



invisible disabilities

A PRIMER



Copyright 2007 by Groundwork Press. All rights reserved. No portion of this booklet, except for brief review, may be reproduced, stored in a retrieval system, or transmitted in any form or by any means without written permission of the publisher. For information contact Groundwork Press.

Published by Groundwork Press
445-5525 West Boulevard
Vancouver, BC V6M 3W6

Cover and book design by Jennifer Lee

Some of the material in this booklet has been adapted from *Adoption Piece by Piece: Special Needs* and *Living with FASD: A Guide for Parents*, both published by Groundwork Press. To order copies or for more information, visit www.groundworkpress.com.

Are you an adoptive parent with a daughter or son who has an invisible disability such as deafness, vision impairment, Attention Deficit Disorder (ADD), or depression?

An invisible disability, just as the term suggests, is a challenging condition which is not readily visible to the eye. Your child isn't in a wheelchair and, to most people, looks just like any other child. Perhaps other children tease your child at school because they think he acts "funny". Or, perhaps your child has been sent to the principal's office because she keeps talking out of turn in the classroom. Are you worried that your child's behaviours at school and with his or her peers will become less manageable as he or she grows older? If your son or daughter has been diagnosed with an invisible disability such as ADD, Attachment Disorder or Fetal Alcohol Syndrome (FAS), it is important you have the tools at hand to make certain he or she has all the opportunities and supports available to live life to its fullest potential.

As you grow with your child, you discover things over time that you might not have known before. You might have suspected that he or she had a disorder of some kind, but you did not know the name. Perhaps many medical tests and many doctors later have given you not only the name of the disorder, but also inspired the need to conduct your own research and become an advocate for your child. As it stands, you may even know more about the disability than your family doctor.

It is important to educate yourself on your child's special need and be able to communicate to others about the various behaviours and challenges that your family face. Organizations such as the Federation of Invisible Disabilities in Canada (www.fidsbc.ca) provide parents and professionals with resources to help you communicate about the issues related to invisible disabilities.

Sometimes people are not always that understanding. A teacher may want the child to "snap out of it" or a grandparent might scold the child by calling him or her a "bad kid." Many people tend to make assumptions based on outward appearances. If a child looks just like any other child, people often expect him or her to behave like his or her peers. While many people would be willing to accommodate the special needs of a child in a wheelchair, they may be unaware or less supportive of a child who outwardly looks like anyone else but who has a "hidden" condition such as the challenges under the umbrella of Fetal Alcohol Spectrum Disorder (FASD) or dyslexia.

HOW CAN I HELP EDUCATE OTHERS?

Parents of children with invisible disabilities often express frustration at not being taken seriously by others. They complain that their doctors and educators don't fully understand the service needs of their children. As a result, parents often end up having to educate service providers to access services, a process they describe as exhausting. Often they find themselves blamed for problems and accused of being inadequate parents.

Remember that, along with loving your child and wanting the best for him or her, you also possess a great deal of knowledge about your child's circumstances. When speaking to professionals and others about his or her condition, refer to recent studies that have been done and present a report by a pediatrician or speech pathologist if one is available. Having some concrete information to pass on will present a more convincing case and show that you've done your homework. In addition, use your own notes to demonstrate challenges that he or she and your family face on a daily basis in relation to the invisible disability.

Speak calmly and try not to get angry or upset. Assume that most people know very little about your child's condition or set of conditions. Organize a meeting and invite your child's teachers, the school principal, pediatrician and any other service provider that is involved with your child's life. At the meeting, give them information about your child's condition, the challenges he has yet to move through and the hurdles he's already overcome. Set up a plan that involves working with these professionals regularly to meet achievable goals.

WHAT IF I MY SON OR DAUGHTER IS CALLED NAMES?

Few children avoid being called names during their school years; however, calling a child a name that is connected to his or her invisible disability could damage his or her self-esteem, making it difficult for the child to develop a healthy peer group. If you discover that your child is being called names at school, talk to him or her to get a sense of how the child is feeling and what kind of situation led to the event. Depending on the severity and frequency of the name-calling, it might be necessary for you to speak to your son or daughter's teacher or school principal about the incident. Once again, educating others about your child's disability will foster greater understanding in the long run and minimize the labels and name-calling.

Ask your son or daughter's teacher if she's willing to facilitate an invisible disabilities awareness day at the school whereby students hear stories by parents and professionals about the difficulties children who live with invisible disabilities may encounter. The children at the school don't need to know that your son or daughter has an invisible disability. Creating opportunities to engage with others on this topic, either at the school, your church or the local community centre is a step in the right direction.

