

**The Crisis Response,
Sound Response
And
Victim Response
Systems**

**For People with Developmental Disabilities
In Dane County**



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Crisis Response System For People with Developmental Disabilities In Dane County

Beginning in 1990, Dane County recognized an increasing need to develop a response to individuals with disabilities who were in crisis. These crises presented in two main categories:

1. Where an individual was identified as “being-in” crisis and could not be maintained with their current supports, or
2. Where the caregiver’s capacity to provide the necessary support had diminished.

While the County has a history of contracting with the Waisman Center to provide behavior interventions (see attached TIES program description), not all situations could be resolved by this singular program. As a result, the response to both types of situations was to remove the individual from the situation, either to an existing opening in the system, or if no appropriate opening existed, to an institutional setting, such as a psychiatric hospital, nursing home or mental health institute. These responses were neither effective nor efficient. Something more was needed.

Development of the Crisis Response System

Recognizing this need, the County attempted to develop an alternative response. The first consisted of identifying one or two Adult Family Homes where the County would pay the Sponsor a minimal amount to keep a “vacancy” available for emergency situations. The County would pay a premium amount per day for an emergency placement. This response worked well when the primary caregiver could no longer provide the necessary supports to the person in crisis. However, it was soon discovered that placement in the “temporary vacancies” became long-term, resulting in the need to continuously develop new Adult Family Home with crisis vacancies.

Further, this response did not/could not address the need of individuals who needed a neutral, quiet environment to regain control in their lives. The Adult Family Home typically had other family members or other people with disabilities present, who would often exacerbate the difficulties of the individual in crisis. It was equally unfair to the other members of the household to introduce a disruptive presence.

The County had reviewed similar programs (Adult Family Home, Group Homes) across the nation who reported similar disappointing results.

By 1996, recognizing that the Adult Family Home response was not working (short-term admission to psychiatric hospitals, mental health institutes, and nursing homes remained at previous levels), the County and the Developmental Disabilities Coalition (an organization of providers of developmental disabilities services in Dane County) formed a committee to further develop a Crisis Response System. The committee identified that it was not always necessary or desirable to remove people in crisis from their living environment. In fact, it was most often advantageous to provide the necessary interventions in the person’s home to assure continuity beyond the immediate crisis. However, if the individual in crisis had a roommate with a disability, the roommate may need a safe place to go until

the crisis was resolved. With this as a basic premise, the Committee identified eight key components to provide a comprehensive crisis response:

1. Clinical expertise in crisis management
2. A readily available workforce trained in crisis intervention techniques;
3. Immediate support coordination, if the individual in crisis did not have a system's Case Manager;
4. Access to psychiatric consultation;
5. Evaluation, design and/or purchase of environmental adaptations that would allow the person to remain in their home and provide an immediate source of funds;
6. An alternate living environment when either the individual in crisis or their roommate needed a safe, neutral home;
7. Built-in incentives to prevent short-term interventions from becoming long-term supports; and,
8. Systems administration to assure the Crisis Response was coordinated, comprehensive, effective and efficient.

The first step in addressing these key components was to look to existing services system to ascertain which of the components our current provider could incorporate. The following agencies/programs were identified as being uniquely qualified to take lead on the various components:

- ◆ Clinical Expertise in Crisis Management – Waisman Center TIES
- ◆ Workforce Development - Waisman Center TIES/Mobility Training & Independent Living
- ◆ Case Coordination – United Cerebral Palsy
- ◆ Psychiatric Consultation – Mental Health Center
- ◆ Environmental Adaptations & Funding – Waisman Center Adaptation and Modification Project and United Cerebral Palsy
- ◆ Alternate Living Environment –Creative Community Living Services (CCLS)
- ◆ Built-in Incentives – group process
- ◆ Systems Administration/Coordination – Dane County Adult Community Services Intake Unit & Waisman Center TIES

The committee recognized there would be overlapping responsibilities between the lead agencies; regular communication and meetings (at least quarterly) would lessen any confusion and eliminate duplication of efforts.

