

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

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Early inclusion can teach children

By Beth Casper

Three-year-old Sarah Beddor started preschool last year in a program from which her older siblings had graduated. Sarah was the only child with a disability in the class. This year, she is one of two children with disabilities in the class.

Sarah's mother, Gail Dorn, is pleased with Sarah's inclusion in the classroom. "She is considered just one of the kids," Gail said. "She is comfortable and accepted, even with the other students' parents. She isn't singled out at all for having Down syndrome."

Sarah's place among her peers helps her learn valuable social and behavior skills that she may not learn from other children with Down syndrome. She is learning how to share and cooperate with other children, develop friend-

ships, and express herself.

For now, Gail feels it is more important for Sarah to work on social skills than be pulled away from her friends to work on speech therapy. That doesn't mean Gail has eliminated Sarah's early childhood services. She still has speech, physical, and occupational therapy, but teachers don't take Sarah away from activities with other students. Sarah receives speech therapy, for example, by herself and at a time when she wouldn't miss out on peer activities.

Gail believes, however, that including Sarah in every class with her peers isn't always going to be the most helpful for Sarah.

"I feel like I owe it to my child to help her meet her full potential," Gail said. "I want her to be accepted as a full member of society. When she is young, it is pretty easy for her to get along with the group and be included, but when she gets older I am going to have to question if it is in her best interest to sit through advanced algebra. She may need to work on skills that are more meaningful for her—how to count out exact change for a bus, how to cook, and how to behave in a job interview."

According to research from the University of North Carolina's Frank Porter Graham Child Development Center, inclusion for young children with disabilities is important for the same reasons Gail wants Sarah in an inclusive preschool class: Young children with disabilities learn adaptive, social, and communicative skills, as well as realistic life experiences. Students without disabilities learn more realistic and



Sarah, 3, laughs aloud while playing with her older sister's toys.

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Inclusion: Children learn how to develop language

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accurate views of people with disabilities, develop positive attitudes about people who are different from them, and see individuals who are successful despite challenges.

David Hertzog, now 6, spent the last two years in two programs—one where he was the only child with a significant disability and one designed specifically for children with disabilities.

In the community-based program, David, who has Down syndrome, was one of 30 children in a classroom with two teachers. Inclusion helped him learn how to interact with his peers and learn social skills. He was invited to birthday parties and to come over to play. He learned invaluable skills, such as taking turns and sharing, making and expressing decisions, sitting still while teachers explained a game or lesson, and self-monitoring of his behavior.

“It was realistic,” said Julie, David’s mother. “There were only two teachers so he wasn’t constantly looked after and prompted. Socialization was such a large part of the inclusive program, and, at an early age, inclusion is so important because so many attitudes can change. Kids ask questions, but once those are answered, they see children with disabilities as typical rather than atypical.”

The school-based program, especially for children with disabilities, was where David received speech,



Nick, 8, enjoys school when he is challenged. Being in a regular education classroom has encouraged Nick, who has autism, academically and socially. Here he plays a computer game with his mom, Jodi.

occupational, and physical therapy, and one-to-one attention from teachers.

“David needed the individual attention because he had significant delays that could be better addressed by trained therapists,” Julie said.

Julie and Gail emphasized that parents need to decide for themselves to what extent inclusion is appropriate for their child. What is most important is having the options and opportunities available for parents, they said.

Jodi Holstad, whose 8-year-old son Nick has autism, supports inclusion for her son. Jodi has seen the difference inclusion in the classroom and outside of school makes for Nick. He is learning appropriate social behaviors by being around children his own age, and he is being challenged in the regular education classroom. In the past, he was simply intolerant of different or new environments and wasn’t succeeding in school because he wasn’t challenged, she said.

Joey Stern, a 9-year-old with autism and mental retardation, spent his preschool year in an inclusive Montessori program. His father Mike Stern offered an example of how inclusion helped Joey: During circle time, a child with typical needs would try to pass an object to Joey so that it could continue around the circle. When Joey wouldn’t take it, the child next to him would just keep trying to give the object to him

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Sarah’s mother, Gail Dorn, plays with her.

skills, make decisions, interact with their peers

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until finally he took it. Joey learned the game due to being with typical peers.

Joey has learned other skills as a result of inclusion, said his father. “He rides a bike and swims like a little fish. That’s about being with kids with typical needs.”

John Hoffman, coordinator of PACER’s Early Childhood program, wants his daughter, Hope, who was born with spina bifida, to experience all kinds of “natural environments” where she can learn social skills with children her own age. John and his wife Yvette feel that the local park’s swings and sandbox, a neighbor’s child, and the nearby pond provide ample opportunities for Hope to learn how to make friends and interact socially, develop gross and fine motor skills, and build the skills that every child needs to grow up. They asked to have early childhood intervention specialists help Hope with skills, such as balance, at the park. They also want Hope included in regular education classes in school.

