, research shows that older youth, especially older youth with disabilities or "special needs" are remaining in the system longer, on average, than youth without disabilities. According to 2005 data presented by the Child Welfare League of America, a full 58 percent of foster youth who were emancipated (i.e. "aged out") that year had been in the system for at least the three consecutive prior years. Among foster youth with identified disabilities, *67 percent* of those who exited care via emancipation were in the system for at least three years.

Lack of adult support system: For most parents, the goal is to help their children become mature, self-sustaining and happy adults who find productive work, develop meaningful relationships and earn a living wage. But youth with disabilities in foster care are at a severe disadvantage in moving toward healthy adulthood. Having a disability, compounded by the fact that foster care youth may lack a supportive adult network to help them develop personal attributes and abilities to navigate through some extremely complex systems, impedes their efforts to develop educational, occupational, social, personal and life skills for success.[8]

Specific risk factors: In addition to the above, children and youth with disabilities have one or more of the following: functional limitations, intellectual limitations, physical limitations, communications/sensory difficulties, lack of self-protection skills, lack of access to information about personal safety and may have learned compliance to authority that can result in failure to recognize abusive behavior as maltreatment.[9]

See Handout 2 - Common Case Characteristics of Abuse and Neglect Involving Children with Disabilities

See Handout 3 - Checklist for the Healthy Development of Foster Children in Appendix A.

Impact on the family

Contemporary family life already poses significant day-to-day obstacles. Having a child with a disability may complicate matters. Whether the child has a disability that has been diagnosed or has an undiagnosed disability, parents and other caregivers may experience added stress in caring for a child with a disability because:

- As infants, they may cry more or be harder to soothe then other babies; some babies need almost constant care.
- Young children with disabilities may not reach developmental milestones as early as other children including walking, talking, toilet training or getting dressed without help. A parent may feel frustrated, helpless, angry or have a sense of failure.
- Children of any age with disabilities may have behaviors that are difficult to handle, leading to heightened frustration by caregivers and/or teachers.

A child with a disability may also alter the family configuration. A child may need more daily care than the other children and/or may have multiple medical needs that require a great deal of time and care. There may be increased financial demands associated with medical or educational needs and equipment or

assistive technology. There may be difficulty obtaining affordable, trained childcare resulting in limited leisure time or restricted social activities for the parents/caregivers. Physical and emotional fatigue may rob parents/caregivers of the energy needed for other activities and relationships with their spouse, children and extended family members. Families may feel isolated and need support and understanding from other families facing similar challenges. In addition, siblings may feel resentment or anger toward their brother or sister, suppressing feelings of frustration, anger and guilt that can lead to sadness and sometimes depression.

While parenting a child with a disability has its challenges, it also has its rewards: close family bonds from working together as a team; learned patience and compassion for others and family pride associated with achievements. Families of children with disabilities, like other families, are best able to provide a safe, nurturing environment for their children when they:

- Have community and family supports and strong attachments among all family members;
- View their child as a child first, the disability is secondary;
- Focus on positive attributes of their child rather than the negative aspects of the disability;
- See and use information about the disability to facilitate their understanding and work with the child;
- Are aware of available support groups and other resources;
- Have opportunities for respite and time available to take care of themselves. [10]

Siblings of children with disabilities face many of the same issues parents struggle with. Next to the mother, the person who spends the most time with a child with special needs is the brother or sister. Although any sibling relationship is complicated in any family, the following are five unusual concerns found in sibling relationships where one child has a disability.

1. Resentment
2. Future concerns
3. Loss, isolation and sadness
4. Over identification
5. Guilt

Small Group Activity: Read Handout 4. Divide into small groups. Each group should discuss why you think these issues are a concern to siblings. Each small group reports back to the large group.

LEARN MORE
The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs, edited by Donald J. Meyer

Or at www.siblingsupport.org

Rights and responsibilities

Advocacy is about working with people to support them in ways that are responsive to their own needs and best interests. Successful advocacy efforts for children with disabilities include understanding rights, entitlements and responsibilities and what to do if your, or their advocacy efforts are not working. There are *laws* and other civil rights that pertain to issues regarding children with disabilities. The *rights* are the clear expression in the laws of what these children are entitled to. Rights are meaningless unless they are respected by others. Rights as specified by laws may be denied or simply ignored by others. Individuals may take steps to have them enforced through appropriate advocacy and the through the appeals process. Remember – any program receiving public funding has due process procedures, however, they vary from system to system (e.g. timeliness). The following are a few of the laws in place to protect children with disabilities and their families.

Children and youth in foster care are two to three times more likely than other students to have disabilities that affect their ability to learn.[11]

- Special Education – Special education describes an educational alternative that is beyond those met by traditional educational programs or techniques, that focuses on teaching students with academic, behavioral, health or physical needs. If a child has a developmental, physical, learning or emotional disability, the Individuals with Disabilities Education Improvement Act (see below) entitles him/her to a free and appropriate public education. When problems arise in regard to a student's special education program, informal action at the local level is often most successful in resolving the problem. Many times the problem can be worked out through informal meetings or discussions involving the parents/caregivers, teachers, administrators or therapists.

    - **The Individuals with Disabilities Education Improvement Act of 2004 (IDEA of 2004; also called IDEIA)** – IDEA is the nation's special education law. It requires states to provide a free appropriate public education (FAPE) in the least restrictive environment appropriate to meet individual student needs. Further, it requires public school systems to develop a suitable Individualized Education Program (IEP) for each child that outlines specific special education and related services to reflect these individualized needs. It also mandates that particular procedures be

followed in the development of each IEP. Each student's IEP must be developed by a team of knowledgeable people and must be reviewed at least annually. The team includes the child's teacher; the parents/caregivers, subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents'/caregivers' or agency's discretion. If parents/caregivers disagree with the proposed IEP, they can request a due process hearing and a review from the Indiana Department of Education.

- **Article 7** – Article 7 refers to the Indiana Administrative Code (IAC 7-32 through 7-47) that contains Indiana's special education regulations and special education due process. There are certain rights (also called procedural safeguards) under federal and state laws; these are listed in the Notice of Procedural Safeguards and Parent Rights in Special Education. This notice must be given to parents/caregivers in their native language or in a means of communication they can understand. For a more detailed explanation of these rights or questions, you may contact any of the following resource agencies.

Indiana Protection and Advocacy Services Commission (IPAS) IPAS provides information and referrals, technical assistance, training and advocacy to protect the rights of all individuals with disabilities. 4701 North Keystone Avenue, Suite 222 Indianapolis, IN 46205 (317) 722-5555 (Phone) (317) 722-5564 (Fax) Toll-free: (800) 622-4845 (Voice) Toll-free: (800) 838-1131 (TTY) www.IN.gov/ipas	**Indiana Department of Education, Center for Exceptional Learners** The Center for Exceptional Learners provides state-level support for public school students with disabilities from ages 3-21 and ensures Indiana is in compliance with the federal Individuals With Disabilities Education Act (IDEA). 151 W. Ohio Street Indianapolis, IN 46204 (317) 232-0570 (Phone) (317) 232-0589 (Fax) Toll-free: (877) 851-4106 (Voice) www.doe.in.gov
About Special Kids (ASK) Formerly Indiana Parent Information Network (IPIN) ASK provides information and access to resources about children with special needs.	**IN*SOURCE (Indiana Resource Center for Families with Special Needs)** *IN*SOURCE provides information and training to assure effective educational programs and services for children with disabilities*

7275 Shadeland Ave., Suite 1 Indianapolis, IN 46250 (317) 257-8683 (Phone) (317) 251-7488 (Fax) Toll-free: (800) 964-4746 (Voice) Toll-free: (800) 838-1131 (TTY) www.aboutspecialkids.org	1703 S. Ironwood Drive South Bend, IN 46613 (574) 234-7101 (Phone) (574) 234-7279 (Fax) Toll-free (800) 332-4433 (Voice) www.insource.org

The IDEA requires states to implement procedures to protect the rights of children entitled to special education services who are in the custody of a state agency (a "ward of the state"), or whose parent or guardian cannot be identified or located. An Educational Surrogate Parent (ESP) has the same rights and responsibilities as a parent for purposes of special education decision-making. This means that the ESP has the authority to, among other things, review the child's educational records, consent to special education evaluation, accept or reject Individualized Education Program (IEP), request an independent evaluation and request mediation or a hearing to resolve special education disputes.

Federal law is clear about who can be appointed an ESP for decision-making in special education matters. An individual having special education decision-making authority:

1. Is not employed by the department of education, a public agency, or any other agency involved in the education or care of the student;
2. Has no personal or professional interest that conflicts with the interests of the student who the educational surrogate parent represents;
3. Matches the student's cultural and linguistic background to the extent possible; and
4. Has knowledge and skills that ensure adequate representation of the student.

How will this help me as a GAL/CASA volunteer?

- You may recommend a child be tested for developmental or learning disabilities.
- If a child is in special education and/or receiving services from the school, you may verify that a child has a current IEP and that the programs and services prescribed are appropriate and meet the needs of the child.
- You may educate a child's foster parents and/or birth parents about available resources and supports that can assist in ensuring a child's rights are being fully exercised.

- You may be able to become an Educational Surrogate Parent. (Please check with your local GAL/CASA program director regarding local policy.)

LEARN MORE
For a more extensive explanation of educational rights and responsibilities you can go to http://www.insource.org/pdf/GEN_TRAINING_PACKET.pdf

- **Section 504 of the Rehabilitation Act** – this is a federal law that requires public schools to provide accommodations so children with disabilities can participate in and benefit from public education. The school determines eligibility and develops the 504 Plan for eligible children. Students with disabilities who are not covered by IDEA - that is, students who need accommodations in education but do not need specially designed instruction – have a plan similar in purpose to the IEP. See Rehabilitation Act below.

