

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

The New Jersey Family Support Act led to the creation of nine Regional Family Support Planning Councils that provide valuable information about services and supports to families caring for loved ones with developmental disabilities. Family Support Councils also gather information, monitor services, and make recommendations to the NJ Division on Developmental Disabilities (DDD) about needed programs and funding.

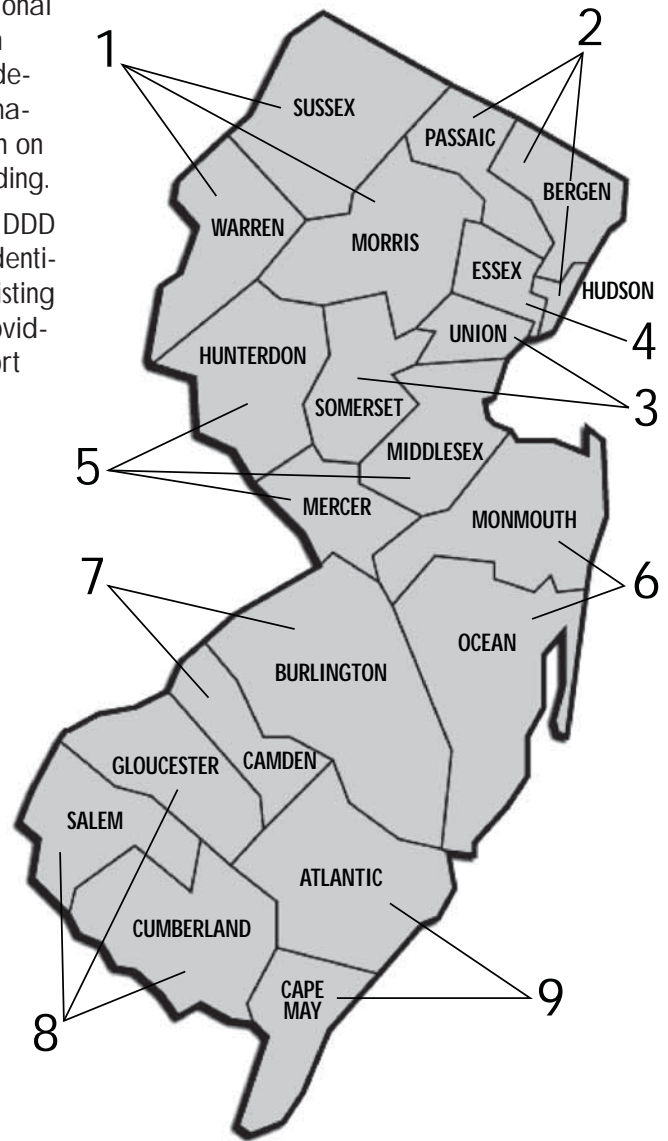
Regional Family Support Planning Councils form a partnership with DDD to make sure that services and supports are consistent with needs identified by families in the region. Beginning in 1989, organizations assisting people with disabilities began to understand the importance of providing support to families caring for individuals at home. Family support began with respite programs and grew to include other activities following the passage of the Family Support Act in 1993. This Act created the regional councils and assigned the NJ Council on Developmental Disabilities as the agency to coordinate their activities throughout the state. The Act assured families a role in planning the State's service delivery system. Councils continue to work to create the best possible services and supports for families and people with disabilities in New Jersey.

THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with a developmental disability.

The system of Family Support shall include, but not be limited to:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers



BASIC PRINCIPLES ESTABLISHED IN THE LEGISLATION

All individuals have the right to belong to a family unit where enduring relationships can be fostered.

Families are the major providers of support, care, and training for their family member with a developmental disability; and are continually searching for ways to support their relative instead of placing them outside the home.

Failure to provide needed supports can result in premature placement in a setting outside the home.

Visit the NJ Council on Developmental Disabilities' web site at: www.njcdd.org, click on the link for Family Support, and the number corresponding to the Regional Family Support Planning Council in

your area. Or contact Monique Wilson, New Jersey's family support coordinator, 609.341.3112 monique.wilson@njddc.org, for additional information.