“Children with disabilities and special health care needs have every right to all community activities that are available if they didn’t have these needs,” John said. “They don’t have to be involved in every activity, but they have to have the options open to them.”

How does inclusion help?

The Council for Exceptional Children, Division of Early Childhood, defines inclusion as “a value, [which] supports the right of all children, regardless of their diverse abilities, to participate actively in natural settings within their communities.”

Inclusion can help children:

- make friends
- notice similarities between themselves and others
- develop better language and communication skills
- develop patience and compassion
- build interdependence and ability to deal with obstacles
- learn to accept others as they are
- learn to become more assertive
- learn by imitating others

What the law says....

Even though federal law does not use the word “inclusion,” it uses the terms “natural environments” and “least restrictive environments.”

For children under age 3, federal law (Part C of the Individuals with Disabilities Education Act) states that “to the maximum extent appropriate, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate.” (Sec. 303.12) “Natural environments means settings that are natural or normal for the child’s age peers who have no disabilities.” (Sec. 303.18) “States must include policies and procedures to ensure that the provision of early intervention ser-

vices for any infant or toddler occurs in a setting other than a natural environment only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment.” (Sec. 303.167)

For children over age 3, services are to be in the least restrictive environment, which, according to the law, means: “Each public agency shall ensure (1) that to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and (2) that special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”

Ask the expert: Exploring “natural environments”

Lynda Cook Pletcher, who has 25 years of experience in the field of early intervention, is the training coordinator at Connecticut’s A.J. Pappanikou Center for Excellence in Developmental Disabilities. The center was awarded a federal grant, “Project of National Significance: Early Intervention in Natural Learning Environments.” *Early Childhood Connection* interviewed Pletcher to learn more about the concept of natural environments. The following are her views.

Q What are natural environments?

Pletcher: Federal law, the Individuals with Disabilities Education Act (IDEA) Part C, states that early intervention services are to be provided in “natural environments.” The law states: “To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate.”

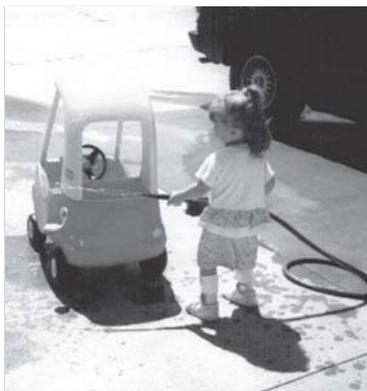
The language has created a sense that “natural environment” is only about a setting or a place where early intervention services are performed. However, I believe that natural environments are much more than settings. Natural environments are about all of the places, spaces, people, and activities that promote learning for young children. Our project uses the term “natural learning opportunities” rather than “natural environments” in an effort to help us think differently about how we provide early intervention services—not just where we go for those services.

Natural learning opportunities are as diverse and numerous as the wide, open world. We are talking about things that interest the child and things that interest the family. Think about the activities that promote growth and developmental changes in a normal fun way. For example, a family that lives near a

big park loves to swing, play in the park, walk to the park, and use the park swimming pool. Identifying these family activity settings helps parents and professionals see the learning opportunities for this particular child and family. A child can learn balance on a swing, social skills by interacting with people in the park, a sense of direction by walking or using a wheelchair to go to the park, and gross motor skills while in the swimming pool.

The common way of doing early intervention is for a professional to come into a family’s home or childcare setting for an hour a week to teach the child or do therapy. Instead of participating, the parents do something else while the child is receiving therapy. Because it is in the home, not a clinic or special classroom, we think we are providing services in a natural environment.

The concept of natural learning opportunities presents a fundamental shift in the role of the service provider and the way we do things.



The Hoffmans had tried unsuccessfully in physical therapy to have their daughter Hope stand by herself for 3 seconds. But when Hope began washing her own car (after watching her dad wash his car), she balanced for a full 8 seconds because she was interested in the activity.

Q What are the benefits of a child learning in a natural environment?

Pletcher: The benefits of learning in a natural environment are similar to those of learning in an inclusive environment. For example, it is ironic to put a child with language delays in a classroom with children who do not speak and expect him or her to talk.

The drawback for families who are segregated from typical experiences is that they can’t participate in the natural things they love to do. Infants and toddlers generally don’t spend a lot of time in segregated programs. They spend a majority of their time at home and in their community with families—their natural environments.

All children learn best if they are motivated. If a child wants to look at a book 20 times, parents and professionals should try to build learning opportunities around that activity. Pick out activities that the child

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Calling parents: Opportunities to make a difference

By Beth Casper

Veneta Lykken's involvement in the Governor's Interagency Coordinating Council on Early Childhood Intervention (ICC) will have no direct impact on her own children, but she knows that her work will pay off for the thousands of families who now have infants and toddlers.