  How will this help me as a GAL/CASA volunteer?

  - You may recommend a child be referred for an initial educational evaluation, which is a different type of evaluation than "tested for developmental or learning disabilities" as mentioned above.
  - If a child is found eligible for a 504 Plan, verify that the Plan has been created and that the federally mandated process has been followed in developing the Plan.

- **Family Educational Rights and Privacy Act (FERPA)** – FERPA is a federal law that protects the privacy of student educational records. The law applies to educational agencies and institutions that receive funding under a program administered by the U.S. Department of Education. FERPA gives parents certain rights with respect to their children's educational records. These rights transfer to the student when he or she reaches the age of 18 or is attending a post-secondary institution. In general, the rights include:

  - Access to their educational records
  - An opportunity to seek to have the records amended
  - Some control over the disclosure of information from the records

  How will this help me as a GAL/CASA volunteer?

  - You may educate the family about and/or help the family gain access to and understanding of the child's educational records.
  - You may assist a youth transitioning out of care (and is 18) access and understand his or her own educational records.

For more information contact: Family Policy Compliance Office
U.S. Department of Education
400 Maryland Ave., SW
Washington, D.C. 20202
(800) 872-5327 or (202)260-3887

- **Medicaid** – Almost all children in foster care have or are eligible for Medicaid services. Medicaid is the state-federal health care assistance program for low-income children and families, senior citizens and people with severe disabilities. This medical assistance program was created to provide health care and make reimbursements for reasonable and necessary medical care to children and adults meeting eligibility requirements. In Indiana, youth in foster care are covered until the age of 21. Medicaid is administered by the Office of Medicaid Policy and Planning (OMPP), a part of the Indiana Family and Social Services Administration (FSSA).

  Medicaid Waivers – Some children may be eligible for Medicaid Waiver Services Program. Medicaid Waiver Services provide for Home and Community-Based Services to be provided as an alternative to institutional care. These additional services are not traditionally paid for by Medicaid. They are tailored supports that enable a child to live successfully in home and community settings. There are five types of Waiver Programs in Indiana – these encompass services for children whose needs are primarily medical in nature or children with developmental disabilities.

How will this help me as a GAL/CASA volunteer?

- You may verify the child is covered by Medicaid. If not, recommend an application be made immediately.
- If appropriate, you may verify an application has been submitted for Medicaid Waiver Services for the child. If an application has been submitted on behalf of the child and the child has been deemed eligible, you may verify the child is receiving all the needed and appropriate services.
- If an application is appropriate and has not been submitted, *encourage immediate or early application,* as there are historically long waiting lists.
- Obtain a copy of the Consumer Guide to Indiana Medicaid Waiver Home and Community-Based Waiver Services Programs Fourth Addition, March 2007 at http://www.in.gov/gpcpd/2359.htm. This consumers guide describes Indiana's Medicaid Waiver Programs as well as other home and community services that help children and adults with disabilities (of any age) receive supports they need to live, work and recreate in the community (not in an institutional setting).It explains the services

available, application process, how to choose a provider, what to do if there are problems, lists additional resources for information or assistance and more.

For more information, contact your local Department of Child Services or:

Office of Medicaid Policy and Planning
Indiana Department of Family and Social Services
402 W. Washington St.
Indianapolis, IN 46204
(317) 233-4455
Web site: www.in.gov/fssa

- **Vocational Rehabilitation Services (VRS)** – VRS was created to assist people 14 years and older with disabilities to achieve greater independence through employment. It is a state-federal partnership employment program that serves any Indiana citizen with a disability who wants to find or return to work. VRS works in collaboration with a variety of public and private agencies to enhance employment opportunities and provides individualized services to support people with disabilities to prepare for, obtain or retain employment. In Indiana, the VRS is administered through the Bureau of Rehabilitation Services, Division of Disability and Rehabilitative Services (DDRS), a part of the Indiana Family and Social Services Administration (FSSA).

How will this help me as a GAL/CASA volunteer?

- You may recommend that a youth with a disability, transitioning out of foster care, receive a vocational rehabilitation evaluation.
- You may assure that vocational rehabilitation services are involved with the youth before and during the transition period.

For more information contact: Bureau of Rehabilitative Services
Division of Disability and Rehabilitation Services
Indiana Department of Family and Social Services
402 W. Washington St.
Indianapolis, IN 46204
Toll free: (877) 241-8144
Web site: www.in.gov/fssa

- **Americans with Disabilities Act (ADA)** – prohibits discrimination because of a disability, in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunications. To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. See Available Resources section for contact information.

Equal access rights ensure that individuals with disabilities have access to programs, services, buildings and housing. Continual barriers confronting individuals with disabilities include physical inaccessibility to governmental and public places; medical providers' reluctance to provide accommodations in the provision of their services or outright denial of all types of services due to lack of awareness of disability issues and the laws in place that protect equal access rights.

Because of equal access rights, people with disabilities have the following available to them:

- Freedom from discrimination on the basis of disability in seeking or keeping housing that is affordable, appropriate and accessible
- Where public transportation is provided, it must be safe, reliable, affordable and accessible
- Physical environments that are adjusted for inclusiveness and accessibility
- Work, volunteer and education opportunities
- Access to key health and support services
- Access to civic, cultural, social and recreational activities

How will this help me as a GAL/CASA volunteer?

- You may assist the family or youth understand and advocate for "reasonable accommodations" in acquiring services in the community and within the "system."
- You may investigate and verify that parents and children do have access to all the places and services they need.

- **Fair Housing Act** – The Fair Housing Act prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status and national origin. Its coverage includes private housing, housing that receives Federal financial assistance and state and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or deny a dwelling to a buyer or renter because of the disability of that individual, *an individual associated with the buyer or renter or an individual who intends to live in the residence*. The Act requires owners of housing facilities to: make reasonable exceptions in their policies and operations to afford people with disabilities

equal housing opportunities (e.g. a landlord with a “no pets” policy must grant an exception to this rule and allow an individual who is blind to keep a guide dog in residence); allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as to common spaces. See Available Resources section for contact information.

How will this help me as a GAL/CASA volunteer?

- You may help the family or youth that is transitioning out of care understand and advocate for “reasonable accommodations” in acquiring safe and suitable housing.

- **Indiana Fair Housing Act** – Substantially equivalent to the Federal Fair Housing Act. Gives citizens of Indiana the right to be treated equally when renting or buying property and when securing a loan to purchase property. Housing discrimination is prohibited on the basis of race/color, national origin, religion, sex, disability or familial status. Familial status includes families in which one or more children under 18 live with: a parent; a person who has legal custody of the child (ren); the designee of the parent or legal custodian; anyone securing legal custody of a child under 18. See Available Resources section for contact information.

  How will this help me as a GAL/CASA volunteer?

  - You may assist the family or youth that is transitioning out of care understand and advocate for “reasonable accommodations” in acquiring safe and suitable housing.

- **Indiana Civil Rights Law** – It is the public policy of the state of Indiana to provide equal opportunity to all of its citizens and declare it is unlawful to discriminate in the areas of employment, real estate, education, public accommodation and credit – on the basis of race, religion, color, sex, disability, national origin, ancestry or familial status (housing). See Available Resources section for contact information.

  How will this help me as a GAL/CASA volunteer?

  - There is a very broad area of coverage under this law. You may assist the family in obtaining contact information for the Indiana Civil Rights Commission or the U.S. Department of Justice.

- **Rehabilitation Act** – The Rehabilitation Act prohibits discrimination on the basis of disability in any programs conducted by federal agencies, in

programs receiving federal financial assistance, in federal employment and in the employment practices of federal contractors. See Available Resources section for contact information.

How will this help me as a GAL/CASA volunteer?

- There is a very broad area of coverage under this law. You may help the family obtain contact information for the U.S. Department of Health and Human Services, Office for Civil Rights.

- **Supplemental Security Income (SSI)** – SSI is administered by the Social Security Administration. It is a program that pays benefits to adults and children with disabilities who have limited income and resources. A child's eligibility to receive SSI is focused on the child's ability to engage in age-appropriate activities. When reviewing a claim for SSI, the Social Security Administration is not as concerned about what the child has been diagnosed with, but rather what effect will this medical condition have on his ability, as he continues to grow and mature, to engage in various age appropriate activities and eventually on his ability to be employed.

  How will this help me as a GAL/CASA volunteer?

  - When a youth with a disability turns 18, if he meets eligibility requirements, he can apply for monthly SSI payments. You may want to verify if a child would be eligible for SSI.
  - If a child is not eligible for SSI, you can refer the child to the appropriate resources.

LEARN MORE

For more extensive information on rights and responsibilities for children with disabilities, you can go to:

http://www.in.gov/ipas/files/0482-187_Appeals_Process_Guide_final.pdf and

to http://www.adagreatlakes.org

Common Barriers and Solutions You May Encounter

Poor identification of children with need: In a national probability sample of child welfare agencies, researchers found that although more than 94 percent of agencies had policies regarding the assessment of all children entering foster care for physical health problems, only 47.8 percent had inclusive policies for

mental health assessments and only 57.8 percent had inclusive policies for developmental assessments. Research also shows that community health care providers are more likely to identify/refer children entering foster care for evaluation and treatment of physical health and educational concerns, but less consistently identify developmental and mental health problems.[12]

Possible Solutions

- Assessments – A youth should be screened for mental health and developmental needs and receive the appropriate intervention and support services; a recommendation can be made if appropriate.
  - Children 0-3 years old may qualify for Indiana's First Steps System. First Steps is a locally-based, coordinated system that provides early intervention services to infants and young children with disabilities or who are experiencing developmental delays and/or have a diagnosed condition that has a high probability of resulting in developmental delay. To read more about First Steps you can go to http://www.in.gov/fssa/ddrs/2813.htm.
  - Assure the child has all appropriate assessments as needed including, but not limited to, physical, mental health, developmental, educational and any others as appropriate.

