

Crisis, What Crisis? Supporting Persons with Challenging Behaviors in the Community.

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Individuals labeled with severe disabilities and challenging behaviors are often subjected to involuntary and non-beneficial stays in psychiatric or criminal justice facilities. This paper, based around a young woman's experience in the summer of 1998, describes Dane County's Crisis Response program: a service model which was developed by the UW-Madison's Waisman Center and Dane County Human Services and is designed to provide positive and community oriented crisis support alternatives.

Life in Madison, Wisconsin

Dane County, one of Wisconsin's 72 counties has a population of approx. 400,000. It surrounds Madison, the capital city which is home to the University of Wisconsin-Madison. While the state of Wisconsin runs three public institutions for individuals with developmental disabilities it does not operate any community services. These are planned, administered (and additionally-funded) by the individual counties and their quasi-independent human services boards. In 1999 Dane County's Adult Community Services division provided a wide variety of services (vocational, residential, case management, transportation etc.) for approx. 1200 adults with developmental disabilities through a variety of predominantly subcontracted agencies and programs. Dane County, as a participant in the Robert Wood Johnson Foundation Self-Determination initiative, is in the process of transforming its service system into a system of Self-Directed-Supports? (Chart 1).

Lizz's story

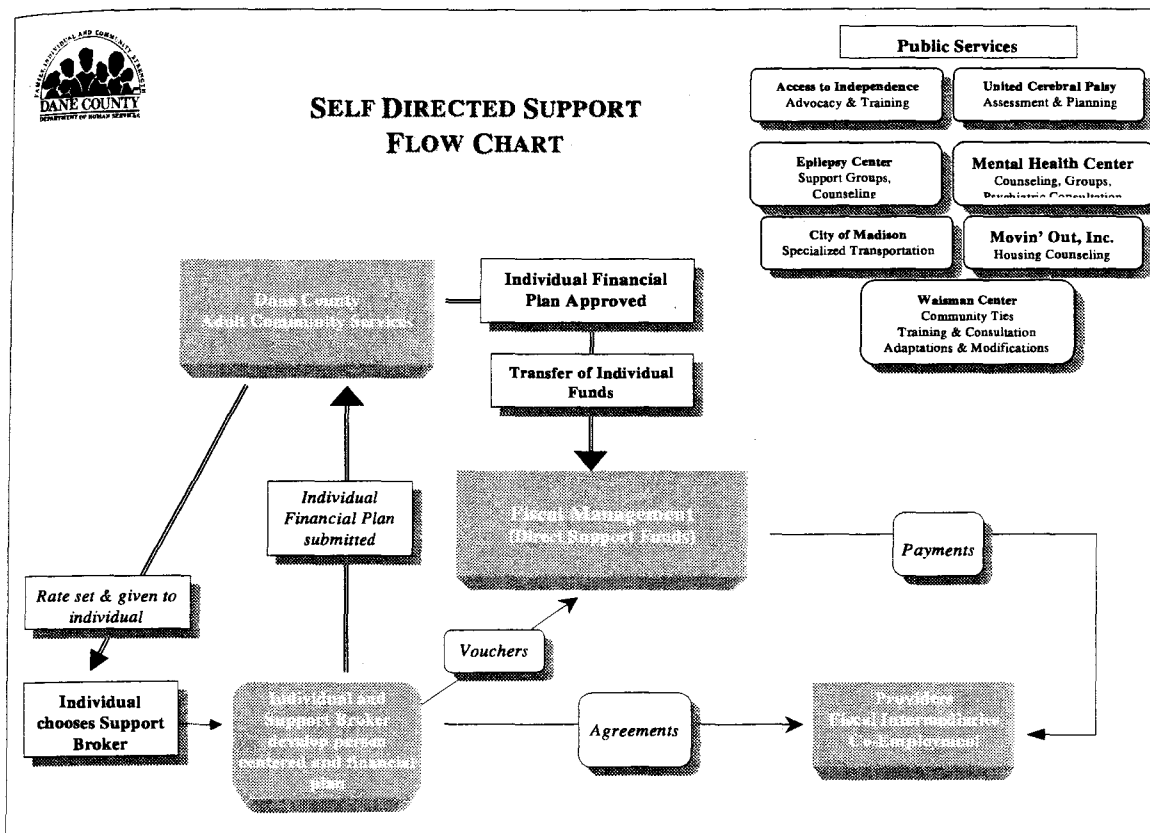
Lizz G., a young woman who lives and works in Madison, receives a variety of support services funded through Dane County Human Services. The following describes Lizz's experience with the Dane County Crisis Response program. Lizz G., the youngest of three daughters was born prematurely with a hiatal hernia, and so she was kept

propped for the first seven month of her life, and never lied on her stomach, in order to keep food down. The hiatal hernia cured itself after seven difficult months (and) our physician was not concerned when she was late doing most things (1).