Minnesota's ICC advises and assists the Department of Children, Families and Learning about early intervention services for young children with disabilities (or at risk for disabilities) and their families in the state. The ICC makes recommendations to the governor, the legislature, and the state agencies serving infants, toddlers, and young children with disabilities and their families.

Veneta, a Minneapolis resident who has five children ages 6 to 21, is beginning her third year on the council this fall. She hopes that her enthusiasm will draw new parents to the council, especially parents of children ages birth to 7.

"It's always good to hear from new voices and to think in different ways," Veneta said.

Veneta said she has learned about politics, the state's budget process, and how to approach the legislature about early childhood issues. She has also worked on developing the Individual Interagency Intervention Plan (IIIP), which reduces paperwork for parents whose children receive services from multiple agencies. The ICC has also helped launch a secure Web-based system for Individualized Family Service Plans (IFSPs)

The ICC meets once every other month for about five hours. New members attend an orientation and are helped by a mentor. For information on how to apply, call Judy Swett at PACER at (952) 838-9000 or call Jan Rubenstein at (651) 582-8436 or e-mail Jan.Rubenstein@state.mn.us. For more information, visit <http://cfl.state.mn.us/ecfi> and click on the Part C button. Parents are also encouraged to apply to their local Interagency Early Intervention Committee (IEIC).



Veneta Lykken hugs her 8-year-old daughter Roxanna, who has been diagnosed on the autism spectrum. Veneta has four other children as well—her youngest is 6.

and IIIPs so that parents can eliminate redundant data entry and team members can access the plans to coordinate delivery of services and provide up-to-date information.

Veneta knows that her time on the ICC is well spent.

"I wanted to learn more about how the system works and decisions are made at the state level," she said. "I thought I could pass that to the local level while making sure that parents' voices were represented at the state level. This is how I could give back for all of the support I received when my kids were young."

Veneta served on the Minneapolis Interagency Early Intervention Committee (IEIC) for 5 years before being appointed by the governor to the ICC. IEICs are local coordinating councils made up of parents and representatives of the school district, other agencies, service providers, and county government. They plan and coordinate their community's system of early intervention services. The 95 IEICs in Minnesota apply for funding through the ICC.

"No matter what is being discussed at the ICC meeting, it still comes down to children and families," Veneta said. "I am not expected to know everything, but what I can contribute is a parent's voice and I can ask questions. There are a lot of conversations about theory and practice. As a parent, you bring the reality to the table. You can tell people what is really happening out there."

Meet the staff: Virginia Richardson's visionary thinking

By Beth Casper

Virginia Richardson, one of the first people trained at PACER to conduct workshops for parents, began working as a PACER parent advocate in 1980. She had served on the organization's board as a member and board chair for two years. Virginia is now the parent training manager of all of PACER's parent advocates.

It is her daughter, Debbie, however, who gave her the expertise and crucial insight to help parents for the last 22 years.

Debbie was diagnosed with mental retardation and epilepsy as a toddler. In the early '60s, Debbie's neurologist told Virginia that there were two competing philosophies for educating a child like Debbie: either place her in a segregated classroom with children with similar disabilities or keep her in a regular education classroom for as long as possible.

Most of Debbie's schooling was completed before the Individuals with Disabilities Education Act (IDEA) was passed, but Virginia and her husband didn't need a law to know how they felt about Debbie's education.

"Even though the psychologist and social worker came to our house and told us Debbie was severely retarded, we choose to keep her in the regular classroom for first grade," Virginia said. "Much to everyone's amazement, Debbie learned to read and write in first grade."

Virginia and her husband, Sam, were visionary in their thinking about Debbie's education, at a time when information was much harder to find.

"The availability of information nowadays is staggering to me in a hopeful sort of way," Virginia said. "When professionals gave Debbie the label of mental retardation, I went to the library and found a book with less than a page of description about her disability. I



Virginia Richardson is PACER's parent training manager.

firmly believe that information is power. Some parents are two steps ahead of where I was when Debbie was growing up. I've seen parents find information on methodology or the child's disability that the professionals weren't aware of at the time."

Virginia recognizes that other changes within the early childhood system are now better for parents and children with disabilities. She said that she appreciates that Minnesota made the decision several years ago to start serving children from birth, instead of 3 years old and up.

"Many states weren't doing that, and still aren't, so parents in those states who need services for very young children may have to use county services," she said. "The

availability of county services can vary greatly from county to county."

Early on, Minnesota parents of children age 5 and younger were included in the planning process of the early childhood intervention system. Virginia said she thought at first that this was expecting too much of young parents of children with disabilities.