CHALLENGES AND SOLUTIONS

The challenge

Dan's school principal has just phoned the boy's parents to tell them that he is being suspended for one week after stealing some equipment from the gymnasium. Dan has a condition related to FASD and this is not the first time he has taken something from his school.

The response

Dan's parents talk to their son at home that night about the incident. They know that because of his disorder he doesn't fully understand the consequences of his actions, however, they want to express to Dan that they do not agree with what he did. The parents set up a meeting with the school principal and teachers to explain how their son's FASD causes him to act in ways that aren't always predictable. With the help of Dan's parents, the educators come up with a consistent set of rules around discipline and develop a school schedule tailored to Dan's challenges.

The challenge

Penny is in the grocery store with her daughter Molly when a woman walks past her and tells her to control her child. Molly is jumping up and down in the aisle. She has Conduct Disorder and Penny has struggled before with taking her out in public and having people raise their eyebrows and make inappropriate comments.

The response

Penny remains calm. She tells the woman that her daughter is adopted and has an invisible disability called Conduct Disorder, which means she can sometimes act out. She explains that she and her family are working to help her daughter control her behaviour, but that it takes time.

The challenge

Aaron has dyslexia. When his teacher writes questions on the blackboard he sometimes has a difficult time understanding them. When students start putting up their hands to answer the questions he feels bad because, as he says, "Everyone gets it and I don't." Children with dyslexia experience a tremendous amount of frustration with both math and writing due to sequencing difficulties.

The response

Aaron's mother introduces his teacher to the multi-sensory teaching approach, which refers to helping the child learn through more than one of the senses. Oftentimes children who are dyslexic have trouble reading words on a page or blackboard. They sometimes mix the words up or the words become fuzzy. In this case what is needed is for the teacher to read the words aloud and have students repeat the words after they are learned. To determine the students' learning levels and draw on their strengths, the teacher gives the children a phonic spelling test. Working with the class, the teacher can focus on having the children learn and say words, identify phonemes and spelling, and recognize letters and reading.

TYPES OF INVISIBLE DISABILITIES

Invisible disabilities is an umbrella term which captures a wide spectrum of hidden disabilities or challenges, which includes Neo-Natal Abstinence Syndrome (NAS), FAS, Attention Defecit Hyperactivity Disorder (ADHD), autism, brain injuries, and learning disabilities. The definitions below represent many of the most common invisible disabilities. We encourage you to seek out further information on specific areas of interest.

Language Disorders

Easier to detect in younger children, language disorders are characterized by problems in articulation, expressive language and receptive language (listening and speaking). Children with a language disability often have no difficulty with spontaneous language (situations where one initiates whatever is said). They do, however, have problems with demand language (where someone else sets up a circumstance in which you must communicate).

Speech Disabilities

These problems occur when using words, sentence structure, and style. Children may misenunciate common words and mix up their sentences. This may relate to auditory difficulties.

Dyslexia

One of the most common reading disabilities, individuals with dyslexia frequently mix up letters and words and are unable to distinguish the sequences of letters and sounds in written words.

Dyscalculia

Dyscalculia is an inability to work with figures. It is a problem with the whole concept and language of mathematics.

Dysgraphia

Dysgraphia is the inability to write legibly, often caused in part by fine motor and perceptual difficulties. In some cases, the child's brain has trouble interpreting what their senses are telling them to do.

Attention Deficit Disorders

C.H.A.D.D. Canada (Children and Adults with Attention Deficit Disorders) defines ADD/ADHD as a treatable medical condition commonly characterized by the presence of inattentiveness and/or hyperactivity and impulsivity at developmentally inappropriate levels. Not everyone with ADD is hyperactive and impulsive. Children

with the Predominantly Inattentive form of ADD are generally not impulsive, but have great difficulty with attentiveness and organization.

Conduct Disorder

Conduct Disorder is defined as a persistent pattern of conduct in which the basic rights of others and major age-appropriate social norms or rules are violated. The behaviour pattern is typically present in the home, at school, with peers, and in the community.

Children or adolescents with this disorder usually initiate aggression, may be physically cruel to other people or to animals, and frequently and deliberately destroy other people's property. They may engage in stealing with confrontation of the victim, such as mugging, extortion or armed robbery. At later ages, the physical violence may take the form of sexual and physical assault or, in rare cases, homicide.

Conduct Disorder problems are often preceded by other problems, including oppositional defiant disorder, Attention Deficit Disorder, and family dysfunction.