A neighbor, who had an older disabled son and babysat for Lizz at times, expressed concerns which prompted us to make an appointment at Georgetown University hospital with a doctor who confirmed our suspicions and told us that she thought Lizz was profoundly and severely retarded. Appointments at the Doman Delacato Institute resulted in a regimen of 16 hours a day of constant "hands on" therapy - broken into 15-minute sessions.

Lizz went absolutely rigid when we tried to pattern her ... so we gave up on that and tried to do the rest of the schedule in moderation. Visits at the Kennedy Institute at John Hopkins in Baltimore and contacts with the Montgomery County Association for Retarded Citizens led to Lizz's enrollment in the MCARC's preschool. While she was in the pre-school program we heard about autism, and finally had a label to pin on Lizz. Instead of isolating Lizz when she misbehaved, her teacher would keep her in the room with the other children and give her a little special attention. Lizz stayed in the preschool until she entered one of Montgomery County Schools for developmentally disabled children. Developmentally disabled children were kept in segregated schools. Because Lizz has no expressive speech we tried signing. Everything was both said and signed; Lizz never signed back. Next we went to the University of Maryland and worked with a professor who told us that kids with autism fixated on their hands too much and rather than promote that with signing, we should try to get Lizz to keep her hands in her lap and to learn to make choices. And so behavior modification began, the prize being music and listening to a tape recorder when she made a choice.

Chart 1



In 1983 we moved to Madison, Wisconsin and Lizz's started School at Jefferson Middle School. One of the main reasons for moving to Madison was the Lou Brown program of training children for life that was being integrated into the Madison school programs. Lizz learned how to order in a restaurant, how to communicate with velcroed pictures and photographs and she even held many different jobs over her school years in order for us to determine the things she liked to do. Lizz was sixteen when she had her first seizure; and she started becoming self abusive.

Lizz was put on Dilantin first, then Tegretol, and life with medications started. As Lizz got older her behaviors were causing more and more problems at home and we came in contact with Paul White. We started having meetings with Paul, Lizz's teachers, and job coaches to try to figure out some way to deal with the tantrums that were occurring.

Paul White is the primary Program Consultant of Community TIES, a Waisman Center program, subcontracted by Dane County Human Services to provide a variety of positive behavioral support services for individuals with developmental disabilities who have challenging behaviors. Services include direct consumer support and counseling, consulting with support teams, and the training of direct care givers in positive behavioral support strategies. The

coordinator of Dane County's Crisis Response program is a full time staff member of Community TIES and thereby an integral part of the proactive components of positive behavioral supports available to individuals with developmental disabilities in Dane County (chart 2).

At age 21, Lizz graduated from high school. She had

Characteristics of the Dane County Crisis Response:

- 1.) Pro-active (Crisis Response only one component of a comprehensive system of positive behavioral supports)
- 2.) Individualized, flexible, and creative (in cooperation with the individual, his/her family and involved service providers)
- 3.) Quick and easy access
- 4.) Community based services (As an alternative to inappropriate placements in more restrictive settings)
- 5.) Free of charge
- 6.) Cooperative effort of existing agencies/ programs

Chart 2

three different jobs and was supported by two different vocational agencies. (Two years later) Lizz moved into a supported residential home with her longtime friend Amy (and a live-in staff person), and she adjusted more readily than any of us could have imagined or hoped for. She was even a bridesmaid in her sister's wedding. Aggressive behaviors and tantrums did take place, and the meetings with staff of her residential and vocational supports plus Paul White continued to take place about every six weeks. In the spring of 1998 Lizz was becoming more aggressive, first at work and then at home. At home she started sleeping less and getting up more and more at night, finally to the point that she was barely sleeping at all. A tiny nick in her ear - perhaps a pick with a fingernail or even a snip while getting her hair cut was picked continually and finally became an obsession with her. Bandages - and later on stitches - didn't stop Lizz from reopening the cut in her ear. At the same time, Lizz started disliking everything that she had previously liked. She had always liked water and now would throw a tantrum if you tried to put her in the tub.

