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Children's Services Practice Notes is a newsletter for North Carolina's child welfare workers produced four times a year by the North Carolina Division of Social Services and the Family and Children's Resource Program, part of the Jordan Institute for Families and the School of Social Work at the University of North Carolina at Chapel Hill.

*In summarizing recent research, we try to give you new ideas for refining your practice. However, this publication is not intended to replace regular supervision and peer consultation—only to enhance them.*

#### Let us hear from you!

If you would like to comment about something that appears in this or any other issue of Children's Services Practice Notes, please do so! Address your comments to:

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## HELPING CHILDREN WITH SPECIAL NEEDS

When a child is diagnosed with a medical condition, there are often serious implications for the child and her birth, foster, or adoptive family. To support these children and their caretakers, helping professionals need information.

In this issue we present you with basic information on Fetal Alcohol Syndrome, Failure to Thrive, and Attention Deficit Disorder. In addition to descriptions that will help you recognize and understand the nature of these conditions, we offer you guidelines for working with and supporting these families.

We also feature an important resource for families and practitioners working with children with special needs: the Family Support Network.



## NEGLECT AND FAILURE TO THRIVE

*The girl lying in the crib has thin arms and legs and wispy, dull hair. She looks weak, underfed. The child's cries sound hungry to you, but her mother makes no move to feed or comfort her. As you explain that her daughter needs to be examined by a physician, you wonder: is failure to thrive always caused by neglect?*

This article will explore the relationship between failure to thrive and neglect, outline the characteristics of high risk groups, and discuss successful intervention strategies.

### THE CONDITION

In the medical profession, the term failure to thrive (FTT) is used to diagnose children, primarily infants, who are underweight and malnourished.

Doctors compare the infant's weight and height and assess how that fits to standard weight/height charts.

A child is said to be suffering from failure to thrive when a doctor or medical professional finds the child's 1) weight for his or her height is below the 5th percentile of the population on a standard weight/height curve; 2) actual weight is 20% or more below the ideal weight for height; 3) weight gain is significantly slower than normal; 4) triceps skinfold thickness (a measurement of the total body fat) is below the 15th percentile for the population (Schmitt & Mauro, 1989). Less precise indicators can be found in the sidebars on pages 2 and 3.

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## NEGLECT AND FAILURE TO THRIVE

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Despite the scientific criteria doctors use, failure to thrive is difficult to detect—it is often misdiagnosed for people who are short, normally lean, or for infants who have rapid shifts in their height, especially between 6 and 12 months of age. Usually FTT infants are delivered at full term and are healthy at birth.

Failure to thrive can occur due to organic or nonorganic reasons, although many infants with FTT have both types. Organic failure to thrive results from congenital or genetic causes, such as illnesses that affect the respiratory or cardiovascular systems. Nonorganic failure to thrive results from accidental, neglectful, or deliberate action on the caretaker's part. The majority of the nonorganic FTT cases are due to caretaker neglect. Because of this, FTT has long been a concern of child protection workers.

### CHILDREN AT RISK

Children at high risk for nonorganic failure to thrive often come from families in which the mothers have experienced abuse and neglect in their childhood. These mothers often have difficulty relating to others, suffer from chronic depression, and feel overwhelmed and inadequate. They may be uncooperative with social workers or medical staff.

**Mothers of infants with nonorganic failure to thrive prioritized their needs as more important than their child's and blamed their babies for not gaining weight.**

Joseph Fischhoff and colleagues have conducted a study concluding that mothers of nonorganic FTT infants tend to have character disorders, such as narcissistic personality disorder or dependent personality disorder (Fischhoff, Whitten & Pettit, 1971). People with character disorders create challenges for successful intervention because their behaviors are ingrained and difficult to change.

Another study found that mothers of FTT infants tended to blame their babies for failing to gain weight, interpreted the meaning of their babies' crying in negative ways, and had difficulty bonding to their infants because they prioritized their own needs as more important (Haynes, Cutler, Gray, O'Keefe & Kempe, 1983).

