

Families list their needs for support .....page 1

Two family stories, two different experiences .....page 2

Family support principles and resources .....page 3

State agencies describe their family support services .....page 5



ABOUT THIS ISSUE

Welcome to our new, updated version of *delAWARE*. *delAWARE* has always been a partnership between the Center for Disabilities Studies (CDS) and the Developmental Disabilities Council (DDC). This year we are welcoming a new partner, MBNA. The Helen F. Graham Grants Program of MBNA is funding *delAWARE* for the next three issues. We want to express our great appreciation to MBNA for this year of funding.

We also hope you enjoy our updated format. It's a little zipper with more graphics and photos. We will continue in our tradition of highlighting issues and information about the needs of Delawareans with disabilities and the supports and services available to them.

Additionally, the Center for Disabilities Studies has a new product, *delAWARE*, A *Research Brief*. Each issue of A *Research Brief* will focus on a single area of research. It may be original research conducted at the CDS, or it may be a summary of national research on a single topic, like our first issue on staff retention and training. Together, these two publications should provide members of the disability and greater communities with up to date information about needs, research, services, and supports in specific areas.

This edition focuses on family support by bringing you a variety of family stories. Just what is family support? That's an interesting question, and one that is not easily answered. By sharing their

stories, five families offer a window into their homes and their experiences and talk about the things they need. We believe this is a more powerful way of defining family support than a standard article. 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 support funded by the Administration on Developmental Disabilities (ADD). These grants are designed to improve current services, increase collaboration 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) 831-4450 or tellis@udel.edu for more information.

Enjoy the issue.

Sincerely

Theda M. Ellis  
Editor

*delAWARE* is sponsored by the University of Delaware's Center for Disabilities Studies and the Developmental Disabilities Council and funded by the Helen F. Graham Foundation. Comments may be made by calling (302) 831-6974 or TDD at (302) 831-4689, faxing (302) 831-4690, or writing to Ms. Theda M. Ellis, University of Delaware, Center for Disabilities Studies, 166 Graham Hall, Newark DE 19716-3301.

Editor: Theda M. Ellis, Associate Director, Center for Disabilities Studies; Copy editor: Nina Leech; Reporters: Theda M. Ellis, Carla Koss; Design & Production: Cindy Dolan

# Real Needs of Real People



In the last issue of *delAWARE*, mental health advocate, Linda Hance, wrote about Comprehensive Community Mental Health Services for Children and Their Families, a five-year grant awarded 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 of families of children with significant 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, and 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, the only help we had was a nurse overnight and one four-hour period during the week. Lizzie had to be turned constantly, and she went back to the hospital twice, so I could not work or go anywhere! 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 Heckerts

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

Continued on next page

Upper right photo: President George Bush with the MacDonald family during a recent visit to Delaware.



## Real Needs... From previous page



Gary Heckert Sr. and Jr. on a golf outing.

away. You can't lock the doors of a childcare center to keep your child safe. The result is that there have been only three times in his life when Barbara wasn't with him, and she worried the whole time and couldn't really enjoy herself." He goes on to say, "We're lucky! I have a good job and can support my family. Many families are not so lucky. Many parents lose a job they need because of the time it takes to care for a child."

Beth and Gary agree that respite continues to be a major need for families. When Lizzy gets sick, family vacations and Christmas visits are cancelled. "I took her to a five-day conference by myself. It was so demanding trying to care for her in a strange place, to get up, get ready, and go to meetings. I won't be able to do that again." Beth believes that respite would allow her to do things with her son, Joe, when Lizzy is sick. Gary agrees. "We have two other children who need time. The only respite we were offered was an overnight at Camp Fairlee Manor in Maryland. By the time I drove an hour and a half to drop our son off at noon on Saturday and returned to pick him up the next day at 1:00 pm, it wasn't much of a break."

A closely related need for families is home health assistance. A home health aide can assist with the personal care of dressing, bathing, and feeding that is needed to help a parent or allow the parent to go to work, go to the grocery store, and take care of other needs. Although the state offers home health assis-

tance to families, there is no one to hire right now. If a family is lucky enough to find an aide and the aide doesn't show up, Mom or Dad can't go to work. 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 peer 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. "The rules that were set up to protect individuals and families can now isolate them."

### Vision for the future

Finally, what do these parents hope for their children? Beth assumes Lizzy 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."