Difficulties ensuring children have access to services: The National Survey of Child and Adolescent Well-Being reported service use across three sectors: education, mental health and primary care. Results from this study demonstrated that only half of children ages 0-5 years deemed at high risk of developmental and behavioral problems had received educational, mental health or primary care services over a 12-month period after initial contact with child welfare. In addition, youth and caregivers can encounter providers who are not willing to accept Medicaid and consequently placed on lengthy waiting lists for much-needed services.

Possible Solutions

- Appropriate services - If there are mental health or developmental concerns, the youth should be referred to a specialist such as a pediatric pediatrician, psychologist or neurologist for further diagnosis and treatment and/or First Steps if the child is 0-3 years old. A recommendation can be made if appropriate.
- Medicaid and Medicaid Wavier Services – Most children and youth in foster care should receive Medicaid. Some youth may be eligible to receive Medicaid Waiver Services. Application for Medicaid Wavier Services should be made on behalf of the youth. If eligible for these services, the youth should receive appropriate services or be placed on the correct waiting list.

Lack of accessibility and communication: Children, youth and/or families with disabilities should have access to the same goods and services as those provided to people without disabilities. Accessibility applies to both physical and communication access. Because of access "issues", a youth and/or family may be denied use of the full range of needed services.

Generally, access to the courts is a fundamental right under the state and federal constitutions. State and federal statutes require that people with disabilities be afforded equal access to courthouses, courtrooms and court services. Their access must be just as effective as the access provided to other members of the public.

State and local government services, programs and activities – including those of administrative and judicial courts – must be "readily accessible to and usable by" individuals with disabilities. In short, the Americans with Disabilities Act (ADA) applies to all judicial programs and services, and to all participants, jurors, lawyers, parties, witnesses and observers.

Possible Solutions

- Physical access - If a facility or service location has architectural barriers that prevent physical access, those barriers should be removed or "reasonable accommodations" should be made, such as meeting the youth and/or family in a different location that *is* accessible. Another example of "reasonable accommodations" would be making an exception to a "no pets allowed" policy for people with service animals.
- Communication access – This applies to auxiliary aids, services and other types of program access. Child welfare facilities and service providers must ensure that they effectively communicate with youth and/or families who have a range of disabilities, including people who are deaf, hard-of-hearing, or have a speech, vision or learning disability. There are a variety of auxiliary aids and services to help facilitate communication, such as language interpreters, TDDs, Braille, readers or large print.

***Small Group Activity** – Read Handout 5, Obstacles Families May Encounter in Accessing Resources. Divide into small groups. Each group should identify ways these obstacles might be overcome. Each small group reports back to the larger group.*

Obstacles in obtaining appropriate educational supports: Although children and youth with disabilities are entitled to special educational services and supports, they routinely are denied many of these accommodations because of the lack of educational advocates. There is often a lack of clarity and a lack of

communication regarding the respective roles and responsibilities of caseworkers, GAL/CASAs, foster parents and birth parents when working with school systems. Frequent placement changes that children and youth experience can result in incomplete transfer of information, poor tracking of previous services received and new requirements for assessments and services.

Possible Solutions

- The correct educational placement and supports – A youth should be screened for educational needs and receive intervention and support services and, when necessary, be referred for special education services. Youth in care with special education needs should receive appropriate school placements and services.
- An identified and active educational advocate(s) – A youth must have at least one engaged adult with the authority to make education and special education decisions. The youth should also have other caring adults who can assist their educational advocate decision-maker and act as advocates. (Individuals with Disabilities Act [IDEA])
- School stability - A youth should remain in his school of origin when possible and it is in his best interest. They should be guaranteed seamless transitions between schools and school districts, including immediate enrollment, prompt transfer of records and continuation of their Individual Education Plans (IEPs).
- Full range of options and resources – A youth should have access to and opportunity to participate in <u>all</u> academic and non-academic aspects of the school experience – remember, children with disabilities are entitled to supports necessary to participate successfully.
- Access to early childhood education and services – Young children in foster care should enter school ready to learn, which includes full access to Early Intervention (EI) services such as Indiana's First Steps program.

Lack of well-coordinated transitioning services: Transition is the process that takes young people with disabilities from childhood to adulthood. The transition process promotes movement from school to post-school activities as well as from living in state care to independent living.

Youth with disabilities transitioning from foster care to adulthood frequently do not receive critical services and supports to ensure their safety, stability and well-being after they "age-out." They typically lack coordinated and well-executed transition plans. A youth's transition plan needs to be created and in place well before a youth ages-out of the child welfare system.

Possible Solutions

- Coordinated plans – Federal law guarantees a youth with a disability transitioning from foster care the right to assistance in moving from school

to post-school activities. The transition process promotes movement from his/her school to post-school activities as well as from living in state care to independent living. One plan is school based; the second plan is based in the youth's child welfare case plan through the agency responsible for caring for the youth (the Indiana Department of Child Services or a community-based provider). Although they are separate, both plans should be well coordinated so that the goals are consistent and everyone working with the youth knows who is responsible for each activity.

- The school based plan for transition – This plan must be designed to produce an outcome based on the youth's needs, preferences and interests. The youth and his or her team select goals for adulthood. The desired outcome can include any number of goals, such as post-secondary education, vocational training, integrated employment, supported employment, continuing and adult education, adult services, independent living and community participation. A GAL/CASA can attend the planning conferences to insure all areas are addressed and in place.
- The child welfare case plan for transition – This plan should have the same outcomes as the school-based plan. Services and supports should be designed to assist in meeting these goals. A GAL/CASA can insure the transition plan has been created and all elements of it are in place prior to the youth leaving the child welfare system.

LEARN MORE

To learn more about Transition go to *The Passage from Youth to Adulthood*
http://floridaschildrenfirst.org/pdf/Foster_Final_Proof.pdf

Transition from School to Adult Life: A Guide for Families
http://www.insource.org/materialsIND.htm

When a parent has a disability

In the United States, more than 8 million families include at least one parent that has a disability. What if the *parent(s)* is the person in the family with the disability, not the child? Researchers have demonstrated that children can be safe at home with appropriate services to the family when needed.[13]

How can you best serve the child and assist in preserving the family?

- Help families identify their family's needs as it relates to the child and plan ahead to meet those needs.
- Help families understand and interact with the child welfare system and the disability community.
- Help families access services. Work to ensure the child welfare system makes reasonable efforts to preserve the family and accommodates the individual's disability.
- Ensure families receive services that are appropriate for their environment and disability.

Small Group Activity *- Read Handout 6, A Hypothetical Scenario. Divide into small groups. Each group should identify ways these obstacles might be overcome. Each small group reports back to the larger group.*

Summary

There is enormous overlap of youth with disabilities and young people in the foster care system. Indeed, many advocates for these youth assert that foster care is a disability issue because the prevalence of disabilities among these youth is so high.

Child protection investigators, caseworkers and foster parents are often not fully equipped with sufficient training, tools and supports to ensure the identification and assessment of children and youth with disabilities in foster care. They are under-prepared for the challenges associated with caring for a child or youth with special needs including children and youth with disabilities. This may result in underreporting, inappropriate placement decisions and inadequate provision of services for children and youth with disabilities in foster care.

The critical needs of the children and youth with disabilities in foster care strongly affect these children's safety, well-being and opportunity to grow up in permanent families and to lead a meaningful and productive life. Here are five ways you can help:

- Assist in identifying a child that might have an undiagnosed disability
- Help to prevent an unnecessary change in placement and/or assist in reunifying a child with his/her family by ensuring all appropriate supports and services are in place
- Advocate to improve the educational services and supports to the child if needed
- Advocate to improve the mental and physical health services and supports that are age appropriate for the child if needed

- Assist in ensuring a seamless transition of an older youth in foster care to comprehensive independent living services and supports in the community

AVAILABLE RESOURCES

Indiana Protection and Advocacy Services Commission (IPAS) – IPAS is a federally mandated independent state agency, and was created in 1977. It is charged with protecting and promoting the rights of individuals with disabilities, through empowerment and advocacy. IPAS receives no state funding (only federal funding) and is independent from all service providers. It provides information and referrals to individuals and families, technical assistance such as advice and support for those self-advocating, individual representation and advocacy using non-attorney advocates and legal counsel and advocates for system change.

If you have a child with a specific disability, you can get information about a number of different disabilities, and internet links to other resources, by inserting http://www.in.gov/ipas/2360.htm into your internet browser.

4701 N. Keystone Ave., Suite 222
Indianapolis, IN 46205
(317) 722-5555 (Phone)
(317) 722-5564 (Fax)
Toll-free: (800) 622-4845 (Voice)
Toll-free: (800) 838-1131 (TTY)
www.IN.gov/ipas

Toll Free Resource Guide - Indiana Statewide Disability Information Numbers – See Appendix C

Americans with Disabilities Act (ADA)
ADA Information Line
(800) 514-0301 (Voice)
(800) 514-0383 (TTY)
Web site: www.ada.gov

Fair Housing Act
Office of Program Compliance and Disability Rights
Office of Fair Housing and Equal Opportunity
U.S. Department of Housing and Urban Development
451 7th St., S.W., Room 5204
Washington, D.C. 20410-2000
(800) 669-9777 (Voice)
(800) 927-9275 (TTY)
Web site: www.hud.gov/offices/fheo

Indiana Fair Housing Act
The Indiana Civil Rights Commission (ICRC)
Indiana Government Center North
100 N. Senate Ave.
Room N103
Indianapolis, IN 46204
(317) 232-2660 or (800) 628-2909 (Voice)
(800) 743-3333 (TTY)
(317) 232-6580 (Fax)
E-mail: icrc@crc.in.gov

Indiana Civil Rights Law
The Indiana Civil Rights Commission (ICRC)
Indiana Government Center North
100 N. Senate Ave.
Room N103
Indianapolis, IN 46204
(317) 232-2660 or (800) 628-2909 (Voice)
(800) 743-3333 (TTY)
(317) 232-6580 (Fax)
E-mail: icrc@crc.in.go

Rehabilitation Act
Office for Civil Rights
U.S. Dept. of Health and Human Services
233 N. Michigan Ave., Ste. 240
Chicago, IL 60601
(312) 886-2359 (Voice)
(312) 353-5693 (TDD)
(312) 886-1807 (Fax)

Social Security Administration
(800) 722-1213
Web site: www.socialsecurity.gov

Telecommunications Act - Requires manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by people with disabilities, if readily achievable. This act ensures that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, pagers, call-waiting and operator services that were often inaccessible to many users with disabilities.