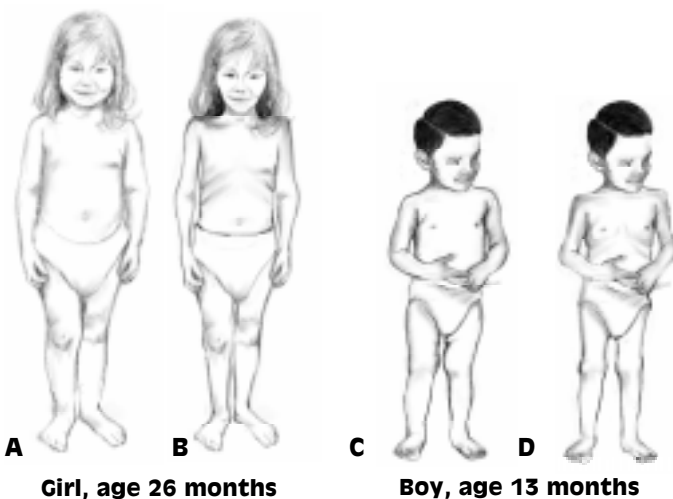
### INTERVENTIONS

Early intervention is important with FTT children and their families. Those children who go untreated experience continued growth deficits, mental retardation, deficits in cognitive skills (especially language), and problems in personality development. Treatment of children with failure to thrive involves close monitoring of the child's growth, nutrition, and developmental status over a long period of time. Children sometimes require remedial help such as infant stimulation programs (Hathaway, 1989).

Because of the nature of the symptoms, working with a child who has been diagnosed as failure to thrive requires collaboration with doctors and other medical staff. These professionals are mandated by law to report suspected cases of neglectful nonorganic failure to thrive to their local CPS agency.

In addition to the collaboration requirement in FTT cases, social workers often must decide whether to re-

### RECOGNIZING THE SIGNS



**The figure at left illustrates the differences between adequately fed children (child "A" and "C") and those who should be examined for failure to thrive (child "B" and "D").**

Illustrations courtesy of G. S. Huntington & N. Simeonsson, N. North Carolina Weight Gains Study. Illustrations by Gina Harrison. Used with permission.

## TRAITS ASSOCIATED WITH FAILURE TO THRIVE

### Growth Retardation

- Child falls below the 3rd percentile in weight and height

### Physical Description

- Wasted body, thin arms and legs
- Large stomach
- Red, cold and wet hands and feet
- Thin, wispy, dull, and sometimes falling hair
- Dark circles around the eyes

### Physical Symptoms

- Refusal to take food
- Vomiting
- Diarrhea

### Psychological Description

- Sadness
- Expressionless face
- General lethargy
- Withdrawal, detachment
- Unresponsiveness
- Depression
- Bursting into tears, frequent whining
- Little or no smiling
- Diminished vocalization
- Staring blankly at people or objects
- Lack of cuddliness
- Lack of proper stranger anxiety

### Developmental Retardation

- Motor
- Language
- Social
- Intellectual
- Elimination

Source: Iwaniec, D., Herbert, M., & McNeish, A. (1985). Social work and failure-to-thrive children and their families. Part I: Psychosocial factors. *British Journal of Social Work, 15*, 243–259.

move the child from the home. The criteria used to make this decision usually include the severity of the child's condition, the mother's openness to intervention, and whether a plan of safety involving a relative, neighbor, or other interested person can be established.

In some cases, a placement decision may be postponed because the baby requires hospitalization. This type of separation provides an opportunity to assess the mother's ability and willingness to care for the child upon discharge, while ensuring the child's safety during the hospital stay.

If the decision is made to keep the child at home, intensive support of the family often leads to successful recovery. In a paper published in the *British Journal of Social Work* (1985), Dorota Iwaniec, Martin Herbert, and A.S. McNeish reported on one such intensive in-home program working with FTT infants and their caretakers.

Once the child had been diagnosed, the immediate focus was on attending to the safety and needs of the child and family. The child was enrolled in day care, and routine, ongoing contact in the home was scheduled with health visitors, volunteers, and neighbors to provide moral support and assistance with child care. If the family needed help with housing or other issues of subsistence, that was addressed.