Clinical Expertise in Crisis Management

Creating capacity and developing expertise in the assessment, identification, and quick implementation of crisis related interventions (often for individuals with dual diagnoses) was accomplished by expanding the Waisman Center's TIES program. Adding acute crisis management responsibilities to TIES' system of positive behavioral supports not only assured programmatic consistency within Dane County's service system. It also helped to avoid the unnecessary duplication of services that can occur when pro-active (crisis prevention) services and re-active (crisis response) services are provided by separate entities.

In addition, assigning crisis response responsibilities to an established provider such as the TIES program greatly facilitated the process of expanding and refining the cooperation with providers

outside of the DD service system (mental health service providers, criminal justice practitioners) which is crucial for effective crisis management.

Workforce Development

The difficulty in developing a trained workforce was to have a number of people readily available, but not to have them sitting around waiting for a crisis to occur. The committee decided to selectively recruit a worker pool from the existing provider workforce. With the knowledge and encouragement of our providers, the Waisman Center TIES program contacted direct care staff who had previously completed the Waisman Center sponsored training: Managing Threatening Confrontations and were considered optimum candidates as CRS staff. These staff would agree to be on-call for crisis situations. Typically, the staff who worked for daytime support agencies would be recruited for evenings, and residential staff would be recruited for weekdays, and both would be available on weekends. In turn, these CRS staff would be paid at a premium rate, usually the equivalent of time and one-half of their regular pay.

Many of the newly recruited CRS staff would have previously completed various necessary training (Universal Precautions; Blood Borne Pathogens; Medication Administration) as part of their regular employment and would receive additional training on challenging behaviors and training specific to how the CRS operates, their responsibilities and the various components.

The last challenge in developing a CRS worker pool was the system of paying the staff. After a number of false starts, the County contracted with Goodwill Industries to act as a “temporary help” agency to payroll the staff and provide the necessary staffing benefits, such as Workers Compensation and professional liability insurance.

Currently, CRS has a trained worker pool of over 20 people. Workers are recruited and trained as needed. There has not been an open recruitment and workers are added by word of mouth. If demand increases, an open recruitment may be implemented.

In those occasions, where the crisis occurs in the familial home of a person with a developmental disability, the Mobility Training & Independent Living Program (MT&ILP) can provide:

- Occupational Therapy related assessment
- Related skills training in personal and daily living skills
- Longer-term come-in support staff

These individuals are typically receiving day support services and are on the waiting list for residential services. MT&ILP staff keep Dane County Intake apprised of continued need or need for alternative living.

Support Coordination

In 1993, the County began contracting with United Cerebral Palsy (UCP) to provide short-term support for individuals on the waiting list. The program, entitled the Adult Services Assessment and Planning Program (ASAP), provides assessment, planning, short-term consultation/coordination and referral to generic resources within Dane County. ASAP has provided assessment and planning services to individuals in institutional settings, family homes and when individuals have found

themselves without a stable home. It was a natural process to extend the ASAP program to individuals accessing the CRS who did not have system's case managers.

Access to Psychiatric Consultation

Dane County has had a contract with the Mental Health Center to provide counseling to adults and children with developmental disabilities. The Mental Health Center expanded its services to include a psychiatric consultation within 48 hours and has provided an accelerated access to counseling services.

Environmental Adaptations & Funding

As part of a growing systemic need, the Waisman Center has developed the Adaptation and Modification Project. This Project is designed to help people live in the community by providing safe environments that can accommodate challenging behaviors and/or physical accessibility and has become another component of CRS. Under the contract with the United Cerebral Palsy ASAP program, the County has advanced \$5,000 (that can be replenished) to be used in emergency situations for people on the waiting list. This availability was expanded to include the CRS.

Alternate Living Environment

The problem of having an alternative living space available on a continuous basis was easily resolved. The County contract with CCLS included support to people living in a duplex that had been modified in previous years to accommodate a 4 bed group home, plus an attached apartment for staff. As Dane County moved away from congregate living, only two people with disabilities were living in the home and they had expressed an interest in moving to another location. Instead of giving up the lease on the home, the County continued to contract with CCLS to lease the home. The contract included maintenance of the home with the maintenance staff living in the attached apartment. The maintenance staff has no role in the CRS other than assuring the home is prepared to receive visitors.

