Welcome to our new, updated version of Delaware: A newspaper for people with disabilities, their families, and the professionals who support them. Delaware has always been a newspaper of stories—five families offer a window into their homes and their experiences and talk about what the things they need. We believe this is a more powerful way of defining family support than a standard page of text. You’ll note the difference between the families of young children and the families of adults. We have come a long way, but we’re not there yet!

This edition also highlights Delaware services and supports for the families of persons with disabilities. Because of the limits on space in this edition, our descriptions are by no means complete. Finally, forty-two states have planning grants for family supports funded by the Administration on Developmental Disabilities (ADD). These grants are designed to improve current services, increase collaborations across agencies, and identify systems gaps that make it hard for families to get services. The CDS, along with many other partners and state agencies, has submitted a proposal for Delaware. If funded, we want to encourage any individual with a disability, or his or her family members, to participate in the actual planning process. Please contact me at (302) 831-4850 or tel/911@udel.edu for more information.

Enjoy the issue.

Sincerely,
Theda M. Ellis
Editor

Real Needs of Real People

In the last issue of Delaware: A newspaper for people with disabilities, their families, and the professionals who support them, Anna Wise, Delaware’s mental health advocate, wrote about the need for a comprehensive community mental health services program for children and their families. Anna’s five-year grant awarded to the Division of Child Mental Health in 2000, our second year, has been extended to the Division of Child Mental Health. Now in its second year, their Sussex County Parent Advisory Council has worked with the Parent Information Center of Delaware to identify the needs and goals of families who care for children with disabilities.

Real Needs

• An increased amount of more flexible respite services provided in the home
• Child care in inclusive settings, staffed by trained, sensitive, and competent personnel
• After school, Saturday, and summer recreation programs for all ages
• A system of care that is responsive to families and needs
• Improved interagency collaboration, especially at times of transition
• Collaborative problem solving involving families, professionals, educators, and appropriate therapists (Families want assistance that goes beyond just giving suggestions.)
• Professionals who are prepared to meet with families so information does not have to be repeated
• Providers respect families’ contributions, time, situations, and feelings
• Information from providers regarding the different service systems and the expected roles, rights, responsibilities of families, and professionals in these systems
• Advocacy programs for families whose children are involved in the Juvenile Justice System
• Financial assistance for extended families who care for their children’s children who have disabilities
• Outcome based and effective services across the life span
• A massive educational program to sensitize the community at large (particularly teachers, physicians, school staff, and legislators) to invisible disabilities
• Encouragement of employers to offer flexible hours, job-sharing, and leave for families who need to care for their children with disabilities

Real People

To put a human face on what families need, we asked Beth MacDonald of Family Voices and Gary Heckert, president of The Arc of Delaware, to share some of their own experiences as parents.

The MacDonalds

A time of high stress for Beth is when her 12-year-old daughter, Lizzy, who has SED Congenita, a form of dwarfism, is admitted to the duPont Hospital for Children for an extended stay. “The time to make daily trips to the hospital has to come from somewhere,” Beth explains. Ronald McDonald House is great, but I can’t leave my son to go stay there for a month. It takes all the time I normally use to do the laundry, fix the meals, and spend time with my son to go to the hospital every day.” And it doesn’t stop with the hospital stay.

“When Lizzy came home from surgery with a full body cast and a halo, I had to stay home and take care of her.”

Money becomes another major issue for families during these times. “Those daily trips to the hospital require a lot of gas and childcare for the other children,” Beth suggests that temporary assistance with food stamps can help families during these periods. “I gave up my career to take care of my daughter. We are not asking the state to be caregivers for our children. It would be nice to know that I don’t have to go hat-in-hand to everyone to do that.”

The Heckert

Gary Heckert’s wife, Barbara, left her career to care for their 17-year-old son, Gary Jr., because his needs are intense as well. “Gary Jr. doesn’t speak and he liked to run off,” according to his dad. “We were never able to find childcare or even after school programs that would deal with his running away”.

Continued on next page
Brian Hansel was born with Down syndrome three years ago. “It took some time to adjust to the shock when the doctor told me,” says Brian’s mother, Mimi, “but he put me in touch with the state. It was a good thing because I didn’t know anything about disabilities and what my son needed. My first son, J.D., was born without disabilities. “Within five days of Brian’s birth,” continues Miami, “he needed open-heart surgery and was transferred to it, the job is jeopardized. However you look at it, the job is jeopardized. What parents want Again, Gary and Beth add a personal touch to the list at the beginning of this article. Gary is clear and concise. “My vision is consumer-controlled spending,” he says. “I want resources available to my son that my wife and I can direct and control. In the past, parents took whatever was offered. That day is ending. Younger parents want more for their children. We need to start dialogues with the governor and the state to talk about ways to get the most service for the funds that are within the budget guidelines.”