## More real people

# Two more families, two more stories of family support

*In the early Spring of 2001, two Delaware children 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.*



Brian Hansel was born with Down syndrome three years ago. "It took some time to adjust to the shock when the doctor told me," admits Brian's mother, Marni, "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 Marni, "he needed open-heart surgery and was transferred

baby daughter was a treat to show off to family and friends.

"Suddenly," remembers Lee, "at eight months, Kimmy began to show signs of something. She was eventually diagnosed as having microcephaly (an abnormal smallness of the head). We didn't know what to do. Groups work for parents who have children with Down syndrome because there are so many of them, but there are only, maybe, three children with microcephaly in the area."

"And there's no list of things that someone with microcephaly needs," adds Dorothy, "or directions on how to go about meeting those needs, what's available from the state, what Medicare and Medicaid can do. You learn indepen-



Dave and Marni Hansel with their family.

dently of one another. And we didn't know what to ask for. It was only in the last couple of years that we discovered that Medicaid would have paid for Kimmy's diapers, but we didn't know we had to ask for it—and they didn't offer!"

"Our faith really helped us at this time. We are active members of the Christian Community of Believers and attend Pike Creek Valley Baptist Church. This community is very helpful whenever Brian needs surgery."

For example, volunteers from the church came into the Hansel home every day following the March 2000 surgery. The church's volunteers scheduled their time so that someone was always holding Brian. Other church members volunteered their time to clean, cook, and help Marni care for herself and her family.

In comparison, Kim Waninger was born "normal" 21 years ago. Lee and Dorothy Waninger brought their first-born home from the hospital with no more than the usual first-time-parent jitters. Their

### A learning curve and a double-edged sword

Contrary to the Waningers' experience with their baby and the state, the Hansels receive a lot of aid from the system of supports and services. Combined with the support from their family and faith, the state helped the Hansel family understand Brian's special needs. "As Brian has gotten older," notes his mother Marni, "he has had a reduced illness level, and we manage better. The learning curve: Now, we know what needs a specialist and what is 'normal' kid stuff."

Marni recognizes that giving birth to a baby with developmental disabilities is more sup-

ported in today's society. She refers to her home-life as the "Hansel family support structure framed in 21st-century society." The borders of this structure are defined by supports that are key for people with disabilities to live independently in the community:

- people-first language
- better medical technology
- increased funding for programs that serve individuals with special needs
- laws, such as the Americans with Disabilities Act of 1990 and the Individuals with Disabilities Education Act of 1990 and Amendments of 1991
- an increased awareness of people with disabilities as valuable people
- inclusion and a leaning toward home-based life rather than institutionalization
- children and adults with disabilities featured in books, ads, and television programs
- an increased tolerance for difference, and reduced discrimination

Because many of these supports didn't exist when Kim Waninger was diagnosed with a disability, her parents feel that they have been fighting an uphill battle. "The nurse from (Visiting Nurse Association) told me early on," remembers Kim's mother, Dorothy, "that I'd have to be an advocate for my daughter. I've never forgotten that. How right she was! It's always a fight. If you don't network, you're sunk. I had to find out from another parent that extra speech therapy was available for my daughter."

"And Kimmy just had corrective surgery," adds Kim's father, Lee, "and requires a special \$400 chair to sit in. If the therapist at school hadn't told us about the chair, we wouldn't have known and would have undermined our daughter's recovery."

In comparison, Marni Hansel's well-defined struc-





The Waningers—Brent, Kim and Megan with Lee and Dorothy.

ture of family support lists all of the people, agencies, and services that have addressed Brian's special needs since he was born. In the medical column are First State Health Insurance, Brian's primary care physician and medical specialists, the staff at Alfred I. duPont Hospital for Children, and Medicaid. In the program column are the Division of Mental Retardation's respite care (which supplies money for baby sitters); Women, Infants, and Children; the Birth-to-5 forums; Early Educator; Nurses 'n Kids (which supplies physical, occupational, and speech-language therapists); and Child Development Watch.

All the activity around all this support felt like a juggling act for Marni last year, after the birth of her third son, Jimmy. "I get a lot of help, but it's time-consuming," explains the busy mother. "I'm grateful for all the services, but for about a year, therapists were coming every day of the week. I was crazy trying to coordinate all of these dates. Nancy Colley (the nursing program administrator for Early Intervention) coordinated these services for me through Child Development Watch."

