

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

Understanding children's mental health

Parents search for new ways to handle behaviors

Summer 2003



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Families of children with mental health needs face unique challenges. As with any disability, the sooner a child with mental health needs begins receiving intervention services, the sooner that child has an increased chance to succeed at home and in school. Unfortunately, one in 10 children nationwide has mental health needs, but less than 20 percent of these youngsters are receiving the care that they need, said Renelle Nelson, coordinator of PACER's children's mental health project.

Most of the time, a specific diagnosis is not clear for a very young child. Children with mental health needs don't follow a predictable pattern of behaviors. PACER advocates have talked to parents whose children at a young age had the inability to play with other children, show emotion, or control their emotions. Others have said their child was aggressive toward other children, and many parents complain that it is difficult to find babysitters or keep child care services.

Parents usually need to hunt for innovative ways in order to deal with their child's



(Above) Tina McRae and her twin daughters, Jacqueline and Felecia, 6. (Right) Monica Richards, her husband Wayne, and their two children Adrian and Nattie. Both families have struggled to understand their child's behaviors, and both are looking forward to a successful future for their children.



behaviors or emotional disorders. They may struggle with behaviors that don't seem to make sense and situations they don't know how to control. Many parents feel frustrated and alone.

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Mental health: Despite reluctance to diagno

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PACER Center offers a wide range of support for parents of children with emotional or behavioral disorders—parents can problem-solve with advocates, attend workshops specific to mental health needs, meet other parents with similar situations, and find out about other resources. PACER recommends that parents keep a record of their child's behaviors to show a doctor what happens in a week or a day.

“Doctors are often reluctant to put labels on children early because so much can change in the early years when a child is developing,” said Virginia Richardson, PACER's parent training manager.

The following stories show a wide range of disabilities, but there is a common theme



Adrian enjoys playing baseball.

throughout—a parent's determination. Each parent revealed the same kind of positive outlook and tireless spirit as the other.

Richards family

Two years ago, Monica Richards was told that her child, Adrian, who was then 6, would be in jail or dead by age 16.

Adrian has been diagnosed with disabilities ranging from post-traumatic stress disorder to oppositional defiant disorder, but Monica believes that he

will succeed just like his 8-year-old peers.

Adrian is proving her right.

In April, Adrian began spending most of his time with the mainstream second-grade class instead of being moved around from special class to special

Looking for technology training? Try Project KITE!

When Sarah first entered kindergarten, her teacher didn't know how to include her in the reading circle because Sarah has Down syndrome. Sarah's parents asked the kindergarten teacher and the special education teacher if they would be willing to attend technology trainings at PACER that would help them include Sarah not only in the reading circle, but in all aspects of the regular classroom.

Sarah's parents and teachers attended five 3-hour sessions over the next three months, and each team member received a computer, digital camera, printer, and several software programs for use during the training.

The results were astounding.

Sarah's teachers created reading boards for her to follow along during reading circle, a special program with photos of all of her classmates so she could choose a friend to play with during recess, and a big chart of activities so Sarah would know what was

happening next. Her parents noticed a big difference in her enthusiasm for school and her progress in learning.

You can take advantage of this free training!

Project KITE (Kids Included through Technology are Enriched) is seeking teams of parents and professionals for Fall 2003. Trainings will take place at PACER Center. This is open to parents of young children (ages 3-6) with disabilities. Children must participate in a preschool, kindergarten, or early childhood program with typically developing peers. Participants will learn through hands-on opportunities to select and customize technology for young children with disabilities. Each family and classroom will receive a free membership to the Software Lending Library, a computer, digital camera, printer, and several customizable software programs to use during the training.

For more information, call Kari Jaehnert or Brad Buelow at 952-838-9000 or visit www.pacer.org/kite

For these young children with EBD, there is help

class. Since Adrian doesn't handle transitions well, he used to end up in the detention room for up to one-third of the school day.