Federal Communications Commission
445 12th St., S.W.
Washington, D.C. 20554
(888) 225-5322 (Voice)
(888) 835-5322 (TTY)
Web site: www.fcc.gov/cgb/dro

U. S. Department of Justice
Civil Rights Division
950 Pennsylvania Ave., N.W.
Disability Rights Section – NYAV
Washington, D.C. 20530
(800) 514-0301 (voice)
(800) 514-0383 (TTY)
Web site: www.ada.gov

Contents of Appendices

APPENDIX A. Participant Handouts

Handout 1 - Is This A Child With A Disability?

Handout 2 - Common Case Characteristics of Abuse and Neglect Involving Children With Disabilities

Handout 3 - Checklist for the Healthy Development of Foster Children

Handout 4 – Sibling Issues and Seven Ways Parents and Professionals Can Help Siblings of Children With Disabilities

Handout 5 - Obstacles Families May Encounter in Accessing Resources for Children with Developmental Disabilities

Handout 6 – A Hypothetical Scenario

Appendix B. Resource Materials

A Continuum of Disabilities

A Glossary of Disabilities

Additional Resources

Appendix C. Toll Free Guide

Indiana Statewide Disability Information Numbers

ENDNOTES

[1] Sara Munson, This is Forgotten Children: A Case for Action for Children and Youth with Disabilities in Foster Care (Children's Rights and United Cerebral Palsy, 2006), page 5

[2] Ibid

[3] Ibid

[4] Munson, This is Forgotten Children:, p. 3

[5] Sullivan and Knutson, 2000, as cited in Peggy O'Neil, Abuse and Neglect of Children with Disabilities: A Collaborative Response, (Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University, 2003)

[6] Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions, (National Council on Disability, February 26, 2008), p. 36

[7] Mary Steinberg and Judith Hylton, Responding to Maltreatment of Children with Disabilities: A Trainer's Guide, 1998, (Oregon Health Sciences University), as cited in Peggy O'Neil, Abuse and Neglect of Children with Disabilities: A Collaborative Response, (Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University, 2003)

[8] Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions, (National Council on Disability, February 26, 2008), p.25-30

[9] Risk Factors for Abuse and Neglect That Are Specific For Children With Disabilities, as cited in Peggy O'Neil, Abuse and Neglect of Children with Disabilities: A Collaborative Response, (Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University, 2003)

[10] Impact Of A Child's Disability on Family Life, Abuse and Neglect of Children with Disabilities, Virginia Department of Social Services, Child Protection Services, 2000, as cited in Peggy O'Neil, Abuse and Neglect of Children with Disabilities: A Collaborative Response, (Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University, 2003)

[11] Courtney, M.E. & Piliquin, I., The Wisconsin Study of Youth Aging Out of Out-of-Home Care: A Portrait of Children About to Leave Care (1998)

[12] Addressing the Developmental and Mental Health Needs of Young Children in Foster Care, Author Manuscript, (National Institutes of Health - Public Access, 2005)

[13] Preserving Families Affected by Disabilities (PowerPoint presentation, 2008), National Disabilities Rights Network Foster Care Legal Back-Up

APPENDIX A - HANDOUTS

Table of Contents

Handout 1:Is this a child with a disability? 3
Handout 2: Common Case characteristics of abuse and neglect involving children with disabilities 5
Handout 3: Checklist for the healthy development of foster children 6
Handout 4: Sibling Issues 7
Handout 5: Obstacles families may encounter in accessing resources for children with developmental disabilities 9
Handout 6: Hypothetical scenario 10

Handout 1

IS THIS A CHILD WITH A DISABILITY?

It is sometimes not obvious that a child has a disability. However, one can sometimes pick up on "soft signs" that may indicate a need for further investigation. The following is a checklist of **"RED FLAGS"** that may be useful to you if you have questions about a particular individual. **PLEASE NOTE: THIS IS NOT A DIAGNOSTIC TOOL!** It merely "flags" certain behaviors or indicators that could suggest a need for further testing or questioning. The letters after each behavior suggest that this might reflect an:

I	=	Input Problem
P	=	Processing Problem
O	=	Output Problem

If you find that you have checked five (5) or more of these behaviors, get some additional information about this child through further questioning or testing. Perhaps she/he is a yet "unidentified child with a disability." Do not make that determination without consulting the appropriate professionals.

PLEASE NOTE: If certain behaviors or clusters of these behaviors, have recently manifested, it could be an indication of some type of victimization, NOT a disability.

DOES THIS CHILD…

(1) _____ Squint his eyes constantly (I)

(2) _____ Shield his eyes from bright lights (I)

(3) _____ Blink his eyes constantly (I)

(4) _____ Have difficulty focusing on objects (I)

(5) _____ Hold objects very close to eyes (I)

cont'd next page

Michael Crocker, 1994. Reprinted with permission

Handout 1 (cont)

DOES THIS CHILD….

(6) _____ Have eyes that seem misaligned (turned inward / outward / downward) (I)

(7) _____ Ask for things to be repeated frequently (I)

(8) _____ Watch your lips carefully as you speak (I)

(9) _____ Display poor/jumbled speech (I – O)

(10) _____ Speak unusually softly (I – O)

(11) _____ Lack interest in school/home life (I – P)

(12) _____ Display a short attention span (I – P)

(13) _____ Have behavioral outbursts (I – P)

(14) _____ Display unusually withdrawn behavior (I – P)

(15) _____ Display aggressive behavior (I – P)

(16) _____ Display self-stimulatory behavior (P)

(17) _____ Display self-abusive behavior (P)

(18) _____ Mix up sounds of words / orders of numbers (P)

(19) _____ Reverse letters consistently / numbers (P – O)

(20) _____ Display obvious confusion with directions (P – O)

(21) _____ Display difficulty with writing for age (P – O)

(22) _____ Display impulsive behavior (P)

(23) _____ Display a low frustration level (P)

(24) _____ Display very poor reading for age (P)

(25) _____ Misinterpret questions consistently (P)

REMEMBER…The above are "RED FLAGS" that may suggest further inquiry, <u>NOT</u> diagnosis.

Handout 2

COMMON CASE CHARACTERISTICS OF ABUSE AND NEGLECT INVOLVING CHILDREN WITH DISABILITIES

Multiple forms of maltreatment

Multiple perpetrators of maltreatment

Maltreatment of long duration

Inadequate or inappropriate healthcare

Inappropriate use of misuse of prescribed treatments

Misleading caretaker behavior and statements

Use of the disability to explain or minimize the child's condition

Blaming injuries or conditions on child

Empathy for caretakers clouds concerns for child

Concerns and reports of maltreatment overruled by authority figures

Multiple contacts with health care providers and other professionals, with failure to recognize or respond to maltreatment

Ignoring, misunderstanding or misinterpreting signs and symptoms of maltreatment

From "Responding to Maltreatment of Children with Disabilities: A Trainer's Guide." By Mary Steinberg and Judith Hylton, 1998. Oregon Institute on Disability and Development, Child Development and Rehabilitation Center, Oregon Health Sciences University, P.O. Box 574, Portland, OR 92707-0574.

Handout 3

CHECKLIST FOR THE HEALTHY DEVELOPMENT OF FOSTER CHILDREN

1. Has the child received a comprehensive health assessment since entering foster care?
2. Are the child's immunizations up to date and complete for his or her age?
3. Has the child received hearing and vision screening?
4. Has the child received screening for lead exposure?
5. Has the child received regular dental services?
6. Has the child received screening for communicable disease?
7. Has the child received a developmental screening by a provider with experience in child development?
8. Has the child received mental health screening?
9. Is the child enrolled in an early childhood program?
10. Has the adolescent child received information about healthy development?

Addressing the Developmental and Mental Health Needs of Young Children in Foster Care, Author Manuscript, (National Institutes of Health - Public Access, 2005)

Handout 4

SIBLING ISSUES

Almost every issue a parent has, a sibling has, too! The sibling experience with a child with a developmental disability mirrors the parent experience. Next to the mother, the person who spends the most time with a child with a special needs is the brother or sister. Although any sibling relationship is complicated in any family, the following are five unusual concerns found in sibling relationships where one child has a disability.

1. RESENTMENT — Families often have emotional and financial resources wrapped up in the “sun” in the families’ solar system, i.e., the child with special needs. Siblings often feel their brother of sister with special needs “gets away with murder.” (Siblings have a clear and unsentimental view of what their sibling can do.) Older siblings, especially in families with older daughters, often have enormous caregiving demands.

2. FUTURE CONCERNS — Siblings worry about having enough money, level of responsibility after their parents die and their role when they themselves grow up. They feel they have fewer degrees of freedom. Children also worry about genetic implications in their own lives.