Certain modifications were made to the house to assure it was a safe and neutral environment. All windows were replaced with plexi-glass, a door was added to the kitchen in order to secure the area, if necessary and doors and doorways were added so the home could separately accommodate more than one individual at a time. The home already had been made accessible, including one of the bathrooms. All appointments were removed to provide a somewhat austere appearance.

Incentives to Assure Short Term Interventions

In order to not repeat the Adult Family Home problem, the CRS was to be limited to seven days for any one individual for a given episode. In addition, the cost of intervention would be billed back to the referring agency, encouraging the agency to aggressively take responsibility for all support. Realizing some situations may require additional time, the referring agency could request a 7 day extension. Agencies were required to provide the Committee with their own internal crisis response system and a plan for how the CRS would fit into what they were presently providing. Most agencies had a paging system with back-up staff, typically middle-management positions. The CRS was designed not to replace agency responses, but to augment it.

The committee needed to define what would constitute a situation where the CRS would be appropriate. It was easiest to define when it was not. The CRS would not be used:

- To respond to staff shortages.

- To respond to homeless situations where alternatives were available (homeless shelters, etc.)
- As alternative to hospitalization where hospitalization was appropriate
- To support individuals who had not been found eligible for service through the County
- As respite for caregivers

All other situation would be reviewed, person by person, for appropriateness of the referral. By limiting the types of emergencies and length of support time, and by building in a financial disincentive to extending the crisis support, the committee felt that short-term interventions would be honored.

System Administration

In order to provide a coordinated and effective response the Dane County Adult Community Services Developmental Disabilities Intake Unit (DD Intake), was given the responsibility to determine – usually in close cooperation with the Waisman Center’s TIES program - what parts of the CRS would respond to any given situation. DD Intake ascertains if the situation meets the criteria for CRS, which agencies should be involved and for what length of time. It also controls access to the Alternate Living Environment. In addition, all key members of the CRS (the CRS Committee) meet quarterly to examine processes and procedures and review CRS usage. Recommendation for changes are discussed and plans for implementation determined.

Limitations of the CRS

At present, access to the CRS is limited in both scope and time frame. Again, it is not the intention of the CRS to replace legitimate uses of psychiatric hospitals, nursing homes or the mental health institutes. It does, however play a significant role in preventing unnecessary stays or helping people transition back to their homes from these more restrictive settings. Ideally, the CRS works best for individuals who have been pre-identified as potentially in need of the CRS. We ask providers and the ASAP program to alert the DD Intake unit and the TIES program of any possible need that is looming on the horizon. This pre-identification - intake into the CRS must be made during the normal 40-hour workweek - is a prerequisite to benefit from the full range of available CRS services which can be accessed 24 hours, 7 days per week..

CRS & the Self Directed Support System

While the CRS was developed prior to Dane County’s efforts to redesign the system of supports for adults with developmental disabilities, it plays a key role in this new system. Briefly, the redesigned system, Self-Directed Supports (SDS), empowers people with disabilities and those that represent them, to define what support are to be received, when and by whom. This transfer of power comes with the transfer of support dollars from the County to a fiscal management agency, where the funds are held until the person with a disability and their Support Broker (previously Case Manager) withdraw the funds to purchase supports. These funds can be spent on any support service they deem necessary as long as the plan of supports provide for safety, protection and preservation of individual rights. Consequently, individuals with disabilities may well choose to receive supports from non-traditional providers.

Typically, the CRS depends on traditional providers to pre-identify people and situations that may need CRS support. While these agencies will alert DD Intake, referrals may come from the Support Broker as well. And where support is being provided in non-traditional ways (a person may wish to

hire their neighbor to provide support), the CRS system can play a significant back-up role as long as the “back-up” plan has been approved by the CRS. Consequently, if a neighbor is to provide direct support and cannot do so, CRS can provide backup if it has been pre-approved.

Sound Response System For People with Developmental Disabilities In Dane County

The Dane County Developmental Disability system has long prided itself in developing creative support models in promoting self-determination for individuals with disabilities. The Waisman-Community TIES program is partnering with Dane County in initiating another such effort. The program is titled "Sound Response."