Since moving into the mainstream classes while still receiving services, he is enjoying school, making friends, going on field trips, and feeling challenged by his schoolwork.

"He's been reading at a 6th grade level and scoring 95 percent on reading comprehension," Monica said. "Some people have been telling me his IQ is below normal, but I know that the reason his academics were delayed was only because he couldn't pull himself together for school."

Adrian's behaviors have been extremely difficult for his teachers and parents to understand, but Monica said she believes there is never a lack of motivation for a behavior.

"I realize that it may not always be logical to you or me, but something triggered that behavior," she said. "Either it was a new teacher who didn't understand his needs or someone tripped him on the bus or he was startled by a loud noise."

Monica remembers the time Adrian bit his favorite teacher because he was terrified to sing in the school holiday program. Of course, the family didn't understand his behavior at the time, but later learned about Adrian's role in the Christmas program.

"But he is on the right track now," she said. "It took me digging a lot more than I would have liked to, but he is doing 100 times better than I would have ever imagined."

Monica spent many hours discussing Adrian's behavior with school staff to try to find solutions.

McRae family

Tina McRae had a feeling that something was not quite right when her daughters, Felecia and Jacqueline, were born. Now, six years later she knows that her instincts were correct.

After talking to many professionals, Tina found out that Jacqueline has mental health issues including

attention deficit hyperactivity disorder, general anxiety, and other health disorders. Felecia has anxiety and depression.

She says that she knows now that "if something doesn't feel right, it probably isn't." But she has also learned that she is not alone—there is

a parent somewhere who has experienced a child's behavior similar to one of Tina's children. When you find that person, she said, you ask a ton of questions.

Tina struggles with her daughters' behaviors because she can't always understand them and can't always find easy solutions.

"It is kind of like walking on eggshells sometimes because the triggers for them are non-specific," she said. "There are so many sensory issues that affect Jacqueline and Felecia—sights, sounds, temperatures—and I can't regulate all of that. I can only control certain things."

When she found other parents to talk to, workshops at PACER to attend, and school staff who were understanding, she felt like a huge weight had been lifted off her shoulders.

"The hardest thing for me is to keep my daughters going when there is no one to keep me going," she said. "But when I found other resources, I felt so much more in control and hopeful."

Tina knows that her daughters will probably need to work harder than some of their peers, but she has confidence that they will grow up with the skills they need.

"I want them to be successful," Tina said.

For parents who have questions about children's mental health needs, call PACER at 952-838-9000.



Felecia McRae

Ask the expert: Defining infant mental health

“The physical, mental and emotional health of the very young child provides the foundation for all further development.”

—Jane Knitzer, National Center for Children in Poverty, Columbia School of Public Health, 1998

Infants can’t develop without attention from adults. Simple interactions such as holding a child when she is crying, rubbing her back, and talking to her in a calm voice help her grow emotionally and socially. Without this kind of touch, babies literally starve for attention.

Studies have shown that without consistent nurturing care, an infant’s development will come to a halt—babies have been known to develop digestive problems and stop eating, and as the baby grows older he or she will begin repeating self-soothing behaviors like rocking.

“Because human infants are vulnerable and remain so for a long time, they rely incredibly on adults to protect and nurture them,” said Christopher Watson, coordinator of the Center for Early Education and Development at the University of Minnesota. “That’s why the concept of infant mental health is so important.”