3. LOSS, ISOLATION AND SADNESS — Siblings experience a loss of innocence at an early age, realizing the world has problems. These feelings are affected by how many children are in the family, as well as how close in age the sibling is to the child with a disability. (A two-child family where siblings are two years apart is going to experience this more than a six-sibling family with 13 years between them.) Siblings feel a loss of a typical relationship with their parents and their sibling. They feel isolated, especially when the topic is taboo in their house or community. They often cannot connect to someone who understands what they are experiencing. (Imagine parents without any of their parent supports.)

4. OVER IDENTIFICATION — Siblings of the same gender and close in age experience this the most. Siblings are embarrassed by the looks and behavior of their brother/sister who has a disability, and worry that peers think they are the same. They worry particularly if they are the youngest that they will develop their sibling’s condition. In the preteen to early teen years, there is developmental embarrassment of their family. (Inclusion is going to affect the sibling who rides on the bus with the child with a disability as much as the child targeted for inclusion. Students will ask for explanations and identify the sib with their brother or sister.)

5. GUILT — Twins and survivors of multiple births where one or more siblings died worry that they somehow caused the disability to occur. They feel guilty about being able to do things their sibling is unable to do, e.g., the excitement of getting a driver's license is diminished a little by the realization their sibling won't ever drive. College-age siblings feel guilty about leaving the "burden of care" on their parents, or having a life of their own. There is often a self-imposed pressure to achieve and to be the "good" kid, but then guilt occurs about being the high achiever or good kid.

Presented by Don Meyer at "The Sibling Support Project Workshop", Fredericksburg, VA 12/97

SEVEN WAYS PARENTS AND PROFESSIONALS CAN HELP SIBLINGS OF CHILDREN WITH DISABILITIES

1. Provide age-appropriate information from a variety of sources. Service providers and specialists should make time for sibling questions and explanations.

2. Provide opportunity to meet other siblings.

3. Listen and encourage good communication.

4. Parents should carve out special time for typical siblings.

5. Learn more about life as a sibling.

6. Encourage parents to reassure kids by making plans for the future and sharing them with the siblings.

7. The single strongest factor about how kids perceive their sibling's disability is how the parents interpret it.

Presented by Don Meyer at "The Sibling Support Project Workshop", Fredericksburg, VA 12/97

Handout 5

OBSTACLES FAMILIES MAY ENCOUNTER IN ACCESSING RESOURCES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

- Non-existent resources
- Denial of services due to not meeting eligibility criteria
- Impersonal or inappropriate service provision, including those culturally unresponsive
- Lack of knowledge regarding the need for services or resources
- Concrete barriers such as lack of transportation or money
- Physical, cognitive or emotional disability in the parent(s)
- Parent(s)' inability to partialize the task of seeking service
- Lack of familial or family support
- The needs of other family members
- Other life stressors such as moving, divorce, job loss
- Lack of time
- Resistance to services from the child with a disability
- Lack of professional expertise
- Others

Reprinted with permission from Virginia Institute for Social Services Training Activities, (October, 2000). VISSTA Course 304: Recognizing and Assessing Developmental Delay and Disability (p. IV-178, Section IV: Participant Resources). Richmond, VA.

Handout 6

Hypothetical Scenario

You are the Court Appointed Special Advocate/Guardian Ad Litem (GAL/CASA) for a child with cerebral palsy. Her father (mother is deceased) has not been able to care for her appropriately, and child protective services has removed her from his home. The father has a developmental disability, which impedes his ability to understand complex information and instructions. Although the father clearly loves the child and wants her returned home, you have concerns about his capacity to keep her safe and provide an appropriate, productive environment for her.

a. What agencies/institutions might be resources for services for your client and her father?
b. What specific support service and accommodations will you request from the child welfare agency to preserve/reunify your client's family and meet the "reasonable efforts" requirements? What arguments will you use to advocate for those services and accommodations, and when will you raise those arguments?

Preserving Families Affected by Disabilities, created by the National Disabilities Rights Network Foster Care Legal Back-Up, with a grant from the Training and Advocacy Support Center.
Reprinted with permission

APPENDIX B – RESOURCE MATERIALS

CONTINUUM OF DISABILITIES

TYPE OF DISABILITY	MILD	MODERATE	SEVERE
Autism/Pervasive Developmental Disorder	Limited range of interests, repetitive play skills, impaired social skills.	Significantly affected verbal and nonverbal interactions, limited range of interest, impaired social skill, difficulty with abstract concepts.	Repetitive movements, resistance to change in environment or routine as well as unusual responses to sensory experience, lack of verbal and nonverbal communications, behavioral disabilities.
Emotional Disturbance	Affective or adaptive behavioral problems.	Significant affective or adaptive behavior problems, social problems.	Constitutes danger to themselves or others.
Cerebral Palsy	Inability to control motor function. Awkward gait.	Spastic, stiff and difficult movement, involuntary and uncontrolled movement, disturbed sense of balance and depth perception.	Spasms, tonal problems, involuntary movement, disturbance in gait and mobility, seizures, abnormal sensations and perception, impairment of sight, hearing, or speech, and mental retardation.
Speech & Language Disorders	Slurred speech, lisp or mild articulation problems which are not developmentally appropriate, inaccurate use of language, delays in responding.	Word finding problems, difficulty in using language systematically, hard to understand.	Significantly interferes with general living skills, Inability to use language to communicate needs or desires.
Blind/Visual Impairment	Near sighted, far sighted, color blind, astigmatism.	Need for glasses, use of a long cane, trained guide dogs. Tunnel vision, ability to see light/dark shadows and shapes. Partial field vision.	Total blindness.

TYPE OF DISABILITY	MILD	MODERATE	SEVERE
Deaf/Hard of Hearing	Difficulty with faint or distant speech or speech in group situations. May result in delay in speech and language articulation, learning disability, and inattention.	May hear only loud speech; may be able to identify environmental sounds; may be able to discriminate vowels but not consonants, social problems, speech and oral language may not develop spontaneously.	Total deafness.
Tactile Sensory Impairment	Inability to distinguish types of touch (e.g., pressure vs. pain) on part of the body.	Partial loss over some or all of the body or total loss on part of the body.	No physical sensation at all.
Epilepsy	Brief periods of fixed staring.	Periods of automatic behavior and altered consciousness.	Convulsions with complete loss of consciousness.
Learning Disabilities	Processing deficits which mildly impacts learning can learn to compensate, mild social problems, difficult in academics.	Significant processing deficits, under-achieving, major social problems.	Impacts significantly across all areas of learning and daily living.
Traumatic Brain Injury	Mild difficulties in sensory perception, motor movement, language skills, memory, or problem solving.	Mild difficulties across main areas or difficulty in one or more domains.	CP, paralysis, mental retardation, visual impairments, hearing impairments, speech impairments. Major secondary disability due to head trauma.

Illinois Joint Training Initiative, Institute on Disability and Human Development, University of Illinois at Chicago, 1996.

© Partnership for People with Disabilities, Virginia Commonwealth University, Revised 2003

Source: *Abuse and Neglect of Children with Disabilities*
Virginia Department of Social Services, Child Protective Services, 2000

GLOSSARY OF DISABILITIES

ATTENTION DEFICIT/HYPERACTIVITY DISORDER (AD/HD)

A neurobiological disorder characterized by developmentally inappropriate behavior, poor attention skills, impulsivity, and hyperactivity. These characteristics typically arise before age seven, are chronic, and last at least six months.

The exact cause of AD/HD is unknown, although scientific evidence suggests it is genetically transmitted and may result from a chemical imbalance/deficiency in the brain. It is not caused by factors in a child's environment.

Impact of Functioning

- **Hyperactivity:** high activity levels not connected with a specific situation or stimulus. Child may be fidgety, have difficulty sitting still or playing quietly, and talk excessively.
- **Impulsivity:** acts before thinking, frequency interrupts others, difficulty awaiting turn, and may not assess danger before acting.
- **Inattention:** child has difficulty sustaining attention in tasks or play; seems not to listen; is easily distracted by extraneous stimuli; fails to give close attention to details, often making careless mistakes in schoolwork of other activities; and often has difficulty following through on instructions.

Many children with AD/HD have great difficulty in school where attention and impulse and motor control are necessary for academic success. They often have difficulty with social skills and self-esteem.

Child and Family Issues

- Child may need medication.
- Child may resist taking medication because it makes them feel "different".
- Medication must be monitored for side effects by a pediatrician.
- Counseling is often recommended to assist parents in behavior management techniques.

* National Information Center for Children and Youth with Disabilities (NICHCY) Virginia Institute for Social Services Training Activities (VISSTA), Virginia Commonwealth University

© Partnership for People with Disabilities, Virginia Commonwealth University, Revised 2003

Source: *Abuse and Neglect of Children with Disabilities*
Virginia Department of Social Services, Child Protective Services, 2000

Continued

AUTISM: PERVASIVE DEVELOPMENTAL DISORDER (PDD)

A neurological disorder, usually evident by age three that affects a child's ability to communicate, understand language, play, and relate to others. The cause is unknown and not due to psychological factors.

Impact on Functioning

Children vary widely in abilities, intelligence, and behaviors, but, may exhibit several of the following characteristics:

- Impaired attachment i.e. unaware of others or abnormal way of relating, delayed or absent smiling and eye contact, touch avoidance, solitary play.
- Communication problems i.e. understanding and using language, speech delays, pronoun reversal, echolalia, rhyming.
- Difficulty understanding abstract concepts.
- Unusual play with objects; may avoid or be preoccupied with them, spin them.
- Difficult with changes in routine and environment.
- Repetitive body movements or behavior patterns.
- Unusual responses to sensory information, e.g., loud noises, lights, certain food or fabric textures.

Child and Family Issues

- Parents may be sleep deprived because many children with autism/PDD have difficulty sleeping,
- Carry over of skills learned at school to home is important.
- Interaction with non-disabled peers is important to provide modeling of appropriate language, social, and behavior skills.
- Respite, support groups, and counseling may be needed.
- Parents need to educate themselves regarding the latest treatments.
- Close collaboration with the school is important to facilitate goal setting and intervention.