The self-abuse continued with Lizz hitting the side of her head at the temple so hard that you could hear her knuckles hitting the scalp. She also started rubbing her nose until the skin came off. Putting her Dad's shirt on her and tying the sleeves - so she couldn't pick at her ear or her nose - worked for about a day and a half and then she started banging her head on furniture; when the corners were covered with towels, she started banging her head on the windowsills.

One evening staff ended up calling 911. Despite several sedating medications given at the hospital Lizz walked the halls till 2 am, so we took her home, where she finally fell asleep. We even borrowed a football helmet to try to use to protect her from the head banging.

At this point Lizz was not sleeping more than 45 minute at a time. She was becoming incontinent and Grace started staying in her room as that seemed to make Lizz feel safer. We went to see a psychiatrist and he prescribed Risperdal; it worked for a few days and then was no longer effective. The psychiatrist doubled Lizz's dosage which caused Lizz to become stooped over, drooling, and her arms turned inward. One night Grace found Lizz on all fours on the floor, unable to hold herself up with her eyes rolled back in her head. Grace called 911 and when the Emergency Service team found Lizz's vital signs to be okay she returned to her home. I spent that night and the next two with Lizz. We were up all night. Lizz would go up and down the steps, go outside and we'd walk for about a block and then come back in and I'd try to get

her to go back to sleep. After three nights I was a zombie. (At this point,) Grace told me that staff was threatening to quit so extra staff was pulled in.

Meanwhile, Lizz quit eating so we started feeding her Ensure. Lizz also was starting to whine and was acting like she wanted to cry but she couldn't. Her psychiatrist had taken her off the first medicine and was now trying various medication. Lizz's team also had another meeting with Paul White who got permission to lock the door (so Lizz couldn't leave in the middle of the night), to use the shirt and helmet, and to get help with wake staff through Crisis Response.

Easy and uncomplicated access is one of the key features of Dane County's Crisis Response program. Initial approval is required by Dane County's Adult Community Services Intake Unit. Services can be accessed at all times if agencies and support teams have previously contacted Crisis Response and developed an individualized response plan.

Crisis Response started to work closely with Lizz, her family and staff, and provided overnight awake staff - one day after being contacted - for 10 of the following 17 nights. Staff gently intervened by using the shirt and helmet when Lizz engaged in self-abuse and provided support, reassurance in an effort to help Lizz to feel more comfortable and safe.

All Crisis Response staff members work primarily for other Human Services provider agencies (vocational, residential, case management) in Dane County and agree when necessary to work additional hours for Crisis Response. Although staff are recruited, trained and supervised by Community TIES (see above) Goodwill Industries of Southern Central Wisconsin, Inc., payrolls Crisis response staff. Staff is paid at an overtime rate (time and a half) compared to the typical support staff pay rate in Dane County.

While providing support at Lizz's apartment staff noticed the need to further modify and adapt Lizz's living environment to enhance her safety. Crisis Response contacted Community TIES. An adaptation and Modification Specialist who quickly assessed Lizz's apartment space and completed needed modifications projects (replacing glass in picture frames with Plexiglas, temporarily covering corners and edges with foam protection, obtaining a partition for the hallway to discourage potentially dangerous trips down the stairs).

The Adaptation and Modification Project (A&M) is another Waisman Center program closely associated with Community TIES and Crisis Response. A&M staff strives to contribute to the creation of environments that are safe, appropriate and assure the persons continued participation in the community.

While Crisis Response staff provided much needed relief to Lizz, her family and staff, Lizz's mother contacted a new primary physician, who had significant professional and personal experience with individuals with developmental disabilities. On a modified medication regime things seemed to improve. Lizz started getting better and she was sleeping. Plans had been made earlier in the spring, before any of these health problems emerged, to take Lizz and Amy to Florida to enjoy the ocean. We had concerns about Lizz going but Amy was very excited to go, everything had already been paid for, and extra help was available in Florida so the trip was on. Lizz was okay on the way down and she slept well the first night and most of the second night. The third morning in Florida they (staff) started seeing some of the previous behaviors. She was getting up at night, her vocals were becoming louder and louder; she was bouncing and high energy. She started kicking and even kicked a panel off the door. On the last day she got sunburned. On the plane home she could barely sit still. They (staff) used the seat belt, shirt and helmet on the plane to keep Lizz restrained and to prevent her from hurting herself. By the time they got home Lizz was already starting to go after her sunburn.

Throughout Lizz's vacation in Florida the Crisis Response team stayed in touch with Lizz's team. The team and her primary doctor felt the need to get a second psychiatric opinion. Crisis Response facilitated and coordinated an emergency consultation with a psychiatrist at the Mental Health Center of Dane County upon Lizz's return from Florida.