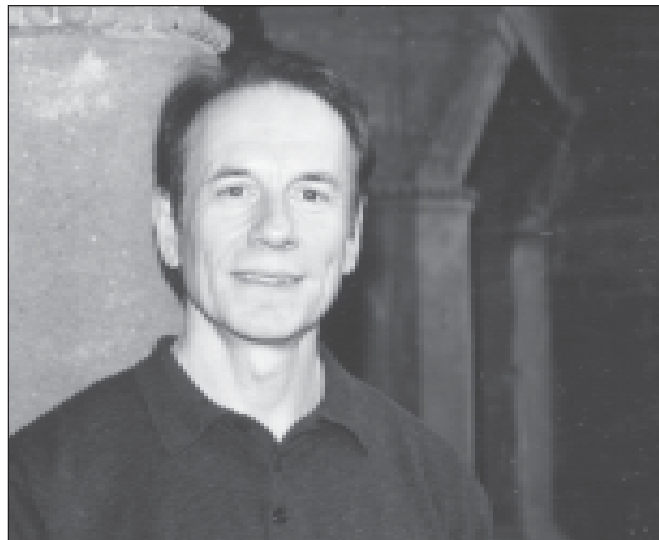
Infant and toddler mental health essentially means that infants and toddlers need to develop good relationships with their parents so that they trust that their needs will be met.

The reason for the recent emphasis on infant and toddler mental health is simple: families are under more stress than ever before and children have more non-nurturing stimulation around them, such as TV and video games.

“Traditionally, we’ve put skill-building ahead of parent-child interactions,” Watson said. “But parents are really the most important part of a child’s life. If parents recognize how important they are to their children, it is so empowering for them.”

All children need interaction and support to develop in a healthy way. However, Watson and others in his field believe that children with disabilities are at a higher risk for mental health issues. For example, a child with a communication barrier or a physical disability may have a harder time making friends, and may be less self-confident.

Parents and teachers who are trained to support children appropriately may be able to help them deal



Christopher Watson is the coordinator of the Minnesota Infant Mental Health Project and two other early childhood projects funded by the Minnesota Departments of Health, Human Services, and Education, as well as the coordinator of the Center for Early Education and Development at the University of Minnesota.

with new situations, feel more confident, and handle conflicts better.

“Our premise is that a child’s first job is to play and explore in a safe way,” Watson said. “Physical and emotional safety comes from adults. Parents need to know how important it is that a child has trust in other people, and that creates a basis for all other learning. Don’t rush ahead to teach your child to read without dealing with the basics of providing responsive caregiving, which sets the stage for later success in school, work, and interpersonal relationships.”

Note: Children can develop mental health disorders in spite of responsive caregiving. Many parents with children with mental health needs have had excellent parent-child interactions.

THE CENTER FOR EARLY EDUCATION AND DEVELOPMENT (CEED) at the University of Minnesota provides information regarding young children (birth to age 8), including children with special needs, in the areas of education, child care, and child development.

CEED has developed several on-line classes for people interested in topics such as “Bridging Education and Mental Health” and “Relationship-based Teaching with Young Children.” For more information, visit <http://education.umn.edu/ceed/default.html> or call 612-625-2898.

Meet the Staff: Coordinating PACER's EBD Project

Renelle Nelson heard about PACER Center 19 years ago from a neighbor bearing cookies as a welcome to the neighborhood. She saw Renelle's 3-year-old son having a major temper tantrum in the living room and knew that Renelle could use some assistance.

Renelle's ties to PACER strengthened as she attended workshops, trained as a volunteer parent advocate, and then became a full-time staff member. She is now the coordinator for the emotional and behavior disorders (EBD) project at PACER.

The boy throwing a tantrum in her living room has grown into a hard-working 22-year-old man, someone of which Renelle couldn't be more proud.

As a baby, Brett was affected by high altitude pulmonary edema—his lungs filled with fluid after traveling from a low altitude to the family's Colorado home at 10,000 feet.

"We didn't know the fallout of that," Renelle said. "We didn't know the damage to his brain. For most of his early childhood, we just had to go with what we saw."

Brett's disabilities include cognitive delays and mental health issues, including obsessive compulsive and anxiety disorders.

"Lots of behaviors kept Brett from being in the classroom without significant supports," Renelle said. "I worked hard with the school to make sure that Brett received services that were not only good for him but also supportive for his staff. Because of that collaboration, school staff would rise to the challenge of meeting his changing needs."