Continued

CEREBRAL PALSY

A chronic condition caused by damage to the brain usually before, during, or following birth. "Cerebral" refers to brain and "palsy" to a disorder of movement or posture. It is not progressive. Symptoms can range from mild to severe.

There are three main types of cerebral palsy:

- **Spastic:** stiff and difficult movement.
- **Athetoid:** involuntary and uncontrolled movement.
- **Ataxic:** disturbed sense of balance and depth perception.

Impact on Functioning

- Inability to fully control motor function, which may include: spasms, tonal problems, involuntary movement, disturbance in gait and mobility, seizures, abnormal sensation and perception.
- Mental retardation **may** be present.
- Impairment of sight, hearing, or speech **may** be present.
- Learning, social, and personal problems **may** develop as a result of the disability and/or attitudes of others.

Child and Family Issues

- Early Identification and intervention to maximize functioning.
- Education/training of family members on meeting the needs of the child with cerebral palsy.
- Respite, support groups, and counseling may be needed.
- Adaptive aids and equipment may be needed for educational and daily living experiences.
- Assistive technology such as computers and augmentive/alternative communication devices may be needed.
- Opportunities for community integration and recreation are important to the development of a sense of well-being.

Continued

DEAFNESS AND HEARING IMPAIRMENT

A person who is hearing impaired is required to process information totally or partially through a sensory channel other than hearing. Hearing impairments range from slight to profound and include:

- **Deaf:** non-functional hearing for everyday purposes.
- **Congenitally Deaf:** born deaf.
- **Adventitiously Deaf:** born with normal hearing, but became deaf later as a result of illness.
- **Hard of Hearing:** impaired, but functional hearing.

Hearing impairments are characterized by difficulty in producing the spoken language and/or an inability to understand auditory information.

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn.

Impact on Functioning

The impact on functioning depends on:

- The extent and type of hearing loss.
- Age of onset.
- Age when remediation began.
- Degree of intelligence of the child.
- Quality of instruction the child has received.

Child and Family Issues

- Child is more susceptible to social difficulties and needs opportunities for socialization.
- Family members need to attend auditory training program to learn communication techniques and skills.
- Counseling and support groups may be needed during adjustment period.
- Close collaboration with the school system is important to meeting the child's needs.
- Parents need to be made aware of the deaf culture. Parents may feel conflicted about either immersing their child in a "deaf culture" or including him/her in the "hearing world".

Continued

DEAF/BLIND

Deaf/Blind refers to a combination of vision and hearing problems, which prevent the use of either vision or hearing as a primary source of learning and communication.

The combination of deafness and blindness is one of the most severe disabilities known. Persons with this dual disability face unique problems of communication and mobility that drastically curtail their sources of information. This disability often promotes an intense sense of isolation and loneliness (Smithdas).

Deaf/Blind includes persons who have no useful hearing and vision and persons who, although severely impaired, do obtain some information through residual hearing and/or vision as follows:

- **Deaf/Blind:** legal blindness and a severe to profound hearing loss.
- **Blind and Hard of Hearing:** legal blindness and a mild to moderate hearing loss.
- **Deaf and Visually Impaired:** profoundly deaf with some usable vision.
- **Visually Impaired and Hard of Hearing** some usable vision and hearing (Virginia Department for the Visually Handicapped, 1998).

Methods of Communication

Children who are Deaf/Blind may use any one or a combination of the following communication methods:

- **Sign Language and Fingerspelling:** either visual or tactile is commonly used by deaf/blind persons who were born deaf. When using tactile sign language, the child places his/her had on top of the signers hand for receptive communication.
- **Restricted Field Signing:** all signing is done within the child's restricted field of vision i.e., within a very small space.
- **Tracking:** the child holds the wrist or arm of the signer in order to place the signs within the child's best field of vision.
- **Braille:** a system of touch reading that uses raised dots to represent the letter of the alphabet and numbers 0-9. Braille has two grade levels: Grade 1 and Grade 2.
- **Auditory-Oral Speech:** used by persons who have sufficient residual hearing to hear and understand speech with the use of amplification and/or who can express themselves through speech.
- **Gestures/Home Signs:** some children with no formal sign language skills rely on gestures or home signs for communication. If appropriate, it is essential that the person most familiar with the child's method of communication be consulted to assist with the communication (Virginia Department for the Visually Handicapped, 1998).

Continued

DEAF/BLIND CONTINUED

Impact on Functioning

The impact on functioning depends on:

- Age of onset.
- The extent of loss of vision and hearing.
- Degree of intelligence of child.
- Child's communication skills.
- Extent of isolation.
- Orientation and mobility skills.
- Social or interaction skills.
- Dependency on others.

Child and Family Issues

- Family members may need training in their child's preferred mode of communication.
- Parents need to know how to help their child use any residual vision or hearing.
- Dependency on others increases risk of maltreatment.
- Child may be isolated and needs opportunities for socialization.
- Parents, teachers, and others need to know the proper way to get the child's attention, most often through touching the back of the hand or forearm.
- Parents may need guidance in helping their child to develop a positive self image.
- Parents may need counseling and support, especially if they blame themselves for their child's disability.

Best Practice in Child Abuse/Neglect Investigations

- Listen to the child whether he/she uses words, signs, pictures, gestures, or behaviors.
- Request assistance from a **qualified mental health counselor who is fluent in sign language.***
- If a qualified counselor is not available, request the assistance of a **certified interpreter**** to assist with communication. In those instances where the child's sign language base is limited, i.e. he/she relies upon gestures or signing that is unique to their home environment, it may be necessary to have an interpreter who is deaf (native signer) along with a hearing interpreter, in order to facilitate accurate communication.
- For those children without usable vision, it may be necessary to work with anatomically correct dolls (Virginia Department for the Visually Handicapped, 1998).

* Contact the Office of Mental Health at the Department of Mental Health, Mental Retardation, and Substance Abuse Services at (804) 371-2134 for a listing of qualified mental health counselors.

* Contact the Virginia Department for the Deaf and Hard of Hearing at 1-800-552-7917 for a listing of certified interpreters.

Continued

DOWN SYNDROME

A condition, associated with mental retardation, caused by chromosomal abnormality that changes the orderly development of the body and brain. Some common characteristics include:

- Distinct physical appearance.
- Poor muscle tone.
- Physical and intellectual developmental delay.
- Mental impairment from mild to severe.
- Health related problems. Lower resistance to infection may lead to respiratory problems.
- Visual problems such as crossed eyes and far- or near-sightedness **may** be present.
- Mild to moderate hearing loss and speech difficulties **may** be present.

Impact on Functioning

There is a wide variation in mental abilities, behavior, and developmental progress in children with Down Syndrome. Research has shown that stimulation during early developmental stages improved the child's chance of developing to his or her full potential.

Child and Family Issues

- Parents may feel guilty about transmission of the disability
- Parents may experience feelings of loss.
- Parents need to be educated on the disability and the child's specific needs.
- Parents need to provide appropriate and continuous stimulation and teach self-care skills.
- Early intervention services to maximize functioning.
- Child may be teased by peers and excluded from groups or activities.
- Child needs opportunities for inclusion in recreational, social, and other activities.
- Child may have an impaired sense of autonomy; needs to practice making own decisions.
- Support groups may be needed.

Continued

EMOTIONAL DISTURBANCE

A condition that, **over a long period of time and to a marked degree**, adversely affects educational and life performance and is characterized by:

- An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- An inability to build or maintain satisfactory interpersonal relationships with peers of teachers.
- Inappropriate types of behavior or feelings under normal circumstances.
- A general pervasive mood of unhappiness or depression.
- A tendency to develop physical symptoms or fears associated with personal or school problems.

The causes of emotional disturbance have not been adequately determined.

Impact on Functioning

The impact on functioning depends on the number and severity of symptoms including:

- **Hyperactivity**: short attention span, impulsiveness.
- **Aggression/self-injurious behavior:** acting out, fighting.
- **Withdrawal:** failure to initiate interaction or retreats from interactions with others, excessive fear or anxiety.
- **Immaturity:** inappropriate crying, temper tantrums, poor coping skills.
- **Learning Difficulties:** academic performance below grade level.

Children with the most serious emotional disturbances may exhibit distorted thinking, excessive anxiety, bizarre motor acts, and abnormal mood swings. They are sometimes identified as having severe psychosis or schizophrenia.

Child and Family Issues

- Parent support groups and respite care may be needed.
- Education and counseling may be needed to assist parents with understanding and managing the child’s behavior.
- Intensive case management and multi-agency coordination is needed.
- Close collaboration with the school system is important in goal setting and treatment.

Continued

EPILEPSY

A physical condition that occurs when there is a sudden, brief change in brain functioning. When brain cells are not working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures.

Seizures can be:

- **Generalized**: all the brain cells are involved; characterized by convulsions and complete loss of consciousness or brief periods of fixed staring.
- **Partial**: brain cells, not working properly, are limited to one part of the brain; characterized by "automatic behavior" that seems purposeful, but is repetitive, unconscious, and usually not recalled, e.g. repeatedly buttoning or unbuttoning a shirt.

Epilepsy does not affect intellectual capacity.

It can be caused by head injury and diseases of the brain, e.g. meningitis, Children with mental retardation or cerebral palsy may also have some type of brain damage that produces epileptic seizures.

Impact on Functioning

Epilepsy is characterized by the following symptoms:

- Blackouts or confused unintelligible sounds, confused memory.
- Episodes of staring or unresponsiveness.
- Involuntary movement of the arms or legs.
- "Fainting spells" with incontinence are followed by fatigue.