To accomplish specific treatment goals, such as creating calm feeding of the child by the mother and facilitating

better relationships between mother and child, researchers used behavioral techniques. These involved role-playing and coaching the desired behaviors (e.g., how to give a child positive cues during mealtimes) and a lot of praise and positive reinforcement.

After the situation stabilized, the intervention focused on long-term needs, such as the mother's relationship to her infant, her depression, and so on. Out of 18 cases, only one child had to be readmitted to the hospital after the intervention had ended more than one year later. ♦

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## SUPPORTING FAMILIES WHOSE CHILDREN HAVE F.A.S.

One out of every 750 children born in the U.S. has fetal alcohol syndrome (Merolla, 1993). Fetal alcohol effect (FAE) and fetal alcohol syndrome (FAS), the more severe manifestation, are organic brain disorders in children caused by a mother's use of alcohol during pregnancy. Poor parenting after birth does not cause FAE or FAS. These are lifelong conditions that can affect anyone, regardless of race or economic status (Montana FAS/FAE Program, 1996).

### THE CONDITION

Fetal alcohol syndrome is caused when a mother drinks alcohol during pregnancy, injuring the fetus by destroying and damaging cells in the central nervous system. This destruction of brain cells results in malformations in the developing brain structures. Several studies indicate that the severity of the disability has to do with the amount of prenatal exposure to alcohol (NCFCRP, 1994). Most children with FAS are born to women who are chronic alcoholics, although even moderate use of alcohol during pregnancy can result in FAE or FAS (Coles, Smith & Falek, 1987).

When they are born, children with FAS are frequently small and have a low birth weight. Often they are born prematurely. Physical characteristics of children with FAS include abnormally small heads, facial irregularities (such as thin or wide lips or malformed or misaligned teeth), widely spaced eyes, short noses, flat cheeks, limb and joint abnormalities, poor coordination, and heart defects. (See sidebar on page 5 for illustration.) Central nervous system damages sometimes are manifested as developmental disabilities, attention deficit disorder, learning dis-

abilities, seizures, developmental delays, and behavioral disorders.

Other common effects of FAS include sleep disturbances, difficulty in peer and sibling relations, hyperactivity, difficulty developing independent skills, and excessive talkativeness (Guiunta & Streissguth, 1988; Vaitenas, 1981; NCFCRP, 1994). It is important to resist the temptation to focus strictly on the negative traits of children with FAS: parents and those who work them have also found these children to be socially engaging, interested in others, affectionate, and good with animals. (See sidebar below.)

Children with FAS cannot be diagnosed definitively until three years of age because they are developmentally incapable of completing the tests until then. However, children and families benefit significantly from an early diagnosis—even a preliminary one. This information can help them shape their expectations and obtain support and intervention for the child, and so avoid the cycle of failure at home and school that is almost certain without diagnosis.

### SUPPORTING PARENTS

The first thing parents need is understandable, practical information about FAE and FAS. Given this information and the proper amount of support, caretakers will begin to get a realistic view of the child's current and future functioning; from there they can develop reasonable expectations.

Parents also need a substantial amount of support. Children with FAE/FAS require a great deal of supervision, and this can be exhausting for birth, foster, and adoptive parents. Day care, respite care, and other relief from parenting allow caretakers to rejuvenate and reenergize. Siblings may also have needs to be addressed (Montana, 1996).

Birth mothers may require special support. They are likely to be active or recovering alcoholics who need help addressing their substance abuse and the affects it may have had on numerous areas in their lives. They may benefit from substance abuse counseling, parenting classes, or nutritional counseling. The stress of caring for a child with behavioral and medical problems may make it more difficult for these women to maintain sobriety. Some mothers may also need help working through feelings of guilt (Guiunta & Streissguth, 1988).