Now she is helping other parents who have children with EBD find the right services to ensure their children can stay in school and make progress. She said that many times parents don't know their children have the kinds of needs that could benefit from special education and related services until school starts.

"There is nothing in the law that says children must be screened for mental health issues," Renelle said. "And since it is not something you typically see, it is



Renelle Nelson

harder to identify and get your arms around. It's also not manifested until something triggers it. School is stressful for kids, and it can often be the trigger."

Comprehensive evaluations of children before they start school would be ideal, she said.

"Early intervention is the key to children's mental health just like any other disability," she said. "The earlier you intervene and receive support, the better it is for the family. Many children aren't identified until they start kindergarten."

Renelle also observes the stigma around mental health issues. She said that there is a sense that someone is to blame, even though blame is inappropriate. Renelle wants to focus on helping the child to reach his or her potential. To do this well, family involvement must be positive and meaningful.

Renelle and other staff at PACER are working to help parents to look at their child's behaviors in a different way.

"Early on it is important to identify the need, develop strategies, and recommend professionals in the community for parents to contact," she said. "People tend to see the behaviors and not the need. We must learn to ask, 'What are the needs? Is the behavior related to the need?' For example, a child may be throwing tantrums just before the reading group in school because he can't read and he would rather go to the principal's office than be embarrassed in the classroom."

Renelle knows that parents have a tough job. Not only may they be grieving about a recent diagnosis, but also it is difficult to "be proactive when your child's behaviors are in your face, intimidating, and threatening."

Renelle said, "We need to remember that children who have mental health needs are often the least understood by staff and families. These children feel vulnerable. We must give families the resources, information and support they need in order to support their children or youth in meaningful ways."

To find out more about PACER's EBD project, contact Renelle Nelson at (952) 838-9000.

Service coordination: Coordinators connect

After Jason was born, Sue and Steve Thoennes spent four hours a day for 14 months applying dressings to his body. Jason had to be covered in bandages from his neck to his feet, similar to treatment for a burn victim, because of a skin disorder called Epidermolysis Bullosa.

The Thoennes family had enough to worry about without having to make phone calls to clear up insurance issues, find therapists to work with Jason, locate nurses to help with dressing changes, and arrange for childcare for Jason's two older brothers while Jason's bandages were changed. Sue and Steve's time was spent finding appropriate pain medication for Jason, keeping Jason healthy because an infection can be devastating, going to all of the many doctor's appointments, and researching the disorder. These



Susan Adair

“ I like becoming involved at the beginning. It helps me to build a relationship with the family. „

—Susan Adair

parents were overwhelmed.

That's why Susan Adair, a service coordinator, stepped in.

The hospital had referred the Thoennes to Washington County's Early Intervention Network for information and services to support Jason's health and development. It is the central intake point for families in Washington County who have children with special needs, a diagnosis, or concerns about development from birth to 3 years old. As one of four service coordinators for Washington County,

Susan Adair helps to connect families with resources and services needed in light of a child's diagnosis or developmental delay.

Susan made many phone calls to line up childcare and nursing care and find answers to tough insurance problems. She listened to the family's concerns and tried to

Understanding Service Coordination

According to Part C of the federal Individuals with Disabilities Education Act (IDEA), each family with a child, age birth to 3, who has a disability or a developmental delay is entitled to a service coordinator who is responsible for coordinating all services across agency lines and serving as a single point of contact in helping parents obtain the services and assistance they need. Service coordination is free for families whose children are eligible under Part C—funding is distributed through the local Interagency Early Intervention Committees.

In general, service coordinators:

- Must be able to perform multiple roles in their work with families: these roles depend on family concerns, priorities, and outcomes.

- Must be able to act in a linkage capacity: service coordinators who do this help families become more knowledgeable about resources and service options, create opportunities for families to make informed decisions about the benefits and limitations of different options, link families with desired resources and services, and allow families to gain new skills.