Timely access to a psychiatrist who is experienced and able to see individuals with cognitive disabilities and who is willing to accept Medical Assistance is a rare commodity in Dane County. Community TIES facilitates a bi-monthly clinic for individuals associated with TIES. A contract with the Mental Health Center of Dane County allows the Crisis Response program to arrange for an emergency, outpatient consult, usually within 24 or 48 hours.

Lizz's team was satisfied with the outcome of the consult. Any undetected, underlying medical

factors that might have been contributed to Lizz's situation were systematically ruled out in the following weeks. Lizz's psychiatrist prescribed a sedative, which curbed Lizz's impulse to rip off the dressings on her sunburn and to dig her fingers in the spots where her skin had blistered. However, it also resulted in further physical deterioration.

Lizz was unsteady on her feet and staff was fearful that she might fall down the stairs. She would just drop every now and then. Lizz had lots of bruises and had to be in pain.

Lizz's team started to question if her two-story house was still a safe place for Lizz to be. Lizz's restlessness throughout the nights and the intensity of her support needs also seemed to negatively impact on her roommate. Lizz's team decided to access the Crisis Response's Safe House providing Lizz with a safer living environment and giving Amy a more than deserved break from dealing with the challenges Lizz was presenting.

The Crisis Response's Safe House is a spacious four-bedroom home in a typical Madison neighborhood. The Safe House is not a facility or program that is staffed at all times, but rather an accessible space with a neutral appearance that can be easily modified, rearranged, and decorated. The house has been modified to accommodate individuals with challenging behaviors by adapting or replacing furniture, fixtures, and household items, that could be easily broken and by controlling the access to potentially dangerous objects, such as knives, cleaning supplies, etc. The Crisis Response Safe House is rented and maintained by Creative Community Living Services, a residential service agency that was willing to transform a former group home for this purpose.

The Safe House would keep Lizz on one floor in a safe environment. There was a window in the door (to her bedroom) so you could watch Lizz and not disturb her; she did not want to be around people at this time. Crisis Response staff, together with home and work staff, supported Lizz at the Safe House. Frequent drives and visits by Lizz's sisters, parents and her roommate helped to keep Lizz awake during the day while staff encouraged Lizz to sleep at night. Lizz's sedating PRN medication was gradually shifted towards the evening and eventually was discontinued. After six days Lizz's various sores were healing up well, further injury had been prevented, and Lizz's appetite and ability to sleep at night were improving. The team decided to have Lizz return home.

Crisis Response continued to provide Lizz's

team with relief staff that was phased out within a week, as it was no longer needed. Lizz's team adjusted and refined Lizz's supports and gradually helped Lizz to return to her typical life. Community TIES continued to work with Lizz and her team and arranged for Lizz to be seen by a psychiatrist through the Waisman Center. A new medication regiment, which was very gradually phased in throughout the fall and winter, helped Lizz to have a fairly successful spring and summer of 1999.

Additional Crisis Response Services

The description of Lizz's experience in the summer of 1998 detailed some but not all Crisis Response services available to individuals with developmental disabilities in Dane County (chart 3). In addition to the services described above (quick access to behavioral consultation, additional support staff, home/workplace adaptations and modifications, outpatient emergency psychiatric consult, safe temporary housing), individuals might benefit from the services of two other existing agencies that are a part of Dane County's Crisis Response efforts:

United Cerebral Palsy (UCP) Adult Services

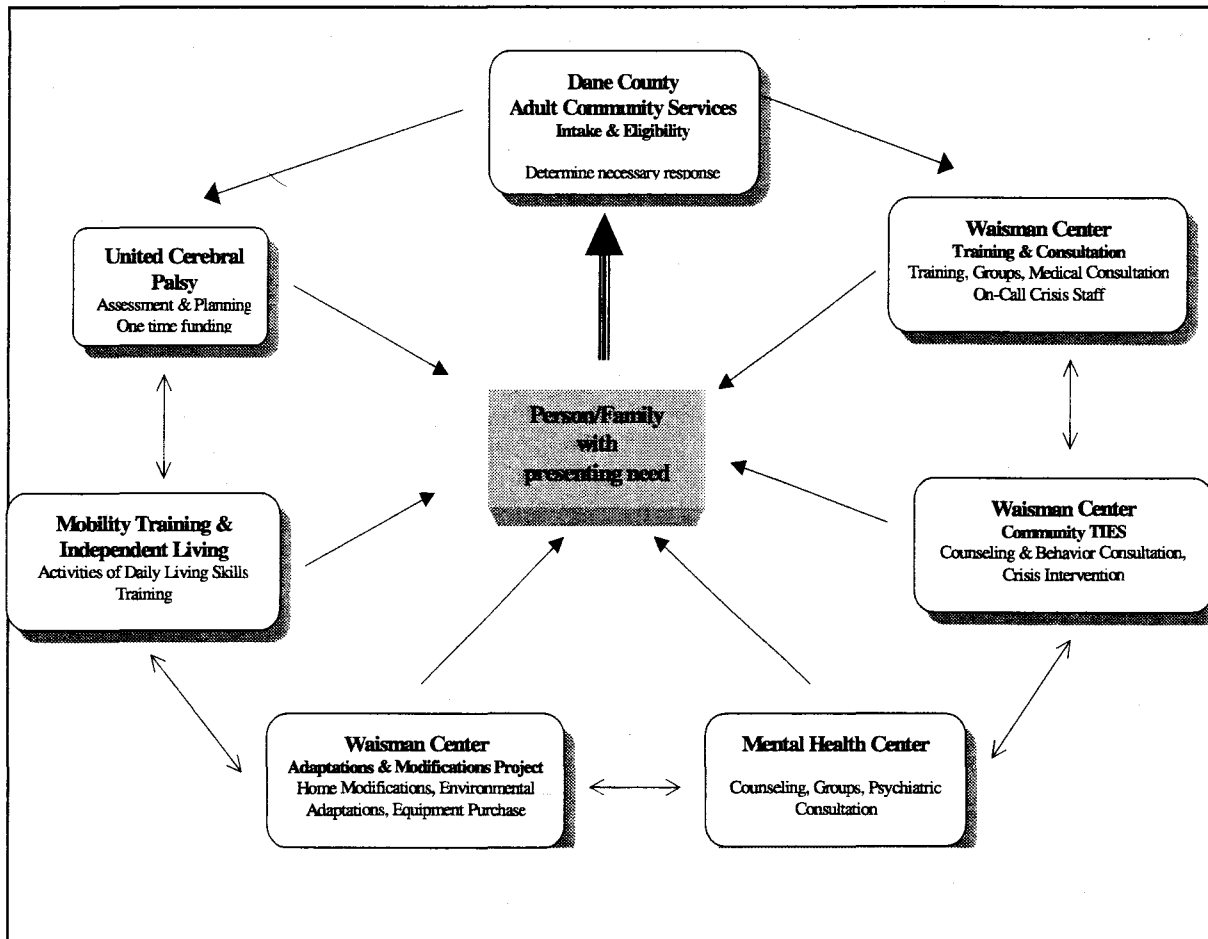
Assessment and Planning assists individuals in transition as well as individuals that are entering Dane County's service system to access needed services. One time cash grants (up to \$1000) may be awarded enabling individuals to remain in their own or their family member's home.

Mobility Training and Independent Living Program (MTILP) provides occupational therapy assessments and skills training in the areas of mobility, personal safety, and daily living.

UCP's and MTILP's services are predominantly utilized by individuals who live without the support of a residential service agency and due to unforeseeable circumstances (such as individual/family health changes) may be in need of additional support.

Implications of Crisis Response services

Between March 1998 and November 1999, 86 Dane County residents accessed and utilized the wide variety of Crisis Response services. Services were highly individualized and were provided in close cooperation with the consumer, his/her family and



involved service providers. Services lasted from 1 day to 200 days, service hours ranged from .5 hours to 1105 hours. Aggression and concerns regarding an individual's safety were the most frequently mentioned reasons for contacting Crisis Response. Young adults, who often had mental health diagnoses in addition to a developmental disability, utilized the various services the most.

Information gathered from participants and support staff indicated that many of the individuals served by Crisis Response had extensive previous experience in more restrictive environments (psychiatric hospitals, Mental Health facilities, and jail). Stays in these more restrictive environments could have been avoided and/or significantly shortened through the involvement of Crisis Response. There was also a documented decline in admissions and a reduction in length of stays at Mendota Mental Health Institute (chart 4). Since such admissions are funded by Dane County reducing their frequency financially justifies

the additional expense for the various components of the Crisis Response. It also seems to demonstrate that through an approach that relies on the strength of existing agencies, emphasizes proactive, positive behavioral supports and allows for person-centered, flexible and creative services, individuals with challenging behaviors can be safely supported in the community.

All quotes: Betty Garvey, Unpublished manuscript. Madison 1999.