When it is necessary to place children with FAS in foster care, there are certain characteristics to look for in

### A BEHAVIOR PROFILE OF FAS

- Extremely active
- Easily Distracted
- Impulsive
- Poor judgement
- Poor communication
- Problems with transitions
- Hard time bonding/keeping friends
- Socially engaging
- Interested in others
- Affectionate
- Loving
- Talkative
- Good with animals
- Makes friends easily

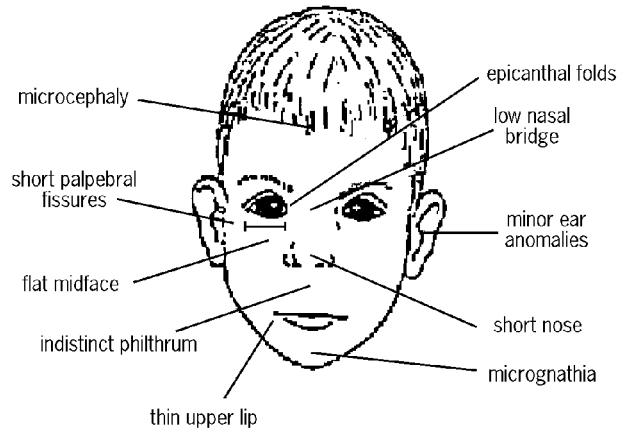
Source: Montana Fetal Alcohol Syndrome/Effects Program, Department of Medical Genetics, Shodair Hospital, Helena, Montana. Reprinted with permission.

## FACIAL CHARACTERISTICS OF FETAL ALCOHOL SYNDROME



Photos courtesy of Carole T. Giunta and Ann Pytkowicz Streissguth, from their article "Patients with Fetal Alcohol Syndrome and Their Caretakers," *Social Casework*, Sept. 1988. Publisher: Families International, Inc.

**Above:** children with FAS. **Right:** Diagram of facial features of FAS. Any one or two of the characteristics at right may be normal, given genetic predetermination. It is the collection of characteristics which assumes diagnostic significance. The features on the left are those most frequently seen in people with FAS. Those on the right are also seen with increased frequency in the normal population (Little & Streissguth, 1982). Note: in the absence of the above external physical characteristics associated with full FAS, a person with Fetal Alcohol Effects (FAE) may still have significant organic brain differences.



- **Epicanthal folds:** fold of skin at inside corner of eye
- **Microcephaly:** small head circumference
- **Micrognathia:** small jaw
- **Palpebral fissure:** opening of eye from side to side
- **Philtrum:** vertical grooves between base of nose and upper lip

Illustration adapted from Little & Streissguth, A. P. (1982). Unit 5: Alcohol, pregnancy, and fetal alcohol syndrome. In Project Cork (Ed.), *Alcohol Use and Its Medical Consequences, A Comprehensive Teaching Program for Biomedical Education*. Dartmouth, ME: Dartmouth Medical School. Reprinted with permission.

foster homes. Giunta and Streissguth recommend placing these children in homes of parents "who are calm and low-key individuals, secure and comfortable with themselves, and who live stable and predictable lives" (p. 457). The authors found that parents who led busy, complex lives were more inclined to be dissatisfied with FAS children's slow development (Giunta & Streissguth, 1987).

Those who are new to parenting this type of child may find connecting with other parents of kids with FAS helpful. Caretakers can benefit from a support group with caretakers of other children with the condition. The Parent-to-Parent program is another resource that helps parents of children with special needs in North Carolina connect with one another. To contact this program, call 1-800-852-0042.

Collaboration with the school system is also critical for social workers serving children with FAS. Because kids with this condition have special educational needs—they function best in a small classroom with clear guidelines and plenty of individual attention—social workers often have to advocate for appropriate educational services. Periodic testing is recommended to assist teachers in designing spe-

cific instructional plans to meet the child's learning needs. Preschool activities should also be considered, not only to maximize the child's development, but also to provide respite to the caretaker.

Finally, caseworkers need to work with caretakers to advocate for children with FAS. Parents will need help exploring all avenues for financial assistance, since FAS children have specialized and often costly medical and educational needs. ♦

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## GETTING TO KNOW ADD AND ADHD

ADD and ADHD. We've all heard the terms, and many of us seen behaviors associated with them. Still, what is attention deficit disorder? In this article we describe these conditions and provide some tips for working with children diagnosed as ADD/ADHD and their families.

Attention deficit disorder with and without hyperactivity (ADD/ADHD) is a neurological condition that impairs a child's learning, social and emotional functioning. It has no known cure.