Several other local, state, and national organizations also strengthen the Hansel family support structure but are time-consuming. On one hand, the Down Syndrome Association of Delaware is a major source of support not only from other families with children who have Down syndrome but also for information and much-needed grant money to send Brian to Gymboree. On the other hand, Marni sits on the association's board, a task that takes her away from home on a regular basis.

Also, helping the Hansels at the state and national levels are the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), The Arc of Delaware, and the Delaware Foundation of

Retarded Citizens, which grants the funding needed to send Brian to specialized day-care sessions. However, in turn, the Hansels recently had to carve time out of their hectic schedules to attend an NDSC convention in Pittsburgh PA. And as a member of NDSS, Marni will attend a conference in San Diego CA. The meeting of national membership will put her in touch with a lot of information and many resources, but it also will put a strain on her family while she's gone.

"Family support is like a double-edged sword," suggests 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've had 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 hadn't had a night to themselves, alone, without their three children, in a long time—and their second daughter could tell: "Megan told us, 'Go out to dinner,'" says Dorothy. "I'll watch Kimmy and (younger brother) Brent."

"Both Megan and Brent can tell when we need to back off," notes Lee, "and they offer help. We know how responsible and capable both of our younger children are, but we told them 'Kimmy'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 Hansel 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," states 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 puzzled by some of the school's choices for Kim's education. Although the Waningers are teachers, they said 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. The IEP (individualized education plan) was the same year after year."

"It was 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 due 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

### 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
- families' cultural, racial, and linguistic identities affirmed 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 served
- mobilize formal and informal support resources for families
- be flexible 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/](http://www.familysupportamerica.org/), telephone (312) 338-0900.

• • •

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

### NCFS 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 tape.
- Flexible: Families choose supports and services they will use.

### NCFS 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 supports to family 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

### Examples of Family Support Services

- For person with a disability*
- diagnosis and assessment
  - therapeutic services
  - medical/dental services
  - home health care
  - recreational opportunities
  - special clothing and diets
  - transportation
  - adaptive equipment
  - housing adaptations
  - adequate health insurance

- For family members*
- information and referral
  - service coordination
  - temporary relief/respite
  - family counseling
  - parental/sibling education
  - day or family member care
  - financial assistance
  - future financial planning
  - mutual support groups
  - housing accommodations

an education until 21 through the IEP process.

"In the second camp, the state and providers, 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 has had at Leach."

"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 frustrat-

Continued on next page



## Two more families...

From previous page

ing. The best-case scenario still doesn't meet her needs. She needs constant supervision because her attention span is 15 minutes. It took years to improve from her original 5-to-10-second attention span. And we had to fight for a full-time one-on-one aide. But the result—she improved from being nonverbal to purposeful communication, she's happy, she's doing laundry and can fill a soda machine and sort money. It's taken a long time to get her to this stage, and no one will continue the progress once she's graduated.

"Independence doesn't enter their minds," continues 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 than 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 suitable day programs are shut down. (Delaware) Elwyn has not taken new people in a couple of years."

A residential program is one alternative the Waningers have crossed off their list because the family wants Kim at home. "We do a lot of stuff together," explains Lee. "We all enjoyed white-water rafting together and canoeing, whale watching. Kimmy always goes with us. We're still a family unit."

## Building their support structure

At about the same time Marni Hansel gave birth to Brian, Lee and Dorothy discovered "family support" in a recently organized group of local parents, teachers, administrators, and therapists. Advocating for a progress-oriented post-21 program, the group laid the foundation for Collaborative Efforts to Reinforce Transition Success (CERTS). This model would continue the program established at the John G. Leach School.

To date, the proposal for continuing education has been written and reviewed and CERTS advocates are looking for funding. Hope runs high for a 2002 start-up date. For the Waningers, a support structure is being built. "We're moving forward," smiles Lee for the first time in a long time.

# And Once Our Children Have Grown

*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 caretakers 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

Thanks to a July 1998 statute enacted in the First State, one answer is Delaware CarePlan, Inc. A non-profit organization, Delaware CarePlan helps a family set up a trust for a child with a disability (a consumer). Defined, a trust is a legal relationship in which a person (or trustee) holds the title to property for the benefit of another person (or beneficiary). In this case, Delaware CarePlan acts as the trustee and the consumer is the beneficiary.