Oppositional Defiant Disorder

Oppositional Defiant Disorder is also a behavioural problem, characterized by a pattern of negative, hostile and defiant behaviour without the more serious violations of the rights of others that are seen in conduct disorder.

Children with this disorder are commonly argumentative with adults, frequently lose their temper, swear, and are often angry, resentful, and easily annoyed by others. They often actively defy adult requests or rules and deliberately annoy other people. They tend to blame others for their own mistakes or difficulties.

Attachment Disorder

Children develop an Attachment Disorder when they experience a traumatic period during a very young age. This experience may disrupt or inhibit the bonding process or attachment development between the child and his or her parents. Attachment Disorders often occur if the child experiences a change or separation from one or more caregivers, suffers from chronic pain, or faces abuse and neglect. These experiences may inhibit a cycle of events that is the foundation of the bonding or attachment process.

Autism

Autism is a lifelong disability of the central nervous system that affects social development and language development, and is characterized by specific behaviours. Autism has an early onset, occurring in infancy or childhood. Symptoms may include the following: unresponsive to people, little or no appropriate play with toys, little or no eye contact, inappropriate laughter and screaming, strong inappropriate attachment to objects, difficulties with abstract concepts, a strong

focus on one topic (perseveration), echoing what is said (echolalia), strong resistance to change in routine, self-stimulatory behaviour (rocking, hand flicking, spinning), hyper- or hypo- sensitivity to sight, taste, smell, touch and hearing, unresponsiveness to words or sounds, distress caused by certain noises, unresponsiveness to cold or heat, temper tantrums, self-injurious behaviour, uneven learning patterns (poor skills in some areas, but exceptional abilities in others).

Sensory Defensiveness

Sensory defensiveness refers to the overcultivation of our protective senses, resulting in a “danger” response. A child with sensory defensiveness may appear to be hyperactive, distractible, and exhibiting behaviour problems.

There are different types of sensory defensiveness, with common symptoms related to each of the sensory symptoms.

- *Tactile defensiveness* refers to under or overreaction to touch.
- *Gravitational/postural insecurity* describes a seemingly irrational fear of change in body position, or of certain types of movement.
- *Visual defensiveness* denotes over-sensitivity to visual input.
- *Auditory defensiveness* is over-sensitivity to auditory input.

Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder is an umbrella term that encompasses all the conditions related to prenatal alcohol exposure. This includes Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS) and Alcohol Related Neurodevelopmental Disorder (ARND). FASD is an organic brain disorder and not a psychiatric disorder.

Fetal Alcohol Syndrome was first defined over thirty years ago. It is an organic brain disorder that refers to a set of physical and mental birth defects a child may develop as a result of his or her mother consuming alcohol during pregnancy. It is characterized by central nervous system involvement, growth retardation and characteristic facial features. A medical diagnosis can only be made when a child has signs of abnormalities in each of these three areas as well as known Fetal Alcohol Syndrome (FAS) or suspected exposure to alcohol prenatally. FAS is also associated with a number of secondary characteristics such as poor judgement, an inability to process information and form causal links, impulsivity, a tendency to be easily influenced and superficial verbal fluency.

Partial Fetal Alcohol Syndrome, which is also known as Fetal Alcohol Effects (FAE), applies to a person with a confirmed history of prenatal alcohol exposure who has some, but not all, of the characteristics of FAS. This does not mean, however, that pFAS is any less severe; it can have serious implications for education, social functioning and vocational success.

Alcohol Related Neurodevelopmental Disorder differs from both FAS and pFAS in that there are few or no characteristic facial features. Individuals with

ARND often have normal or above average intelligence as well as some secondary characteristics that are associated with FAS.

FASD is one of the leading causes of preventable birth defects and developmental delay in Canada and the western world. Health Canada, based on incidence rates found in the United States, estimates that there are one to two per 1000 children born with FASD in Canada. FASD is irreversible.

Prenatal Drug Exposure (PDE) and Neo-natal Abstinence Syndrome (NAS)

This term refers to a spectrum of conditions that may result from exposure to drugs before birth, including opiates, stimulants and prescription drugs. It is not a diagnostic term in itself. A range of drugs such as cocaine, heroin, methadone, Talwin, Ritalin, Codeine, marijuana, inhalants, and Valium affects children.