"It's difficult for parents of young children. They are dealing with the child's disability, the emotional impact of that disability, and the additional responsibilities, and added to that they are asked to be a part of a planning council with people who know the system and understand the language of Early Childhood," she said. "But then I changed my mind. Parents may not know how to plan an early intervention system, but they do know what outcome is right for their child and if the system outcomes are right for other children and their families."

Virginia said that there are some areas that need improvement, however.

"While I think things are improving, there still needs to be work on cultural competency for early childhood professionals," Virginia noted. "There is much more diversity in families than when I began working in this field 20 years ago. There needs to be a new level of

has helped thousands of parents and their children

understanding for professionals who work with these families, as well as more diversity in the staff who work with families. Staff that are going into the homes of families needs to be extremely respectful.”

She said that it is important that professionals understand that they need to learn from families and not just view families as learning from the professional.

She also wants opportunities for families to be able to connect with other families in similar situations. In the first few years of a child’s life, she said, sometimes families aren’t interacting with anyone else but the professionals who work with the child.

“I always found that I received the best coping information from other parents,” Virginia said. “It would be helpful for parents to be able to connect with other families in the same disability group. Parents now can call PACER for this information.”

People who offer resources to families need to verify that the resources are legitimate and worthwhile, she said.

“When I refer parents to a resource, I want to know exactly what parents will find there. Some people are indiscriminate when offering resources, and many parents spend a lot of time chasing resources that they can’t qualify for or are not suited to their needs.”

Virginia hopes that some of her experiences will help

other families just beginning their journey with a child with a disability.

“I really worked hard to manage my own fears so Debbie’s life wasn’t limited by my fears,” she said. “Because of Debbie’s seizures, the school wanted her to take the bus to school. My husband and I chose to have Debbie walk with her brothers and sisters. We made the decision and then we assumed the responsibility.”

“In the same way, I tried to separate my issues from Debbie’s issues. Debbie isn’t fearful. One thing that was extremely helpful was that I taught myself not to worry in 2-minute increments. I worked my way up to 30 minutes by the time she moved away from home.”

She also cautioned parents not to jump to make a decision before a decision needs to be made.

“If I have to make a decision on an IEP [Individualized Education Program], health care, etc., I find out when I have to make that decision,” she said. “I collect information, then I make the decision by the deadline based on the information I have at the time. I don’t go back and second-guess myself about decisions.”

PACER staff, many of whom are parents of children with disabilities, are available to help families with children with disabilities. Call 952-838-9000.

Ask the Expert: Continued from Page 4

loves to do and build on those individual interests rather than designing a program that is the same for every child.

Q How do you encourage parents and professionals to think about natural environments?

Pletcher: Families and professionals need to have on-going conversations about the family’s favorite settings and activities. Service providers then work with the child and family to design intervention strategies so the child is successful.

By combining the wealth of family information with the expertise of professionals, a child can meet goals and objectives while performing daily activities.

A physical therapist may go to the park with the family to offer suggestions about activities that help the most with balance. Maybe the existing swing doesn’t work very well with the child, but the professional can show the parents how to adapt it to work on balance.

Using natural environments ensures that therapists and teachers are also seen as family partners and coaches. The fear people have is that the burden is back on the family—but not if this is a true partnership between early intervention and the family. It is not about placing all of the responsibility on the parent or adding more activities to the parent’s busy schedule. It is not training the parent to be a mini-therapist or interventionist. It is using the entire community, of which an early intervention provider is only a part, to truly nurture, support, and help the child grow and learn.



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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.

Resources

Families with young children often look for good books, videos or Web sites for reliable information. That's why PACER staff members who work with young families are offering some of their suggestions. *PACER Center does not necessarily endorse any of these resources.*

Video:

"Welcome to My Preschool: Communicating with Technology" by the National Center to Improve Practice in Collaboration and the Center for Literacy and Disabilities. \$29.99.

Order at www2.edc.org/NCIP/ and view a video clip at www2.edc.org/NCIP/tour/toc.htm

Book:

"Delicate Threads: Friendships Between Children With and Without Special Needs in Inclusive Settings" by Debbie Staub. Published by Woodbine House in 1998. \$16.95. 250 pages. Order at www.woodbinehouse.com.

This book, which won the 1999 Parents' Choice Award, follows the

friendships of seven pairs of children—each one including a child with a moderate to severe disability—for almost three years. Through the author's eyes, the reader finds out how these friendships develop and compare to friendships between typically developing children.

Web sites:

www.nectas.unc.edu/inclusion/
The National Early Childhood Technical Assistance Center Web site includes information on natural environments and inclusion—from state and federal laws to research.

www.projectexceptional.org
Project EXCEPTIONAL Minnesota is a statewide network for promoting and supporting inclusive early childhood and school-age programs and providers.

www.pacer.org/parent/childhood/index.htm

PACER's Early Childhood Web site lists upcoming workshops, relevant research, past issues of the newsletter, and services provided by PACER.