Symptoms include inattention, impulsivity and hyperactivity at age-inappropriate levels and can vary in degree (Aust, 1994). Inattention behaviors may include poor listening skills, difficulty completing tasks, daydreaming, and/or inability to complete projects. Impulsive behaviors may include low frustration tolerance, interrupting often, acting before thinking, losing things and/or rushing through assignments. Hyperactive children can be overactive (fidgeting, squirming, climbing), underactive (appearing confused, lethargic, sluggish and/or daydreaming), or over-focused (working slowly, intolerant of minor distractions, checking and re-checking work). Children with mild symptoms function fairly normally both in the home environment and in school. Children with severe symptoms can be affected in all areas of their daily living. Ziegler and Holden (1988) identify three important aspects to a child's development undermined



**ADD and ADHD can undermine a child's self-esteem, ability to manage frustration, and his sense of self control.**

by the presence of an attention disorder: self-esteem, frustration management, and a sense of self control.

It was thought until recently that ADD and ADHD are conditions only applicable for children, and that they can outgrow it. Increasingly, experts believe that for some people it can be a lifelong problem.

The causes of attention deficit disorders are not totally known. Until recently, many people thought ADHD and ADD were caused by the overconsumption of sugar, food additives and dyes, vitamin deficiencies, or lead

poisoning. While these aspects may exacerbate symptoms or functioning difficulties, the most recent medical research indicates that ADHD and ADD may be genetic.

AD(H)D is difficult to diagnose. Symptoms vary from child to child and the problems often coexist with various learning, social, and emotional problems (Aust, 1994). If ADD or ADHD is suspected, it is critical that a thorough evaluation be conducted by trained medical personnel. ♦

Aust, P. (1994). When the problem is not the problem: Understanding attention deficit disorder with and without hyperactivity. *Child Welfare*, 74,(3), 215-227. North Carolina Family and Children's Resource Program. (1994). What is ADD/ADHD. In Caye, J. (Ed.) *Performance Based Core Curriculum in Child Welfare*, pp 6-45 through 6-49. Chapel Hill, NC: author.

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### STEPS YOU CAN TAKE

- Provide opportunities for the child and family to become educated about AD(H)D so everyone understands the biochemical nature of the problem, and that sometimes the child may be *unable* more than unwilling.
- Have the child seen by a physician to determine if medication could be useful.
- Ensure that an appropriate educational plan is in place, and that school personnel are equipped to teach in a manner in which the child can flourish.
- Link caretakers to training in behavior management techniques, and ensure an adequate support system.
- Set up individual, small group, or family counseling to help address daily living problems that accompany parenting a child with AD(H)D.

Source: Aust (1994, p. 224-225)

### GUIDELINES FOR PARENTS

- Assign only one task at a time and have the child repeat the instructions.
- Soak success in praise and pride.
- Expectations and consequences should be worked out in advance and followed consistently by all adults in the home and at school.
- Focus on shaping new positive behaviors rather than eliminating the negative ones.
- Develop and maintain a predictable daily schedule, especially for completing homework assignments
- Anticipate and plan for sleep problems; seek medical assistance if they become severe.
- Seek counseling and consultation to help with the day to day management of the child.

Source: (Aust, 1994; NCFCRP, 1994)

## NORTH CAROLINA ISSUES CHALLENGE FOR CHILDREN

Citing the success of the *Families for Kids* counties, the North Carolina Division of Social Services began 1997 by challenging county departments of social services to reduce the amount of time children spend in DSS custody. Currently the median length of stay in DSS custody for a child in North Carolina is 518 days, according to the N.C. Child Placement Information and Tracking System.

In a letter sent out in January, N.C. Division of Social Services Director Kevin M. FitzGerald issued a "Challenge for Children" and asked each of the directors of social services in the state's 100 counties to make reduction of the foster care backlog a top priority during 1997. The "backlog" is made up of all children who remain in the custody or placement responsibility of a county department of social services for more than 12 months.