Because Delaware CarePlan acts as the trustee in each trust, the organization can provide goods and services that aren't covered by government programs, such as a birthday dinner or a weekly check at the consumer's home.

And inheritances can be designated specifically for the trust, a process that avoids turning off Medicaid payments. A plan of care continues to fill the needs of a consumer-beneficiary even if he or she receives the proceeds from an estate or the sale of the family home. Historically, this consumer would lose Medicaid and Social Security Disability Income benefits, and the estate proceeds had to be spent before the consumer could qualify for benefits again.

The goal of each trust is to carry out the plan of care, the consumer's specific needs, when the parents or caretakers can no longer meet those needs. The plan may pay for and monitor a range of currently available services. To date, the prevalent services address the needs of people with mental retardation (MR) and mental health (MI) issues.

Delaware CarePlan requires a minimum deposit of \$5,000 (a modest amount compared to the usual \$250,000 required for a bank trust). This money is deposited into a community account. The pooling of resources allows for greater buying power. The CarePlan funds are currently being invested by the conservative investment managers of the Vanguard family of mutual funds. Once a year, Delaware CarePlan issues a financial report to each beneficiary's family.

Since Delaware CarePlan's start-up in December 1999, the staff has personalized long-term-care plans for 33 Delaware consumers. Although a plan of care can be created for either an adult consumer or a minor, adults make up the majority of Delaware CarePlan's current beneficiaries. With two adult consumers in the family, the Barbers of Newark, DE, illustrate the overwhelming need for the type of "family support" that a program like Delaware CarePlan's can provide.

## Before they had a voice

Jon and Patricia Barber have had their hands full for more than 40 years. Three of their six children had disabilities. After one child with a learning disability died, the Barbers worked harder to do the best they could for all their children, but providing for James and Elizabeth, their children with disabilities, proved nearly impossible. The current system of supports and services was not available, so "family support" meant doing whatever the two parents could muster themselves. Jon supported his family through a job that required a lot of travel. Therefore, Patricia was often alone as she tried to meet the needs of all her children and relied on her training as a nurse when hard questions had to be asked.

The first difficult question arose when James was tested at 2. The test results indicated a range of issues, but they were inconsistent. As a result, the toddler was diagnosed with borderline mild retardation with emotional problems. Patricia knew her son had a severe disability but could only watch as the South Carolina school system put him in "regular" classes for preschool, nursery school, and first grade.

"I knew Jim was both intellectually and emotionally handicapped," stresses Patricia. "Since he was 2, I haven't gotten any satisfaction from the school system. I couldn't place him in a school for (children with retardation) because he tested erratically. I had to teach him not to take his frustrations out on people."



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.

"At this time," remembers Patricia, "Jim wasn't reading at all. I knew my son wasn't getting what he needed, and it affected the entire family. I helped him with his homework every night, which meant that, many times, I did his homework. I wanted to home-school my son, but the state didn't allow it then. There was also a pilot school available to grade-schoolers like Jim. It cost \$2,000 a year! We couldn't afford the tuition, and no (financial aid) was available. Besides, there was no transportation, so even if we could find the money, we couldn't get him there."

When Jim was 21, testers changed his diagnosis to schizophrenia with emotional problems. Still, the trained nurse in Patricia recognized that the prescribed treatments didn't match her son's needs, and his behavior problems escalated. Patricia watched her son lose self-esteem every day and gain a clingy need to be the center of his mother's world.

## Defining "family support" today

Today, Jim is 41, reads at the second-grade level, and can't be alone without fighting loneliness and anxiety. He visits his parents daily in addition to calling two or three times a day. Recently, doctors diagnosed him as having schizophrenic-affective disorder, a more severe disability that requires more specific attention.

As a result, the state enrolled Jim in the Continuum Treatment Team (CTT) program. CTT has met more of Jim's needs. For example, once a month, Jim sees a psychiatrist, and his medication is monitored to find the right dosage and combination for him. Also, Jim meets with his counselor every other week; on in-between weeks, his counselor visits Jim in his apartment. He has someone besides his parents keeping track of his progress.

"I still keep a list of my meds with my parents," admits Jim. "I live alone. I was married once, but it didn't work out. I'm a regular bachelor man now. I live with Boo-boo, my cat. I could use someone to come see me at my apartment—as a friend. My friend Emory and his wife used to live at Georgetown Manor Apartments but had to move out when it wasn't (subsidized) housing anymore. Now, they live too far away for me to see them. It would be nice if there (were) a network or something."