Child and Family Issues

- Compliance with medication is important.
- Communication with the school concerning the medication plan.
- Attentiveness to changes in child's behavior and health, especially if the child is on medication with side effects.
- Parent training on handling seizures and general safety precautions.
- Continuance/discontinuance of typical childhood activities needs discussion.
- Overprotection by parents may develop. Independence and confidence needs to be encouraged with general precautions.
- Child may have feelings of anxiety regarding seizures.
- Child may be teased by peers.

Continued

LEARNING DISABILITIES

A disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written, which manifests itself in an imperfect ability to listen, think, speak, read, write, spell, or do math calculations. Learning disabilities are characterized by a significant difference in the child's achievement in some areas, as compared to overall intelligence.

Learning disabilities do not include learning problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural, or economic disadvantage.

The exact cause is unknown, but most likely is related to subtle neurological deficiencies or to genetically based lags in maturation.

Impact on Functioning

The impact on functioning varies according to the type of learning disability and degree of impairment of the learning process. Learning disabilities may occur in the following academic areas:

- **Spoken Language**: delays, disorders, or discrepancies in listening and speaking.
- **Written Language:** difficulties with reading, writing, and spelling.
- **Arithmetic:** Difficulty in performing arithmetic functions or in comprehending basic concepts.
- **Reasoning:** Difficulty in organizing and integrating thoughts.
- **Organization Skills:** Difficulty in organizing all facets of learning.

Hyperactivity, inattention, and perceptual coordination problems may be associated with learning disabilities. Associated traits may include:

- Uneven and unpredictable test performance.
- Impulsiveness.
- Low tolerance for frustration.
- Problems in handling day-to-day social interactions and situations.

Child and Family Issues

- Child may begin to feel "stupid" and inadequate.
- Parents may begin to doubt their own competencies or become impatient and frustrated with their child.
- Parents need to be educated on specific disability and their child's needs.
- Close collaboration with the school is important in setting goals that build upon the child's unique learning style.

Continued

MENTAL RETARDATION

"Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skill areas:

- Communication
- Self-care
- Home-living
- Social skills
- Community use
- Self-direction
- Health and safety
- Functional academics
- Leisure
- Work "(American Association of Mental Retardation, 1992).

Degrees of mental retardation range from mild to profound. People with mental retardation learn slowly and with difficulty, but they do learn. Mental retardation manifests before age 18.

Causes may include chromosomal abnormalities, asphyxia (lack of oxygen), blood incompatibility between the mother and fetus, maternal infections such as rubella or herpes, and prenatal substance abuse.

Impact on Functioning

The impact on functioning depends on the degree of mental retardation and other factors such as early intervention services, school environment, family involvement, socioeconomic status, and the child's desire and motivation. With appropriate supports, over a sustained period, the life functioning of a person with mental retardation will generally improve.

Child and Family Issues

- Parents may feel guilty about transmission of the disability.
- Parents may experience feelings of loss.
- Denial or overprotection may occur during the parents' adjustment phase.
- Parents and siblings need to be educated on the disability and the child's specific needs.
- Early intervention services to maximize functioning.
- Parents need to provide appropriate and continuous stimulation and teach self-care skills.

Continued

SEVERE AND/OR MULTIPLE DISABILITIES

People with severe disabilities are those who traditionally have been labeled as having severe to profound mental retardation. They frequently have additional disabilities including movement difficulties, sensory losses, and behavior problems. They require ongoing, extensive support in more than one major life activity.

Impact on Functioning

Children with severe or multiple disabilities may exhibit a wide range of characteristics depending upon the severity and combination of disabilities and the person's age.

Characteristics may include:

- Limited speech or communication.
- Difficulty in basic physical mobility.
- Tendency to forget skills through disuse.
- Trouble generalizing a skill from one situation to another.
- A need for support in major life activities including domestic, leisure, vocational, and community areas.

A variety of medical problems including seizures, sensory loss, hydrocephalus, and scoliosis may accompany severe disabilities.

Child and Family Issues

- Early intervention to maximize functioning.
- Adaptive aids and equipment may be needed for educational or daily living experiences.
- Assistive technology such as computers or augumentive/alternative communication devices may be needed.
- Parents need to be educated on their child's disabilities and needs.
- Parent support groups and respite care may be needed.
- Intensive case management and multi-agency coordination is needed.
- Close collaboration with the school system in goal setting and intervention.
- Child needs opportunities for inclusion in programs and activities with able-bodied peers to develop social skills and friendships.

* National Information Center for Children and Youth with Disabilities (NICHCY) Virginia Institute for Social Services Training Activities (VISSTA), Virginia Commonwealth University

Continued

SPEECH AND LANGUAGE DISORDERS

Speech and language disorders refer to problems in communication and related areas such as oral motor function. These delays and disorders range from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech and feeding.

Speech Disorders: refer to difficulties producing speech sounds or problems with voice quality.

Language Disorder: impairment in the ability to understand and/or use words in context. Some characteristics of language disorders include:

- Improper use of words and their meanings.
- Inability to express ideas.
- Inappropriate grammatical patterns.
- Reduced vocabulary.
- Inability to follow directions.

One or a combination of these characteristics may occur in children who are affected by language learning disabilities or developmental language delay. Children may hear or see a word but not be able to understand its meaning.

They may have trouble getting others to understand what they are trying to communicate.

Mental retardation and hearing loss predispose a child to speech impairment. Other causes include neurological disorders, brain injury, and physical impairments such as a cleft lip or palate. Frequently, the cause is unknown.

Impact on Functioning

Failure to detect and treat at an early age or prolonged/continued impairment may affect the development of social relationships and emotional interactions and may increase difficulty in developing academic skills.

Child and Family Issues

- Child may be teased by peers.
- Parents may experience feelings of loss and frustration.
- Parents may deny the disability due to familiarity with the child's speech or a lack of information on normal speech development.
- Parent education on the child's disability, appropriate interventions, and communication techniques.
- Collaboration with the school system is important in goal setting.

* National Information Center for Children and Youth with Disabilities (NICHCY) Virginia Institute for Social Services Training Activities (VISSTA), Virginia Commonwealth University

Continued

SPINA BIFIDA

Spina bifida means cleft spine, which is an incomplete closure in the spinal column, There are three types of spina bifida ranging from mild to severe including:

- **Spina Bifida Occulta**: there is an opening in one or more of the vertebra (bones) of the spinal column without damage to the spinal cord.
- **Meningocele**: the protective covering around the spinal cord has pushed out through the opening in the vertebra in a sac called the "meningocele". The spinal cord remains intact and the opening can be surgically repaired.
- **Myelomeningocele**: this is the most severe form of Spina bifida characterized by a portion of the spinal cord protruding through the back. Sometimes the cord is covered with skin. In other cases, nerves and tissues are exposed. This type of Spina bifida accounts for 96% of cases diagnosed.

Spina bifida results from failure of the spine to close properly during the first month of pregnancy.

Impact on Functioning

The effects of myelomeningocele may include:

- Muscle weakness or paralysis below the area where the cleft occurs.
- Loss of sensation below the cleft.
- Loss of bowel or bladder control.
- Fluid build up in the brain, i.e., hydrocephalus, which must be shunted to avoid brain damage, seizures, or blindness (70-90% of children with myelomeningocele have hydocephalus which can lead to attention and learning problems).
- Impaired mobility.

Child and Family Issues

- Parents may need counseling, respite care, or other supports.
- Trauma of multiple surgeries and separation for the child from home, school, and friends while hospitalized.
- Child needs to access multiple resources for medical, educational, physical, and occupational therapies.
- Intensive case management and multi-agency coordination is needed.
- Parent and child training on bladder/bowel control and mobility exercises.
- Child's emotional and social development may be affected.
- Child needs to be encouraged to be independent within the limits of safety and health.
- Child needs opportunities for inclusion in social and other activities with able bodied peers.

Continued

TRAUMATIC BRAIN INJURY (TBI)

Traumatic brain injury is defined as an acquired injury to the brain, caused by external physical force, resulting in functional disability and/or psychosocial impairment that adversely affects a child's educational performance.

Impairments can occur in cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.

The most frequent causes of traumatic brain injury are related to motor vehicle crashes, falls, sport injuries, and abuse/assault.

Impact on Functioning

Typically, children have no visible impairments after a head injury. Symptoms vary greatly depending on the extent and location of the brain injury. They can be temporary or permanent and range from mild to severe including:

- **Physical Impairments**: speech, vision, hearing, headaches, lack of fine motor coordination, spasticity of muscles, paralysis on one or both sides, seizures, or balance and other gait impairments.
- **Cognitive Impairments**: short- and long-term memory deficits, impaired concentration, slowness of thinking, limited attention span, and impairments of perception, communication, reading and writing skills, planning, sequencing, and judgment.

Psychosocial, Behavioral, or Emotional Impairments: fatigue, mood swings, denial, self-centeredness, anxiety, depression, lowered self-esteem, restlessness, lack of motivation, inability to self-monitor, difficulty with emotional control, agitation, excessive laughing or crying, and difficulty relating with others.

Child and Family Issues

- Early identification and intervention to maximize functioning.
- Children with brain injuries can often remember how they aware before the trauma, resulting in emotional and psychosocial problems not usually present in children with congenital difficulties.
- Attention is often focused on the child's disabilities after the injury, which can reduce self-esteem.
- Family and friends recall what the child was like prior to injury and may have difficulty adjusting goals and expectations.
- The child may need to relearn material previously known.
- Opportunities for success that build upon the child's strengths are important.

Continued

VISUAL IMPAIRMENTS

Visual impairment refers to various degrees of visual loss that cannot be corrected with regular prescription lenses and includes partially sighted, low vision, legally blind, and totally blind.