For individuals who may occasionally need overnight support, Dane County often approves and funds ongoing overnight staffing. This support model assures safety but is staff intensive, costly, and somewhat intrusive. (Individuals are required to share their homes with live-in staff who frequently change.) An alternative approach, when night time intervention is warranted only rarely, is to offer a combination of off-site monitoring with quick response by familiar, professional staff, as an effective service model for assuring safety and promoting independence.

Sound Response strives to supplement direct staff support through the creative use of technical/mechanical supports. These technical/mechanical supports are in the form of a variety of monitoring devices, which already are being utilized in private homes and security systems. These include speaker phones, pagers, motion detectors, smoke detectors, various burglar alarm systems, closed circuit television, baby monitors, personal assistance systems, and door and window sensors, to name just a few. This type of remote support is being embraced in the field of geriatrics and it is anticipated that a broader array of innovative devices will be made available in coming years.

The system combines a number of these devices (based on the individual's needs and wishes) allowing off-site response staff to be alerted and to provide support and intervention only when necessary. The Department of Human Services, in concert with developmental disability residential agency providers, have identified individuals who currently have live-in support, but who could benefit from this new support model. This model will not include individuals who are medically or behaviorally at risk, but who typically sleep through the night and have paid live-in staff "just in case". It does not affect the support participating individuals currently receive during awake hours..

Sound Response is set up in strategically located monitoring sites, which is staffed after typical work week hours. Staff positions are professional and require a degree in human services and extensive experience in the field of developmental disabilities. Staff will receive standard training (Blood Borne Pathogens, Universal Precautions, First Aid, CPR, Medication Administration, Crisis Response, etc.) but also receive specific training around the individuals that they support. Staff have relevant records and protocols available on each individual at the monitoring site, and also spend time with the individual on an ongoing basis so both parties are comfortable with each other. Sound Response staff become part of the individual's team.

Every participating residence has at least one monitoring device placed in the most appropriate area. As day support staff leave the residence at the end of their shift, they activate the device, which will

notify the off site monitoring staff - via a LED light or an alert system - of any unusual activity at the residence.

Depending on the type of the unexpected activity (this could include sounds, temperatures, smoke, or commotion), the monitor speaks to the individual over the phone (or speaker phone) to ascertain immediacy of need; drives to the residence to provide necessary support; contact the current crisis support team; involves the necessary authorities (Fire, Police, EMS); or uses any combination of these responses.

The first of these households was set-up in March 2002. As of August 2003, 101 individuals, comprising 59 households are using Sound Response. Monitoring staff has been hired and trained and additional households are being assessed for types of monitoring devices. The system has expanded and staff has been hired to act as the Responders in Stoughton, Mt. Horeb, on Madison's east and downtown areas, in addition to the original south side location. A west side location is currently being developed.

There is a continuing interest from the Dane County Aging network as well as counties adjoining Dane to the Sound Response system. It is anticipated that the Sound Response system will continue to grow significantly in light of current funding cut-backs. It provides both an increase in individual choice and freedom while providing a cost efficient measure of protection and safety.

Response to Abuse or Neglect For People with Developmental Disabilities In Dane County

Historically, the communities have considered abuse and maltreatment of people with developmental disabilities to be a human service problem. And the people in the human service system have worked in isolation, assuming complete responsibility for the safety and well being of people with developmental disabilities. Law enforcement officials often did not have the tools to respond effectively when a person with developmental disability was a victim of a crime. People with disabilities were viewed as poor historians and often their credibility was in question. They frequently did not receive the same treatment in the criminal justice system as the general population.

Research has shown that 83% of females and 32% of males with developmental disabilities have experienced sexual assault (Hard, 1986). Another study found that of those who individuals with developmental disabilities who were assaulted, 50% had been assaulted 10 or more times (Sobsey and Doe, 1991). Adults with disabilities are 4 to 10 times more likely to be sexually assaulted than rest of population (California Committee on Sexuality of Persons with Developmental Disabilities). As these grim statistics illustrate, people with developmental disabilities are at an increased risk for being victims of sexual abuse, domestic violence, financial exploitation and other crimes.