Jim's father, Jon, agrees that "a network or something" would be a big help. When Jon and Patricia take some much-needed time off, Jim always feels isolated and anxious. "We leave money here for him if he needs it, in case of an emergency," says Jon, "but basically, we're all he's got. His siblings can't be for him what we are."

Jon would also appreciate network-like support for his daughter Elizabeth. Born with spina bifida (a congenital disability involving the spinal column), Elizabeth needs a wheelchair to get around and experiences medical problems that often overwhelm the family. "One thing I would like is a case manager," notes Jon, "somebody who visits Betsy, monthly or whatever, manages her medical issues. She has quite a list and needs some kind of oversight committee for her paralysis, diabetes, eyes, and gynecological and psychological issues. The interviews to get her into the long-term-care system were hit or miss. There was no follow-up. Someone would call, asking about someone we'd never heard of, and hang up promising to get back to us. They never did."

Betsy, now 35, had to begin refusing physical therapy recently because it requires her to be in her wheelchair for four hours at a time, causing her a lot of back and abdominal pain. The frustration escalated as her parents fought for an adequate wheelchair.

"You know, first you have to get in the system; then, you have to get approval," explains Jon. "We started the process for a new wheelchair in January 2000, and Medicaid denied benefits for the wheelchair specified by her doctor. Then, Betsy changed doctors, and the process began all over again with a different chair specification. Since we started the process, she's gained weight because she's gotten so little exercise."



In January this year, Betsy was finally admitted into Emily P. Bissell Hospital, and the staff immediately started reworking her chair. Unfortunately, at the same time, Betsy 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 cysts on her ovaries that feel like appendicitis and twice because of the panic attacks!"

After four decades of feeling alone in the care of their children, Jon and Patricia Barber are keenly aware of the level of support Betsy and Jim have come to expect from them. Because of this understanding, these parents continue to voice their con-

cerns. 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 shoes. The Barbers 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 those 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 Betsy.

For more information about Delaware CarePlan and the support it can provide your family, call (302) 633-4000.

## Delaware agencies voice their successes and frustrations in supporting the consumer's family

### Spanning a spectrum of need



To function well in today's fast-paced and interconnected world, Delaware's families that have members with disabilities look for help from the state's system of supports and services. From housing, employment, and training programs to case advocacy, the system must span a spectrum of need. The programs try to treat not only every consumer with a developmental, psychological, or physical disability, but also the consumer's personal support system. The results often put a smile on the family's face—or frustrate everyone involved.

When Marianne Smith, the Director of the Delaware Division of Developmental Disabilities Services (DDDS), started her career 30 years ago, the only service option was institutionalization at Stockley Center. Today, more than 1200 individuals and families in Delaware receive support from DDDS for a family member living at home—more than any other DDDS service. Their *Family Support Handbook* defines family support as "...those services that help an individual with a developmental disability and their family maintain a functional, intact family unit in the family's home."

Sharon Ayres, Director of Community Services, describes the DDDS range of services. "Services are based on family need and are unique to each family," says Ayres. "We may offer short-term help with stipends on occasion or provide accommodations such as a wheelchair ramp. Once we helped a family repair their roof because the leaky roof made the home unsafe. The family wanted to stay together and they wanted to keep their son at home, but they couldn't afford a new place to live and

they couldn't afford the roof repairs. DDDS's help allowed the entire family to stay in their home, prevented a residential placement, and was a win-win for all of us.

"More typical services," according to Ayres, "are case management, day services, and respite care. Occasionally, we have provided nursing and behavior supports to the family as well. We help families' to link into other state agencies by using the Delaware Health & Social Services 'no wrong door' approach. The family support case manager assists the family to locate and apply for other services for which they may be eligible. These could be services such as applying for Social Security benefits, Medicaid, food stamps, energy assistance, or medical care.

"Funding for all DDDS family support services comes completely from state dollars that have been allocated to the Division by the legislature. Services provided to families are limited by this allocated funding. Ayres continues, "We try to be creative, keep families together, and ultimately reduce the need for individuals to enter residential placements."

#### Who is eligible for family support services from DDDS?

Eligibility is based on having a disability that is attributable to mental retardation, autism, Prader Willi Syndrome, brain injury, or a neurological condition closely related to mental retardation if the condition results in an impairment of general intellectual functioning and adaptive behavior similar to persons with mental retardation and requires treatment and services similar to those required for persons with impairments of general intellectual functioning.