- Should support and strengthen family functioning: a service coordinator's roles should support and strengthen a family and void the development of family dependence on a service coordinator or on service delivery systems.

—from the *National Early Childhood Technical Assistance System and Association for the Care of Children's Health*

families to needed resources and services

find solutions that worked specifically for the Thoennes family. Working together with a social worker and the South Washington County school team, Susan found funding for a special seated walker for Jason that could help him learn to bear weight on his feet. She also suggested music CDs that would calm him during the dressing changes. This funding was essential because the Thoennes family was spending \$5,000 a month on needles, bandages, and nursing care.

“I like becoming involved at the beginning,” Susan said. “It helps me to build a relationship with the family. Maybe the family just had a new diagnosis or they are spending time in the hospital with a premature baby. I can establish that I am someone who can help them through the maze—that they are not alone.”

Sometimes, a child’s disability requires a team of people to be involved, for example, school therapists, private therapists, a public health nurse, several doctors, and a social worker. Susan has set up e-mail groups so that everyone can communicate about medication doses and side effects, upcoming appointments, therapies developmental progress, and how things are going at home.

Even if there are fewer services to coordinate, Susan can help families fill out paperwork, coordinate transportation, and try to find funding for items not covered by insurance.

Susan’s effectiveness is apparent. She connects with families because it is obvious to parents that she cares about them and their children.

Susan knows that she’s helping families with the most important issue in their lives: “This is their child,” she said. “There is not a more sensitive, more emotionally charged subject in life.”



The Thoennes family: Adam, 7, Ethan, 5, Jason 3, Sue, and Davey, 17 months. Steve is not pictured.

Creation Station promises something for everyone

Whether a youngster’s taste runs to making brilliant beads for jewelry, decorating with stickers, or myriad other projects, PACER’s Creation Station, a place for arts and crafts, has something for everyone’s ability.

PACER staff members assist during Creation Station hours, but parents or other adults must accompany participating children to provide supervision. Activities last approximately 90 minutes. Activities are free, with donations toward materials accepted. Reservations are required.

The Creation Station will be open from 10 a.m. to 2 p.m. on Saturdays Aug. 16 and 23. September-May hours are the first and third Saturdays of the month from 10 a.m. to 2 p.m.

For information about the Creation Station and to register for activities, call PACER at (952) 838-9000.



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PACER is a coalition of organizations founded on the concept of Parents Helping Parents. PACER strives to improve and expand opportunities that enhance the quality of life for children and young adults with disabilities and their families. Partial funding for this Early Childhood Project is provided by Minnesota Department of Children, Families & Learning.

PACER’s Emotional and Behavioral Disorders (EBD) Project

Provides information and assistance to parents looking for how to access services for their children with EBD.
(952) 838-9000
www.pacer.org/ebd/index.htm

PACER’s Parent Partnership Project

The Parent Partnership Project for Children’s Mental Health helps families of children, birth to 21, who have emotional and behavioral disorders. Its mission is to teach parents how to access services and resources and how to be successful advocates for their children in educational, correctional, health, and social service settings.
(952) 838-9000

Children and Adults with Attention Deficit Disorders (CHADD)

CHADD is a national nonprofit representing individuals with AD/HD, and it provides education, advocacy and support.
(800) 233-4050
www.chadd.org/findchap.htm

Bazelon Center for Mental Health Law

Bazelon Center specializes in legal advocacy for the civil rights and human dignity of people with mental disabilities. The site includes many useful articles and a lot of important information.
(202) 467-5730
www.bazelon.org

National Alliance for the Mentally Ill

NAMI is a nonprofit, grassroots, self-help, support, and advocacy organization of consumers, families, and friends of people with mental illnesses.
(800) 950-6264
www.nami.org

Federation of Families for Children’s Mental Health

The Federation of Families for Children’s Mental Health is a national parent-run organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families.
(703) 684-7710
www.ffcmh.org