1 SUSSEX, WARREN, MORRIS

PO Box 13
Pompton Plains, NJ 07444

Meet Third Tuesday 7:00–9:00 p.m.
Morristown Memorial Hospital
100 Madison Ave.
Level B, Conference Rm. #2
Morristown, NJ 07962

2 BERGEN, HUDSON, PASSAIC

e-mail:
RFSPC_region2_NJ@yahoo.com

Meet Third Monday 6:30–8:30 p.m.
Secaucus Public Library
1379 Paterson Plank Rd.
Secaucus, NJ 07094

3 SOMERSET, UNION

PO Box 1444
Linden, NJ 07036-1444

e-mail:
rfspc@comcast.net

Meet Second Tuesday 7:00–9:00 p.m.
Children's Specialized Hospital
The Living Room
New Providence Road
Mountainside, NJ 07092

To be effective, family support must: support the entire family; be easily accessible; be flexible; be culturally sensitive and individualized.

Families themselves are able to define their own needs and select their own services.

Family supports must be chosen by families, controlled by families and monitored by families.

4 ESSEX

P.O. Box 56
Bloomfield, NJ 07003
e-mail:
rfspc4@yahoo.com

Meet First Wednesday 7:30–9:30 p.m.
Bloomfield Law Enforcement Bldg.
Law Enforcement Building
1 Municipal Plaza
Bloomfield, NJ 07003

5 HUNTERDON, MIDDLESEX, MERCER

28 Lark Place
Old Bridge, NJ 08857
Meet Second Saturday 10:00–12:00 a.m.

6 MONMOUTH, OCEAN

P.O. Box 76
Lakewood, NJ 08701
e-mail:
RFSPC_NJ6@yahoo.com

Meet Second Thursday 7:30–9:30 p.m.
Lakewood Municipal Bldg.
3rd. Street Rm. 18
Lakewood, NJ 08701

7 BURLINGTON, CAMDEN

P.O. Box 641
Mt. Laurel, NJ 08054
e-mail:
rfspc7@comcast.net

Meet Fourth Tuesday 7:00–9:00 p.m.
Mt. Laurel Library
100 Walt Whitman Ave.
Mt. Laurel, NJ 08054

Durand Academy
111 Gaither Dr.
Suite 10
Mt. Laurel, NJ 08054

8 CUMBERLAND, SALEM, GLOUCESTER

P.O. Box 11
Glassboro, NJ 08028
*(856) 863-8624
e-mail:
rfspc8@hotmail.com

Meet Fourth Wednesday
Gloucester County Library/Mullica Hill Branch
389 Wolfert Road
Mullica Hill, NJ 08062

* Please call council phone number to confirm monthly meeting date and time.

9 ATLANTIC, CAPE MAY

P.O. Box 84
Somers Point, NJ 08244
(609) 641-1877 fax: (609) 641-2842
e-mail:
MaryPhilippi119@comcast.net

Meet Third Thursday 6:30–8:15 p.m.
Arc of Atlantic County
6550 Delilah Rd.
Egg Harbor Township, NJ 08234

Healing Touch

Therapeutic
Massage & Yoga
for People with
Developmental
Disabilities

by Fay Reiter



Nanette Vinson works on
Lawrence Olivari.

Lawrence Olivari, 58, is lying under soft blankets on a heated table having his back rubbed with warm aromatic oil. New age music resonates quietly in the background. Soft lighting, sensory pleasing objects, and scented candles permeate the room where he receives his therapy three times a week.

Olivari sits up; his face is soft, peaceful. Right next to him, Thomas Anthony, 30, is also lying down, asleep actually, as certified massage therapist Krista Palaima works his shoulders.

Both are receiving their treatments at the Hunterdon Developmental Center, where they live. Both have profound mental retardation and Anthony, experiences perpetual tremors from cerebral palsy.

A few miles away in Yardley, Pennsylvania, 11th

grader Caity is sitting in a massage chair, face comfortably nuzzled in a headrest, while certified massage therapist Kathy Perniciaro gently rubs her neck and shoulders. It's just another part of Caity's day at the New Hope Academy, a private school for students with learning and emotional disabilities.

The three recipients of these relaxation and health promoting therapies, usually associated with fancy spas and exotic retreats, are part of a growing movement of complimentary alternative therapy programs springing up at schools and facilities throughout the country. Practices such as massage, acupuncture and yoga have been around for centuries but have grown significantly in popularity during the last few decades.

Although, a substantial number of studies exist in the medical literature touting the powerful benefits of touch therapy in reducing stress and managing chronic illness, few examine specifically the therapeutic effect on the people with developmental disabilities.