A priority for both of these parents is information and support. “A criminal gets more counsel for his rights under Miranda than parents of children with disabilities get,” we have trouble getting information about how to get services and what our rights are,” according to Gary. Beth wants peer support. “As a parent, I need support. Who can I call for help? No one understands like another parent.” She thinks that parents cannot take advantage of support because of the need for qualified childcare. It’s either too expensive or it’s not available so I miss a lot of meetings.” A second barrier to peer support is confidentiality. “If you meet someone, they’re not going to share the information with other parents.”

“Vision for the future Finally, what do these parents want for their children? Beth assures Gary will go to college and have a career. She will want friends, and she’ll need support to attend school, to work, and be independent. Gary, Jr. also looks forward to adult life. “We need a system that understands that life doesn’t stop at age 22 when Gary and his peers leave the school system,” his dad says, “We are working very hard to make sure that in four years, Gary will not become an official non-person. We need a system that understands what people really want and need, and that encourages the individual to continue to develop as a human being.”

In the early Spring of 2001, two Delawareans celebrated birthdays: Brian Hansel turned 3, and Kim Waninger met a life milestone at 21. Both children have disabilities, both have families that love them and want the best for them—and both have thrived when the system of supports and services has worked for them. And this is where their similarities end. Through the voices of the people who speak for them, Brian and Kim tell a story about family support that’s as contrary as their 18-year age difference.

More real people Two more families, two more stories of family support

Two more families, two more stories of family support
The Delaware Foundation of Syndrome Congress (NDSC), the National Down are the National Down the state and national levels

Marni sits on the other hand, Marni sits on the convince us in Pittsburgh. And as a member of NDSS, Marni will attend a conference in San Diego CA. The meeting of national membership will make her put in touch with a lot of information and new resources, but it also will put a strain on her family while she’s gone.

“Family support is like a double-edged sword,” says Marni. “It’s a blessing and a curse at the same time. I feel over-committed. I think it’s very important that families have what they need to support themselves, but a lot of support is overwhelming, pulling at your time.”

In contrast, Lee and Dorothy Waninger would love to know what too much support feels like. Their responsibilities as parents, teachers, and advocates wear them down.

“They have to fight to meet all their daughter’s needs, even for a personal attendant to assist Kim when she came home from school.”

Recently, the Waningers had’t had a night to themselves, alone, without their three children, in a long time—and their second daughter could tell “Megan told us, ‘Gosh, I’m so tired,’“ says Dorothy. “I’ll watch Kimmy and (younger brother) Brent.”

“Both Megan and Brent can tell when we need to ‘back off,'” says Lee, “and they offer help. We know how responsible and capable both of our younger children are, but we tell them Kimberly’s not your responsibility. She’s ours—and then, we went out to dinner.”

The learning component of family support

Like Lee and Dorothy Waninger, Marni Hanel is also a teacher. With a masters degree in education, Marni decided to home-school her son with disabilities for the same reason she teaches her eldest son, J.D., at home and will teach her one-year-old Jimmy when he’s old enough: “because we’re Christians,” says Marni, “and we want to teach our children our value system.” As a result, Marni has already begun research to support her educational choice for Brian.

In comparison, Kim Waninger began her education at the Charles W. Bush School when she was 3. Right away, her parents were paired with some of the school’s choices for Kim’s education. After the Waninger’s went to work for teachers, they had nothing when some of the school’s suggestions sounded wrong to them. “We figured ‘Hey! They’ve got the special-ed degrees. They should know’,” explains Kim’s father. “But for years, Kimmy made no gains. This IEP (individualized education plan) was the same year after year.”

“When we went through parent contacts,” adds Kim’s mother, “that we learned about PIC (the Parent Information Center) and the Disabilities Law Program. The information and training offered by these programs gave us the knowledge we needed to advocate for Kim.”

“We started our process to get Kimmy into John G. Leach School,” continues Lee. “That was seven or eight years ago.”

“Then,” notes Dorothy, “we had to push Leach to push our daughter when she didn’t want to do something. Her disability is such that she will just sit if left alone, and she needed to be taught how to respond appropriately to direction. Over the years, we haven’t necessarily agreed with Leach, but we’ve earned each other’s mutual respect. The staff at Leach became the first to fight for our daughter’s needs.”

Today, Kim Waninger is 21, a beautiful young woman with some physical challenges and the cognitive ability of about an 18 month old. In the years leading up to her graduation from the Leach school, the issue in the Waninger home became the value of post-21 programs. Lee and Dorothy researched three states for progress-oriented programs, and what they found shocked them. Not only is Kim no longer entitled to a continuing education, but a suitable educational program doesn’t even exist.