Impact on Functioning

The effects of visual problems on a child's development depend on the severity, type of loss, age at which the condition appears, and overall functional level of the child. Children with visual impairments may have:

- Gross motor skill development delays.
- Delayed language development, when words are initially paired with objects.
- Impaired understanding of commands.
- Impaired conceptual development in the areas of identification of objects and events, physical space concepts, spatial relationships, and numbers.
- Impaired social functioning due to an inability to understand nonverbal cues or imitate social behavior.
- Impaired expression of affect through facial expression.
- Possible impaired autonomy, self-esteem, and ability to talk to others.

Child and Family Issues

- Early identification and intervention to maximize functioning.
- Education and counseling may be needed to assist parents with understanding and managing the visual impairment.
- Close collaboration with the school system on their child's needs and goals.
- Parents need to provide a home environment that maximizes familiarity and security.
- For children with partial visual impairments, the recommendation to learn non-visual techniques (e.g., Braille, audiotape, computer) may be met with resistance due to the child's desire to see self as "non-disabled".

Additional Resources

NICHCY – The National Information Center for Children and Youth with Disabilities http://www.nichcy.org

- NICHCY is the national information center that provides information on disabilities and disability-related issues. Anyone can use their services. Their special focus is on children and youth (birth to 22).

- NICHCY's website has information about:

  - Specific disabilities - http://www.nichcy.org/Disabilities/Specific/Pages/default.aspx
  - Special education and related services for children in school
  - Individualized educational programs
  - Education rights and the law requires
  - Early intervention services for infants and toddlers
  - Transition to adult life
  - Parent materials
  - Disability organizations

Indiana Youth Law T.E.A.M.

- They work to bring about positive system change in youth's legal issues in the juvenile justice, education, and child welfare systems in Indiana.

- They publish an Educational Advocacy Manual.

- You may contact them at:

  Indiana Youth Law T.E.A.M. of Indiana
  333 North Pennsylvania Street, suite 500
  Phone: (317) 916-0786
  Fax: 317-916-5369
  www.youthlawteam.org

Children's Rights and United Cerebral Palsy (2006), Forgotten Children: A Case for Action for Children and Youth with Disabilities in Foster Care. It is available at: http://www.childrensrights.org/policy-projects/foster-care/children-with-disabilities-in-foster-care

National Council on Disability, February 26, 2008, Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions. It is available at http://www.ncd.gov/newsroom/publications/2008/pdf/FosterCareSystem_Report.pdf

Foster Care – Special Needs

Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions

http://www.ncd.gov/newsroom/publications/2008/FosterCareSystem_Report.html

This February 2008 lengthy report from the National Council on Disability examines the plight of youth with disabilities in the foster care system and proposes several concrete strategies to improve their outcomes

Addressing the Developmental and Mental Health Needs of Young Children in Foster Care.
By: Leslie, L., MD, et al. (July 2006). Child and Adolescent Services Research Center, San Diego: CA.
http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1519416

Are We Ignoring Foster Youth with Disabilities?
Fostering Futures Project. (Spring 2002).
http://www.aap.org/advocacy/hfca/FosteringFuturesAwareness1.pdf#search=%22Addressing%20the%20Special%20Education%20Needs%20Foster%22

Behavior Problems and Educational Disruptions Among Children in Out-of-Home Care in Chicago. (2005).
Smithgall, C., et al. Chapin Hall. [15 pgs]
http://www.about.chapinhall.org/conferences/charting/Apr2006/presentatioNS.HTML

Charting a Course: Meeting the Special Education Needs of Foster Children.
(4-05-06 webcast)
http://www.about.chapinhall.org/conferences/charting/Apr2006/presentatioNS.HTML

Forgotten Children: A Case for Action for Children and Youth with Disabilities in Foster Care (2006).
United Cerebral Palsy and Children's Rights.
http://www.childrensrights.org/pdfs/Forgotten2.pdf

Foster Care and Children with Disabilities.
By: Jackson, E., & Muller, Eve. (Feb. 2006). Project Forum. MASDSE.
http://www.nasdse.org/publications/foster_care.pdf#search=%22youth%20with%20disabilities%20in%20foster%20care%22

Substance Use and Need for Treatment among Youths Who Have Been in Foster Care
(2005). NSDUH Report.
http://oas.samhsa.gov/2k5/FosterCare/FosterCare.htm

APPENDIX C – TOLL FREE RESOURCE GUIDE

TOLL-FREE RESOURCE GUIDE

Indiana Statewide Disability Information Numbers

About Special Kids (formerly IPIN)
A "parent-to-parent" organization that answers questions and provides support, information and resources to Indiana families with children with special needs.

Web site: www.aboutspecialkids.org
Toll free: 800-964-4746
Phone: 317-257-8863

The Arc of Indiana
Advocates for people with intellectual and related developmental disabilities and their families. TheArcLink provides resources and advice on home and community-based services with detailed information on service providers via the Web site.

Web site: www.arcind.org or www.TheArcLink.org
Toll free: 800-382-9100
Phone: 317-977-2375

Area Agencies on Aging (and Disability)
Provides a broad range of in-home and community-based services to eligible older adults and persons of all ages with disabilities. This toll-free number will connect you to your local office.

Web site: www.iaaaa.org
Toll free: 800-986-3505

Breaking New Ground (BNG)
Provides information and resources for people with disabilities working in agriculture and rural families in Indiana who have been impacted by disabilities.

Web site: www.breakingnewground.info
Toll free: 800-825-4264
Phone: 765-494-5088

Center for Disability Information & Referral
Statewide referral services on disability, including providers, support groups, educational and residential facilities. Lends books and videos (part of the Indiana Institute on Disability and Community).

Web site: www.iidc.indiana.edu/cedir
Toll free: 800-437-7924
Phone: 812-855-9396

Children's Special Health Care Services
Helps eligible families with children's medical expenses related to a disability or chronic health condition.

Web site: www.in.gov/isdh/19613.htm
Toll free: 800-475-1355

Civil Rights Commission
Enforces Indiana civil rights laws, prohibiting discrimination in employment, housing, education, public accommodation and credit. This includes Fair Housing and many ADA provisions.

Web site: www.in.gov/icrc
Toll free: 800-628-2909
Phone: 317-232-2600

Disability, Aging and Rehabilitative Services
The part of state government that assists eligible people with disabilities with a broad range of services, including residential and in-home services, vocational rehabilitation, employment, deaf and hard of hearing, blind and visually impaired, independent living, developmental disability programs and more.

Web site: www.in.gov/fssa/ddrs
Toll free: 800-545-7763

Division of Exceptional Learners — Department of Education
Provides information on special education services and issues for individuals from ages 3-22.

Web site: www.doe.state.in.us/exceptional
Toll free: 877-851-4106
Phone: 317-232-0570

Family Helpline
Telephone hotline through the Indiana State Department of Health. Responds to all categories of calls for assistance.

Toll free: 800-433-0746

First Steps Early Intervention System
Refers families to community early intervention programs for children from birth through age 3, who are developmentally delayed or are at risk.

Web site: www.in.gov/fssa/ddrs/4968.htm
Toll free: 800-441-7837
Phone: 317-232-1144

Great Lakes ADA Center (Great Lakes)
The Great Lakes ADA Center answers questions regarding the Americans with Disabilities Act and provides technical assistance and training to people with disabilities and businesses.

Web site: www.adagreatlakes.org
Toll free: 800-949-4232

Hoosier Healthwise Hotline
Assists lower-income residents of Indiana by providing insurance coverage for health care services, including Hoosier Healthwise for Children.

Web site: www.healthcareforhoosiers.com
Toll free: 800-889-9949

INDATA (Assistive Technology)
Promotes access to technology-related services, through information and referral, training, advocacy on funding issues, and device loan and demonstration.

Web site: www.eastersealstech.com
Toll free: 888-466-1314
Phone: 317-466-2013

Indiana Institute on Disability and Community
Provides training, advocacy and research to support inclusive education; community living/membership; integrated employment; and choice for people with disabilities and families.

Web site: www.iidc.indiana.edu
Toll free: 800-825-4733
Phone: 812-855-6508

Indiana Protection and Advocacy Services
Assists people with disabilities to resolve disability-related problems including problems with services and access discrimination issues.

Web site: www.in.gov/ipas/
Toll free: 800-622-4845
Phone: 317-722-5555

IN*SOURCE (Resource Center for Families with Special Needs)
Provides families with information/training to help assure effective educational programs and appropriate services for children and young adults with disabilities. Links families with parents in their community who have been trained to help resolve special education issues and concerns.

Web site: www.insource.org
Toll free: 800-332-4433
Phone: 219-234-7101

NAMI Indiana (National Alliance for the Mentally Ill)
Provides family and consumer support and public education about people with psychiatric disabilities.

Web site: www.namiindiana.org
Toll free: 800-677-6442
Phone: 317-925-9399

State Information Center
Provides general information and referral for all state government services, permits, licenses, etc. The Web site provides common links and an online listing of state agency telephone numbers.

Web site: www.help.in.gov
Toll free: 800-457-8283
Phone: 317-233-0800

United Cerebral Palsy Association of Greater Indiana
Provides information, referral, advocacy, diagnostic and treatment clinics, equipment funding and support services to people with cerebral palsy and their families throughout Indiana.

Toll free: 800-723-7620
Phone: 317-632-3561

Vocational Rehabilitation (VR)
Provides education, training, assistive technology, placement and other services to help people with disabilities find employment. Will refer individuals to their local VR office.

Web site: www.in.gov/fssa/ddrs/4938.htm
Toll free: 800-545-7763 ext. 1319
Phone: 317-232-1319

List compiled by: Indiana Governor's Council for People with Disabilities
150 W. Market St., Suite 628, Indianapolis, IN 46204
317-232-7770
Web site: www.in.gov/gpcpd