However, at the New Hope Academy and Hunterdon Developmental Center, these programs are viewed by administrators, staff, families and recipients as playing a vital role in helping people with disabilities cope with the challenges of daily life.

AT THE ACADEMY

Kathy Rosso-Gana, Founder and President of New Hope Academy, started implementing alternative programming like yoga several years ago.

“I saw that so many kids had body image problems and hated physical education. In addition, many of our kids suffer from depression and have difficulty coping with frustration and stress. The massage and yoga programs have been a significant source of comfort to them.

“There are times, when a situation arises involving a student that requires they meet with me and I will often suggest they have a chair massage first to help them calm down. The students will frequently share their experiences with Kathy, our massage therapist and that is very helpful to them as well.”

Rosso-Gana thinks it is important for the students at the school to be exposed to options like massage and yoga because these are practices they can use throughout their lives.

Pam Pollack, dean of students, believes the Massage and Yoga programs have been extremely valuable in helping students cope with anxiety and stress.

“Students come to New Hope with learning, emotional and behavioral disabilities and diagnoses on the autism spectrum such as Asperger’s Syndrome. These programs compliment the innovative curriculum where students pursue subjects from calculus and social studies to computer animation and chess. The school tries to create an

environment of comfort and trust, and the massage program serves as a vital component to this mission.”

Kathy Perniciaro, a certified Trauma Touch and massage therapist, has been running the program at New Hope for the past seven years.

“I offer a place for the students to relax and de-stress. A lot of these kids are wired differently.”

Perniciaro has developed a program that is just eight minutes, but is effective enough to quiet down the nervous system.

“Often, when I come in, a teacher will tell me that a student is having a bad day and ask me to give them a massage. I will work on their back and shoulders first, and then walk around to the front of the chair and massage their hands.”

Perniciaro uses three different scented creams as part of the treatment; peppermint to sharpen focus, orange to wake them up and lavender to calm them.

“Aromatherapy works on the limbic system, the emotional part of the brain. When you walk into a

At the Academy, massage is offered to teens. They are taken out of class for 15-20 minutes at a time. Massage therapist Kathy Perniciaro works on Alison.



bakery shop and smell wonderful cinnamon rolls it has a similar effect.”

Perniciaro has found her work helpful for students with a wide range of problems including ADD (Attention Deficit Disorder), ADHD (Attention Deficit Hyperactivity Disorder) and disorders along the Autism spectrum.

“I find working with the kids who are in a critical emotional situation most rewarding. They will come to me and put their head down and feel ‘safe.’ We have some children who will say ‘hi’ all year long, but will not get in the chair and then one-day they will come and ask for a massage. It is so gratifying to know that I am making such a big difference in their lives. I offer them a little space of peace.”

Twelfth grader Casey is a regular participant in the massage program.

“When I get stressed out in class or I am not having a good day, I go and sign up for a massage with Kathy P. I sit in the chair and she rubs my back and shoulders, sometimes my hands. She also uses really nice scents. Somedays, I have trouble concentrating and I’ll be flicking my pen. After a session with Kathy, I am more focused and I can pay attention and listen in class.”

Caity, 11th grade, will put her name on the list for a massage if she is feeling upset. She also enjoys the yoga classes.

“Before the massage I am feeling all worked up. But afterwards I feel so much better. When I get into yoga, it gets all the thoughts and clutter out of my head so I can think. Monica, our teacher is so inspirational, she helps push you out of the box and that makes me feel so much more confident.”

Twelfth grader Jake agrees,

“Initially, I felt uneasy about it, but now I feel yoga has helped me so much. I get such a good feeling from the stretching and the workouts. I am planning on taking classes to become a yoga instructor.”

AT THE CENTER

Nanette Vinson has worked at the Hunterdon Developmental Center since 1976. She has held a variety of positions, but a few years ago she decided to pursue certification as a massage therapist and work in this capacity at the HDC.

“This is the ultimate professional experience. I am never going to leave this position. We have some clients who are very self injurious and have to wear protective helmets 24 hours a day. But when they are here, they don’t exhibit any of these behaviors. They are so peaceful here that they can take their helmets off.”

Krista Paliama, another massage therapist, works side by side with Vinson every day.

“Coming here makes the clients feel special. Other people go to spas to feel good, why shouldn’t they? I think it is good for their overall mental health. It is very gratifying to work with them. I know at the end of the day I have given each one an hour of freedom.”

According to Vinson, the massage program has been extremely helpful in calming residents with hyperactivity and tremors.