Part of the inspiration for the challenge comes from the *Families for Kids* initiative. "Although this goal (reducing the backlog) seems challenging in light of available resources,"

FitzGerald writes, "our *Families for Kids* initiative has demonstrated that important progress is possible through establishing backlog reduction and 'one year to permanence' as a clear agency priority." By increasing the amount of teamwork in their agencies, collaborating with other agencies, and involving the community, he says, "the *Families for Kids* counties have reduced the number of children in the backlog by 5 percent."

Those county DSS's that accept the *Challenge for Children* have been asked to submit a statement of acceptance to the N.C. Division of Social Services bearing the signatures of all of the agency's child welfare social work and supervisory staff. So that the state can track their success at reducing the backlog, each participating county must also submit demographic information for each child who was in the backlog on January 1, 1997. Next year, the Division will ask for information on children in the backlog on January 1, 1998.

The Division will publicly recognize those counties that succeed in making significant reductions in the foster care backlog during 1997. Recognition will come in the form of news releases, press conferences, celebrations in the counties, and letters of commendation to boards of county commissioners, county managers, and legislative representatives.

Although a final list was not available at press time, at least 58 counties accepted the challenge by the April 15 deadline. "We're very excited—the response has really been great," says Sara Anderson-Mims, Community Coordinator for the Division. Following is a partial list of those who have accepted the challenge. ♦

### CHALLENGE FOR CHILDREN COUNTIES Preliminary List

Alamance	Macon
Alexander	Madison
Alleghany	Martin
Anson	Mecklenburg
Avery	Mitchell
Buncombe*	Nash
Burke	Orange
Cabarrus	Pasquotank
Caldwell	Pender
Caswell	Randolph
Catawba*	Richmond*
Cleveland*	Rockingham
Craven	Rowan
Dare	Rutherford
Davidson	Scotland
Davie	Stanly
Edgecombe*	Stokes
Forsyth	Surry
Franklin	Transylvania
Gaston	Union
Guilford*	Wake
Halifax	Washington
Harnett	Watauga
Haywood	Wayne*
Hoke	Wilkes
Iredell*	Wilson
Jackson	Yadkin
Jones	Yancey
Lee	
Lincoln	

\* *Families for Kids* counties

### HOW DOES NORTH CAROLINA COMPARE?

How does North Carolina match up to other states when it comes to the length of time children spend in state custody? The figures in the following table represent the median length of stay during 1988–93. The median length of stay in North Carolina today is 17.3 months.

State	Months in Care
Texas	8.7
Michigan	12
North Carolina	18
California	18.1
New York	24.5
Illinois	35.8

Sources: Multistate Data Archive and the N.C. Child Welfare Database.

## HOTLINE OFFERS INFORMATION ON SPECIAL NEEDS

What do you do when the child you are working with has a medical condition you know nothing about? Where can you get information about this condition to give to foster parents and others who are providing services to him?

One option is to call the Family Support Network of North Carolina. Since 1985, the Family Support Network has been providing support and information for families of children with special needs and the professionals who serve them. To meet the needs of these families, this organization maintains a network of parent-to-parent programs across the state, organizes parent/professional training activities, and runs the Central Directory of Resources.

The Central Directory of Resources (CDR) is a computerized resource that can be reached by calling (800) 852-0042. In the CDR's extensive database are printed materials about various disabilities, illnesses and conditions, as well as articles on behavior management and family issues. The CDR's database also contains a comprehensive list of agencies and organizations, in North Carolina and across the country, that provide services and support for people with disabilities.

Here is an example of a typical call to the CDR: the caller identifies herself as a social worker from eastern North Carolina. A few hours earlier, her agency took custody of a child with Prader-Willi Syndrome, and she knows little about this condition. The resource specialist informs her that the CDR has material describing the syndrome, as well as material to help the foster parents with whom she will place the child.

The resource specialist promises to send the material immediately, along with names of organizations that can provide more information about Prader-Willi Syndrome. She also encourages the caller to have the child's foster parents call the CDR if they would like to talk to another parent whose child also has Prader-Willi Syndrome.

The Family Support Network's Central Directory of Resources can be reached by calling: 1-800-852-0042. ◆



**Need to know more about a medical condition? Call the Family Support Network toll free at 1-800-852-0042.**

## IN THIS ISSUE: HELPING CHILDREN WITH SPECIAL NEEDS

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