The disability occurs before age 22, is expected to continue indefinitely, and results in a substantial functional limitation in two or more adaptive skill areas (communication, self care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work), and it reflects the need for lifelong and individually planned services.

#### Division of Services for Aging and Adults with Physical Disabilities

Knowing and meeting the needs of Delawareans with physical disabilities can be a source of both frustration and satisfaction for the staff of the Delaware Health & Social Services's Division of Services for Aging and Adults with Physical Disabilities (DSAAPD). The frustration begins with the government's process for labeling and funding DSAAPD programs.

"We have funding under the Older Americans Act and services for persons with physical disabilities who are 60 years of age or older," begins Marianne Lucia, planning supervisor at DSAAPD. "We have consumers who need similar services but do not qualify because they are between the ages of 18 and 59.

"In-home services, such as home-delivered meals," explains Lucia, "were designed for individuals who are 60 and older. Only a small amount of funding is earmarked by the government for the under-60 crowd. Therefore, fewer Delawareans under the age of 60 benefit from these services. This (labeling-and-funding process) holds true for other services provided by the division."

For example, the under-60 Delawareans with physical disabilities can find some DSAAPD assistance for personal attendant and respite

services and modifications to the home. Unfortunately, limited government funds means limited services, and the waiting lists frustrate many families.

DSAAPD also offers several Medicaid waivers, but these are designated for consumers with physical disabilities who have little income, few assets, and the need for a nursing home's level of care. If a consumer qualifies for one of these waivers, the DSAAPD covers

- personal care,
- adult day-care services,
- respite care,
- personal emergency response services,
- orthotics and prosthetics, and
- assisted-living services.

"Another frustration we have," continues Lucia, "is not enough money, time, or staff to do the things we would like to do. A third frustration is the tug and pull between government rules and the consumer's freedom of choice. An example is the small four-person assisted-living facility that DSAAPD funds. Because of the regulations that the facility must meet to maintain the government's safety standards, we hear complaints from residents and advocacy groups who say we are not allowing individuals to do what they want. Also, the government tends to move slowly, especially when making changes. People tend to need a need addressed NOW."

Although the DSAAPD's frustrations have been difficult for all involved, they have led to a satisfying success story that's beneficial to family support: the legitimization of caregivers.

Historically, consumers have been the main beneficiaries of the respite programs and adult day-care services offered by the Easter Seal Society of Del-Mar, Inc. Other programs address specific consumer

issues, such as the dementia that accompanies Alzheimer's disease. Thanks to all these programs, some consumers get an opportunity to socialize in the community. An afterthought: Some caregivers get a break from their unending responsibilities.

Then, the Older Americans Act of 2000 was reauthorized by Congress. As of March 31, 2001, Delaware can accept federal funds for national family caregiver programs. This legislation shifts attention to the caregiver in the family.

"For the first time," smiles Lucia, "being a caregiver is as important in terms of need as being a consumer. Informal (unpaid) caregivers are legitimized by this legislation. This act gives them what they need to keep going. It gives them hope."

Parts of the act's funding have been designated to provide

- information and assistance,
- counseling services and support groups,
- training,
- supplemental services (that is, any service that will meet the individual's or family's needs), and
- respite care (which means the state gets to define the areas of need).

DSAAPD is currently updating its guide to services for Delawareans with physical disabilities. If you are interested in a copy, call (800) 223-9074, or go online at "www.DSAAPD.com". For general information in New Castle County, call (302) 577-4660; in Milford, call (302) 422-1846. Or go online at Delaware Helpline, or call 1-800-464-4357.

#### The Arc of Delaware

As the outreach coordinator of case advocacy programs at The Arc of Delaware, Debbie Nock oversees a number of

Continued on next page



## Spectrum of need...

From previous 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 DDDS system. We make sure the family

enrolls with DDDS so they can take advantage of programs and agencies in the community."

Besides their more traditional housing and employee 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 volunteerism is down. We need more people without disabilities to volun-

teer 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 joined 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 Rosas, 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."

Rosas describes two family support programs offered through the Division of Family Services. The first, called FACET (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. Herring 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 Rosas.

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 FACET, 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 892-4502 or lhastings@state.de.us.



Debby Nock with April and Colleen Schuibbea.