“Some of our clients are tactile defensive (don’t like to be touched) but will actually enjoy massage. Sometimes we will just work on their hands and feet. It is kind of a mystery why some people find it so helpful.” Clients are referred through the treatment teams for a variety of reasons and some go for massages several times a week. Aromatherapy is also an integral part of the program and the therapists regularly use lotions, collars and lumbar pads as part of the program.”

Kathy Blazek serves as the Quality Assurance Coordinator for the HDC.

“My background is in nursing, so I have always known about the importance of being able to touch people in a way that is helpful for them. The massage has been helpful in getting people to accept touch.”



Yoga student Caity and teacher Monica Welsh

Blazek believes that the effects of the massage carry over to the other training skills that many of the clients are working on. For example, if some residents are learning to feed themselves they have to use their hands. The massage can be a good tool in assisting them in feeling more comfortable with this part of their body.

“The exposure to the room in which they receive the massage is very calming. The music and light stimulates all their senses; smell, the auditory and tactile. For some, we are simply helping them to relax or accept touch. Some of our clients are aging and have arthritis and the massage has therapeutic benefits for them as well.”

John Smith, Director of Professional and Residential Services at the HDC, was involved in the creation of the program in 2002.

“We saw a need to offer more diverse programming with an emphasis on relaxation for our clients who have maladaptive behaviors. In addition, we were interested in meeting the needs of our aging residents. The massage program has been extremely helpful in reducing anxiety and has reinforced positive behaviors among the residents.”

Smith believes that the sensory aspects of the program help clients develop attending behaviors, a critical component of treatment for many of the clients. He described a particular case in which a young woman was able to transition to a more independent living setting in the community as a result of her participation in the massage program.

“The setting and interaction with the massage therapists did so much to increase her feelings of self-esteem and that significantly impacted how she interacted with others. She really enjoyed the scent of the lotions and just glowed after going for treatment.”

Kelly Vasquez, who coordinates direct services for Olivari, said she has seen a marked improvement in Larry’s functioning since he has been receiving regular massage.

“It has helped to reduce the edema in his legs and he has experienced fewer seizures. In general, he seems calmer and more relaxed. And I am thrilled that he is more willing to participate in activities and ambulate on his own, instead of using a wheelchair. When the massage therapists come to pick him up to take him to the massage room, he always has a big smile on his face.” **P&F**



Krista, a massage therapist, works on Thomas Anthony to relieve the shaking associated with his Cerebral palsy.



Anthony is relaxed after receiving his massage treatment.

“LIFE GOES ON”

When I was growing up in the 1960s, we seldom heard about people with intellectual disabilities. When we did, it was in whispers. Once, I overheard my father talking to my aunt. “It’s a shame about Lenny,” Dad said. “He’s a nice guy.” I’d never heard about Lenny. I asked Dad who Lenny was. Lenny, I remember Dad saying, was a distant cousin’s son. “He’s mentally retarded,” Dad said.” (My father reflected the thinking of his time.)

People with intellectual or other disabilities were rarely portrayed on TV shows. Occasionally, non-disabled actors played characters with disabilities. These depictions were seldom like real-life people. (I don’t know anyone using a wheelchair who’s like the detective in “Ironside,” and I haven’t met anyone with a brain injury who’s like the “amnesia victims” I’ve seen on soap operas.)

Things haven’t changed much for people with disabilities on TV. There are 54 million Americans with disabilities, according to the U.S. Census Bureau. Yet, a 2005 Screen Actors Guild report (“The Employment of Performers with Disabilities in the Entertainment Industry”) found that less than two percent of TV characters display a disability. Only 0.5 percent of television characters with disabilities have speaking roles, according to the SAG report.

Given the scarcity of people like me on television, I was delighted to discover that the first season of “Life Goes On” is now on DVD. “Life Goes On” aired on ABC from 1989 to 1993. The show, set in Glen Brook, a fictional Chicago suburb, was a well-acted, well-written drama about the Thatcher family.

The Thatchers’ second son—18-year-old Charles (a.k.a. Corky) had Down syndrome. That in itself was

unusual: most television families don’t have children with disabilities. What made the show even more unique (even today) is that Corky was played by Chris Burke, an actor who has Down syndrome. (Burke was born in 1963 in Point Lookout, N.Y.)