“The needs don’t change,” stresses Lee. “How the needs are viewed change dramatically though. There are two camps concerning the needs of children with disabilities. In the first, basically, you’re entitled to progress, getting an education until 21 through the IEP process.

“In the second camp, the state and provider, the focus changes from progress to glorified babysitting. There’s no learning as a component. We found nothing in three states comparable to what Kimmy had at Leach.”

Examples of Family Support Services

For persons with a disability

• diagnosis and assessment
• family counseling
• home health care

For family members

• information and referral
• service coordination
• temporary relief/reprieve
• family counseling

A newspaper for people with disabilities, their families, and the professionals who support them

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A newsletter for people with disabilities, their families, and the professionals who support them

RESOURCES

Family Support America (FSA) promotes family support as a nationally recognized movement to strengthen and empower families and communities to maximize the development of children, youth, and adult family members. Financially supported by the Robert Wood Johnson Foundation, FSA is building family support state by state. To date, ten states participate. Delaware is not yet part of this network of states.

FSA Principles

• relationships with families based on equality and respect
• growth and development of all family members encouraged
• families become resource for their own members, other families, programs, and communities
• support is culturally, linguistically, and physically integrated to enhance functioning in a multi-cultural society
• participate in and contribute to community building
• advocate for services that are fair, responsible, and accountable to families
• mobilize informal and informal support resources for families in need and continuously responsive to emerging needs of families and communities

These principles are applied to all FSA program activities, including planning, governance, and administration. For more information about Family Support America, www.familysupportamerica.org, telephone (312) 338-2002.

The National Center for Family Support (NCFSS) at the Human Services Research Institute provides technical assistance to 42 states that have Administration on Developmental Disabilities (AID) Family Support Planning grants.

NCFSS Principles

• Family driven: Each family decides the type and amount of support they receive.
• Easy to use: Families are not overwhelmed by paperwork and red tapers.
• Flexible: Families choose supports and services they will use.

NCFSS Goals

• Keep family together until the person with a disability chooses to live independently
• Enhance family’s ability to meet the needs of the family member with a disability
• Improve quality of support to families while minimizing the need and cost of out-of-home placement
• Allow family to participate in integrated leisure, recreational, and social activities
• Make a positive difference in the life of the person with a disability as well as the lives of all family members

Delaware

The Delaware Foundation of

Delaware

Retarded Citizens, which grants the funding needed to send Brian to special-

ized day care schools. However, in turn, the Hanels recently had to carve time out of their hectic schedules to attend an NDSC convention in Pittsburgh. And as a member of NDSS, Marni will attend a conference in San Diego CA. The meeting of national membership will make her put in touch with a lot of information and new resources, but it also will put a strain on her family while she’s gone.

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Examples of Family Support Services

For persons with a disability

• diagnosis and assessment
• therapeutic services
• medical/dental services
• recreational opportunities
• special clothing and diets
• adaptive equipment
• housing adaptations
• adequate health insurance

For family members

• information and referral
• service coordination
• temporary relief/reprieve
• parented/bilingual education
• day or family member care
• financial assistance
• financial planning
• mutual support groups
• housing accommodations

Post-21 programs don’t want to hear that technology exists,’ says Dorothy, “and don’t want to use it because there’s no money and no time. For the most part, I believe they don’t want to be bothered. Having a child with a severe handicap is frustrating...
Two more families...  

Before children and adults with disabilities had a voice in our society, meeting their needs was often difficult and frustrating for their families. These families did the best they could, sometimes fighting the system that’s supposed to help them. Now that the parents or unpaid caregivers in many of these families are aging, their concern is voiced in a frightening question: Who’s going to take care of our children when we can’t anymore?  

An answer in trust  

When Jim was in the second grade, the family moved back to New Castle County. Jim was again assigned to “regular” classes. Everywhere his mother looked, support was elusive.  

“Independence doesn’t enter their minds,” continued Dorothy. “Part of the transition to post-21, we were told—‘You will see regression.’ You’re not going to change the mindset. Our philosophies are so different to the providers. You work really hard to meet your child’s needs for 21 years; then, all you get is adult day care. But all the supports and programs are shut down.” (Delaware Elwyn has not taken new people in a couple in a couple of years.)  

Building their support structure  

At about the same time Marni Haimowitz had a similar experience. Marni and Lee and Dorothy discovered “family support” in a recently organized group of local par- ents, teachers, administrators, and therapists. Advocating for a progressive post-21 program, the group laid the foundation for Collaborative Efforts to Reinforce Transition Success (CERTS). This model would continue the program established by the John G. Leach School.