Legal Advocate

Recognizing this problem, Dane County Adult Community Services (ACS) with start-up funding from the Wisconsin Council on Developmental Disabilities, created a Legal Advocate position in 1999, to enable people with developmental disabilities (and those who support them) to respond

effectively when they are victims of crimes. The primary responsibilities of the Advocate position include:

- ◆ Technical and emotional assistance to the victim when negotiating the criminal justice system and auxiliary services
- ◆ System advocate for the issues of victims with developmental disabilities
- ◆ Bridge between the criminal justice and the human service system
- ◆ Education of both human service providers and law enforcement

The Legal Advocate serves as a liaison to law enforcement, the District Attorneys Office, and Victim/Witness personnel and assists criminal justice workers in identifying the unique needs of victims of crime who have developmental disabilities, especially in the area of communication. Additionally, the Legal Advocate:

- ◆ Provides counseling and obtains generic advocacy assistance for the victim.
- ◆ Does follow-up case management and safety planning with the victim.
- ◆ Provides training to human service agencies on recognizing power and control issues, subtle forms of abuse, and signs of sexual abuse.
- ◆ Trains criminal justice personnel on identifying and communicating with people who are developmentally disabled.
- ◆ Co-leads a support group for women with developmental disabilities who are survivors of sexual abuse or physical violence.
- ◆ Is part of the Dane County Commission on Sensitive Crimes Coordinated Community Response Task Forces on Sexual Assault, Domestic Violence, and Developmental Disabilities and Crime
- ◆ Has partnered with the ACS Community Services Consultant and agencies inside and outside of the developmental disabilities system to present conferences on sexual assault, domestic violence and financial abuse

Since 1999, the Legal Advocate has responded to more than 100 victims of crime. Each year sexual assault has been the most frequently reported crime.

Identification and Reporting

In 2000 Adult Community Services revised its Policy Guidelines for Abuse and Neglect for Developmental Disabilities contracted agencies, using a nationally recognized model approach. All agencies are required to report all suspected or known abuse towards any adult with developmental disabilities for whom the agency provides supports to the ACS's Community Services Consultant. Each contracted agency has at least two employees who have been trained to do internal fact-finding of possible abuse. In this way abuse is noticed and addressed more quickly and in the appropriate way.

The ACS Consultant collaborates with the Legal Advocate regarding the abuse that has been reported to the criminal justice system. Collaboration with the criminal justice system and victim support agencies has demonstrated how important early detection and coordination is in identifying and solving the issues that face people with developmental disabilities who are victims of crime.

In addition, contracted agencies must report all suspected or known neglect to ACS Consultant. Each agency has policies prohibiting behavior by their staff members which, because of the failure to provide adequate food, shelter, clothing, medical care or dental care, creates a significant danger to the physical or mental health of a consumer. The ACS Consultant and the agency's fact finder work collaboratively on suitable solutions to these problems. They also work on prevention through systemic changes and policies.

Community Collaboration

Due to the efforts of the ACS Consultant and the Legal Advocate, in 2001 the Dane County Commission on Sensitive Crimes established a Coordinated Community Response Task Force to deal with crimes toward people with developmental disabilities. County, provider agency and law enforcement staff is part of this committee. The committee continues to work on identifying gaps that victims with developmental disabilities have experienced and developing solutions. Because of this coordinated effort, people with disabilities face are experiencing improved outcomes when involved in the process, just like any other citizen. Already, a number of perpetrators of crimes have been arrested and charged.

With cooperation from the Rape Crisis Center, a support group has been formed especially for women with disabilities who are sexual assault victims. Prior to this there were no counseling or support services for victims of sexual assault who have developmental disabilities outside of the human services system.

These collaborative efforts have demonstrated how important coordination is to identifying and solving significant issues and what better advocated we have become on behalf of people with disabilities when we join with others.

Training

For the last three years ACS has sponsored an annual conference that addresses crimes and people with disabilities. The topics included sexual assault, domestic violence and financial abuse. The purpose of the conferences was to raise awareness in the developmental disability community about these crimes, to introduce the community leaders in the criminal justice system and to people connected to those systems. The department worked cooperatively with the criminal justice system and other providers to organize these events.

Over the past year, staff members from agencies that service people with developmental disabilities have received training and technical assistance from law enforcement officials to enable them to respond to sexual assault in a more effective way. The criminal justice system, in turn, is incorporating training on the issues of crime victims who have disabilities.