Whereas the term Prenatal Drug Exposure is not drug specific, NAS is a specific diagnosis applied to newborns who are withdrawing from intrauterine exposure to opiates such as heroin. The signs and symptoms of NAS are wide-ranging and include diarrhea, water depletion, shock, continuous vomiting and convulsions. Other symptoms include lethargy, wakefulness, irritability, a high-pitched persistent cry, an intolerance to handling, tremors, twitching, jerks and seizures. The baby's skin may be mottled or jaundiced. Excessive sweating might occur. A disturbance in respiratory signs is particularly common and may include hiccups, yawning, coughing, sneezing, or other signs of respiratory distress. Infants with NAS are often born prematurely. They may be small for their gestational age, with a low birth weight and small head circumference. When born, they might have aspiration pneumonia or physical abnormalities such as missing fingers.

The term PDE also comprises alcohol exposure before birth. However, because a pregnant mother's alcohol consumption can result in conditions that are part of Fetal Alcohol Spectrum Disorder (FASD) with their own set of distinctive manifestations and challenges, PDE is most often used to refer to drug exposure alone. Researchers have yet to explore in depth the extent to which prenatal substance exposure affects behavioural development. The impact on a child of an unstable home environment, and poor pre- and post-natal nutrition and care make it difficult to link behaviours to drugs alone.

Epilepsy

Epilepsy takes various forms. These include generalized epilepsy, or *grand mal* which is a major fit affecting all the muscles or the body, with a massive contraction followed by a succession of jerky contractions. *Partial seizures* may affect only a few muscles of the body, or may also involve any of the functions of the brain and cause elaborate hallucinations. In *absence attack* or *petit mal seizures*, the affected person, usually a child, is momentarily inaccessible but does not fall or appear to lose consciousness.

Seizure disorders can be treated with medications, a special diet, or surgery. For many children, the seizures are an isolated disability and those affected can lead almost normal lives. For a child with multiple disabilities, the prognosis is generally a function of the other disabilities.

Hearing Impairment

Hearing is equalled only by vision among the five senses in its importance to our understanding of the world around us. A hearing deficit is therefore a major disability. *Conductive deafness* results from disorders of the external ear, eardrum, middle ear and acoustical link to the inner ear. *Sensorineural* or *nerve deafness* results from disorders in the inner ear (i.e. a damaged cochlea or acoustic nerve). A hearing loss can range from slight to profound, and may be unilateral or bilateral. Such a loss may exist alone or as part of a multiple disability condition. Defining the type and severity of loss is important for treatment. Often, there is a considerable delay in identifying a child with hearing impairment as infants and young children cannot express that they are having difficulty hearing. An early sign of severe hearing loss is a sleeping infant who does not awaken to loud noises. Later signs include lags in meeting developmental speech and language milestones.



also available from *Groundwork Press*

THE PRIMER SERIES:

Adoptive Parents as Advocates

Transracial and Transcultural Adoption

These free booklets are designed to provide quick and practical information to time-challenged adoptive families. Available for download at www.groundworkpress.com

ADOPTION PIECE BY PIECE (3 volumes):

Lifelong Issues, Special Needs, A Toolkit for Parents

Edited by Sara Graefe

This series represents a comprehensive collection of articles from experienced parents and professionals on a variety of topics related to adoption.

LIVING WITH YOUR GRANDCHILDREN: A GUIDE FOR GRANDPARENTS

By Lissa Cowan and Jennifer Lee

This practical guide for grandparents explores the legal, parenting and emotional issues associated with raising your grandchildren.

LIVING WITH PRENATAL DRUG EXPOSURE: A GUIDE FOR PARENTS

By Lissa Cowan and Jennifer Lee

This comprehensive book for parents and professionals introduces caregivers to the challenges of caring for a child prenatally exposed to drugs.

LIVING WITH FASD: A GUIDE FOR PARENTS, 3rd Edition

By Sara Graefe

This updated 3rd edition includes diagnostic criteria, special considerations for infants and adolescents, and an expanded resource list.

ADOPTIVE FAMILIES ARE FAMILIES FOR KEEPS

Text by Lissa Cowan, illustrations by Stephanie Hill

This colouring book will provide social workers, foster parents, caregivers and educators with dynamic and instructive ways to introduce and discuss a wide range of adoption issues with young children.

TARA'S GUIDE TO ADOPTIVE FAMILIES ARE FAMILIES FOR KEEPS (CD-rom)

Text by Lissa Cowan and Jennifer Lee, animation by Dia Media

This companion CD-rom to *Adoptive Families are Families for Keeps* guides professionals and caregivers through over 50 relevant exercises and discussion topics to use together with the activity book.

To order any of these titles, please visit our website at www.groundworkpress.com.



invisible disabilities

A PRIMER