Tony-Award winning stage actress Patti LuPone (best known for her performance on Broadway in “Evita”) played Corky’s mother Libby. Bill Smitrovich played his father and Kellie Martin, (who went on to portray Lucy Knight, a med student on ER, from 1998 to 2000), played Corky’s younger sister Becca. Monique Lanier played Corky’s older sister Paige during the show’s first year. Arnold “the semi-wonder” dog (expertly played by Bullet) more than held his own among the humans on the show. Whether snuggling up to Corky, tilting his head knowingly to one side, or barking in appreciation of LuPone’s singing, a

more lovable mutt has never been seen on TV. (One of the great moments on the DVD, is when Corky, who loves to sing, belts out a song for Arnold.)

The Thatchers were like many working-class families. Drew, tired of working for someone else, dreamed about owning his own restaurant. Libby, a former stage actress, was stuck working for her annoying boss Jerry (played by Ray Buktenica). Paige sought true love and a place of her own. Becca wrote for the underground high school newspaper, entered a regional teen beauty pageant and fell in love for the first time. Corky had his first crush, played the drums, and, like many an adolescent rebelled against authority (in his case, by hanging out with some of the “hoods” at school.)

The Thatcher family dealt with home repairs; relatives’ squabbles (Libby’s parents arrived at their home, suitcases in hand, after a quarrel); absurdity (though

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true-to-life in many respects, this was TV: in one episode, a 600 pound pig escaped from a truck full of pigs on its way to market and landed on the Thatchers’ doorstep); and death (in another episode, the Thatchers’ faced their discomfort when they attended the funeral of a distant relative).

The show’s treatment of the Corky character was featuring a typical teenager with Down syndrome. Although the program always included storylines about the other characters, much of the show’s first season was about the year that Corky is mainstreamed as a freshman at Marshall High School.

“Life Goes On,” neither glossed over nor overmagnified the difficulties involved in mainstreaming. Sometimes, the other kids ridiculed or harassed Corky (trying to take his lunch or pretending to like him, but really laughing at him). At times, his parents and school officials didn’t agree on what Corky’s courses should be.

In one episode, Drew and Libby counseled a couple who have just learned that their new baby girl has Down syndrome. “You have to learn to question authority,” Libby told the new mother.

In a poignant flashback, Libby recalled how the doctors at Corky’s birth advised her and Drew to institutionalize Corky. Though she and Drew knew nothing about Down syndrome or what might be involved in raising a child with a disability, they ignored the physician’s advice and kept Corky at home.

Yet, they were aware that this is a decision each couple must make. When she counseled the woman who had just learned that her baby had Down syndrome, Libby said that she used to advise new parents to keep their children with disabilities at home. But, she and Drew came to realize that not all children with Down syndrome “are as high functioning as Corky”, and that they shouldn’t pressure parents to make a particular choice.

The life experiences of Burke—and of Michael Braverman, the show’s creator and executive producer—gave “Life Goes On” its unusual authenticity.

Braverman met Burke, when he directed him in a pilot called “Desperate.” Though ABC didn’t pick up “Desperate,” the network liked Burke’s work and asked Braverman to develop a pilot for him. “Life Goes On” was the result. The show was about “any family in the country who just happened to have a son with Down syndrome,” Braverman says in a commentary that is an extra feature on the DVD.

In addition to knowing Burke, Braverman’s nephew Charles, who has Down, was mainstreamed into school. This, plus Burke’s experience with mainstreaming, contribute to the accuracy of the show’s depiction of inclusion.

“I felt scared, too,” Burke says in the DVD commentary, “I didn’t know what to do. It was very hard.” Yet, mainstreaming offered opportunities. Corky memorized poetry (“The Raven” by Edgar Allen Poe), took his girl friend to the school dance and ran for class president.

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Kids with disabilities “have dreams just like you do,” Corky said in his campaign speech.

Sometimes “Life Goes On” seems retro. There’s the 80s clothes and the slow pace. The program doesn’t have the hipness of the Farrelley Brothers’ 2005 flick “The Ringer,” which was produced with the cooperation of the Special Olympics. (See *People & Families*, vol. 1, #3)

Despite these minor caveats, “Life Goes On” holds up well. Where else will you find a touching story of a teenager with Down syndrome, great ensemble acting, the superb singing and dancing of Patti Lupone, plus Arnold’s adorable tricks? **P&F**

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NEW JERSEY COUNCIL ON
DEVELOPMENTAL DISABILITIES