To date, the proposal for continuing education has been written and reviewed and continuing education has been provided. Advocating for a measurable post-21 program, the group laid the foundation for Collaborative Efforts to Reinforce Transition Success (CERTS). This model would continue the program established by the John G. Leach School.
Spansing a spectrum of need

In January this year, Betty was finally admitted into Family F. Russell Hospital, and the staff immediately started preparing her for release. Unfortunately, at the same time, Betty began to experience terrifying panic attacks. “She calls all the time on the cell phone we gave her since the panic attacks started,” says her worried father. “She’s needed to go to the emergency room four times in the last two months, twice because she has seen on her own that they look like hallucinations and twice because of the panic attacks!”

After four decades of feeling alone in the care of their children, Jon and Patricia Ayres are keenly aware of the level of support Betty and Jim have come to expect from them. Because of this understanding, their parents continue to voice their concerns. At a time when they should be thinking about retiring, they work to support not only their children with disabilities but also other families in their area. The Ayres advocate for a central source of information, a guide that explains each specific disability, the needs of someone who has that disability, and how to meet these needs. Jon and Patricia joined the teaching staff of the National Alliance for the Mentally Ill’s Family-to-Family Education Program; and set up a Delaware CarePlan for Jim and Betty.

For more information about Delaware CarePlan and the support it can provide your family, call (822) 633-4020.

Continued on next page
programs aimed specifically at helping the family smile: “My job is advocacy for people with mental retardation and other developmental disabilities, which means helping the family get what it needs. A big piece of my job involves information and referral. I also provide case management for 32 Delawareans with disabilities.” Nock oversees a range of tasks, from helping with budgeting and financial decisions to taking someone to a doctor’s appointment.

“When a family calls,” continues Nock, “it needs assistance in many areas, like in obtaining housing or employment for a family member with disabilities. For us to be able to help this family, it needs to be in the DDHS system. We make sure the family enrolls with DDHS so they can take advantage of programs and agencies in the community.”

Besides their more traditional housing and employment programs, The Arc offers the Friend-to-Friend Program. Working like Big Brothers-Big Sisters of Delaware, Inc., The Arc introduces an individual without disabilities to a consumer and schedules a social calendar for the pair of new friends. They meet for three to six hours a month for at least 12 months. The program takes the responsibility of creating a social life off the parents and family and joins two people with a lot to offer each other.

Currently, 62 consumers enjoy the program. “One frustration right now,” explains Nock, “is that volunteers are down. We need more people without disabilities to volunteer their time to meet the need and take the pressure off Delaware’s families.”

The Parent-Mentor Program is a volunteer success story. The Arc pairs up parents who are new to the disabilities field with mentors (or other parents who have experience with disabilities and the state’s system of supports and services). Mentors must complete three months of training before being paired with a new parent. To date, the relatively new program has 17 pairings across Delaware’s three counties. Having a mentor comes in handy for any new parent experiencing discrimination for the first time, for example, or learning what to ask for and where to go to get a child’s needs met.

Having a mentor cuts the frustration level for the entire family.

Finally, the Arc offers the Parent-Education Program. Teaching parenting skills to single parents who have disabilities, The Arc currently trains 15 mothers in this program. The classes range from discipline techniques and parental responsibility to nutrition and health care. Once the parent graduates from the six-month program, she is awarded a certificate of accomplishment. The Arc then directs her to Child, Inc., an advocacy program that helps the parent work with other agencies on her child’s behalf.

If you are interested or know someone who may benefit from any of the programs offered by The Arc of Delaware, call (302) 996-9400.

And what else is happening in family support?

The need for family support is not limited to families of individuals with disabilities. Scott Ross, Administrator of the Office of Prevention and Early Intervention within the Division of Family Services, calls family support a menu for families that they create. “We work to give options to parents to build their own support networks with each other. For instance, we are writing a grant for foster parents to do family support programming. If funded, it will provide resources for foster parents to use in order to support their families as they see fit. Parents are helping us design the system.”

Ross describes two family support programs offered through the Division of Family Services.

The first, called FACTET (Families and Centers Empowered Together) targets families of young children. Located in four childcare centers around Delaware, including the Latin American Community Center, West Center City Day Care, Mary E. Henning Child Care Center, and Hickory Tree Child Care, all parents of young children in the childcare center are invited to participate. A parent council, working with a full-time coordinator, has a budget to do activities that they choose.”

There is also a resource library of books, toys, games, and educational items for families to use. Childcare is provided for evening meetings and programs. “We are finding that parents who join councils are learning to deal with their child or children in very positive ways. They are truly becoming empowered,” reports Ross.

A second program for families of children who are 8-15 is Families Matter! To participate, these older children must participate in a community youth program. Like FACTET, there is a parent council, a coordinator, and a budget for activities. Families Matter! are in 11 sites across the state.

For more information, contact Lynda Hastings, Office of Prevention and Early Intervention at 892-4302 or lhasting@state.de.us.