

**KRONKOSKY CHARITABLE FOUNDATION
ROUNDTABLE DISCUSSIONS**

TOPIC: Respite Care
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PREPARED BY: Stephen Shin

PARTICIPANTS

Invited Representatives

Vicki Aguirre-Cox	Executive Director	Brighton School
Jack Downey	Executive Director	Children's Shelter of San Antonio
John Garcia	Community Management Team	Texas Department of Health
Sheila Langston	Program Planner Provider Relations	Interagency on Early Childhood Intervention
Ken Lawrence Center	Education Specialist	Education Service Region 20/ Community Resource Coordination Group
Jan McGuire	Program Administrator Provider Relations	Interagency for Early Childhood Intervention
Liz Newhouse	Assistant Director	Texas Respite Resource Network
Katy Slokiner	Director of Family Support	CAMP
Patty Teeter Michele Wiley	Executive Director Assistant Executive Director	Respite Care of San Antonio CAMP

Foundation Staff and Trustees

Palmer Moe	Executive Director
Megan Kromer	Director of Program and Evaluation
Stephen Shin	Student Intern

Overview of Agencies

Brighton School

The Brighton School is one of three Early Childhood Intervention [ECI] providers in San Antonio. As a response to ECI's new initiative for respite care, the Brighton school is now currently exploring options to ascertain the most efficient and effective method to provide respite care services.

- Represents the San Antonio Consortium of ECI providers in San Antonio.
- Offers or can arrange a host of ECI services.

Children's Shelter of San Antonio

The Children's Shelter of San Antonio [CSSA] provides an array of services ranging from emergency shelter to respite care programs. Since its merger with the South Texas Children Habilitation Center, the CSSA has begun to provide speech, movement and other forms of therapy.

- Offers emergency shelter, foster care and adoption services.
- Offers respite care within three programs:
 - Homeless Shelter- cares for children to enable their respective parents to gain employment during the day.
 - High School - cares for children whose parents are currently attending to high school or some education program to earn their diploma.
 - Emergency Shelter - cares for children whose parents desperately need respite care for unforeseen reasons, many concerning medical conditions.

Texas Department of Health

The Texas Department of Health (TDH) oversees and funds multiple health care programs throughout the state of Texas. Primarily, the TDH is interested in providing the necessary resources for normal physical and environmental development of a child. Included in this is medical, behavioral and environmental services.

Interagency Council on Early Childhood Intervention

The ECI serves children from 0-3 born with some developmental delay and their parents to alleviate the severe educational and environmental deficiencies that these children face at a pivotal period of development. ECI's goal is to foster an environment that will allow all children to develop to their highest potential.

- Children must exhibit some sort of delay, either in educational, developmental or medical manners.
- ECI offers over 20 types of services including medical, diagnostic, nursing, speech and hearing.
- After over 12 years of petitioning the State Legislature, funding was finally allocated recently for the development of a respite program with the intention of adding respite care to the package of services that ECI offers.
- The ECI has participated in respite care in the past through other programs.
- The ECI currently serves approximately 24,000 children across the state of Texas.
- Though the program has funding, the respite care is budgeted \$1,000,000 over a two year period. The ECI is currently researching and developing the program, with the initial program being modeled after voucher programs.

Education Service Center - Region 20

The Education Service Center [ESC] allocates Texas Education Agency funds towards non-education programs like leisure management, socialization, and respite care.

- The ESC operates on a very limited budget that must cover program expenses and administrative costs. There has no been recent growth in funding.

- Administrative costs are particularly prohibitive because of the structure of the education finance system.
- Particularly in the case of respite care, the system suffers from an inefficiency which does not regard the child's well-being as its ultimate goal. ESC cannot direct respite care services at its discretion; school districts must apply for funding for it, which many do not do. Though most school districts provide adequate in-school services to these children, the school administrators are hesitant to request respite care because it places the school district at the risk of being obligated to pay for residential care which is particularly costly.
- Residential care cost average around \$123 dollars per day which does not include educational or related services.
- Last year, the TEA provided residential care for only three children at a cost of \$92,000 per child for the year. This year, that cost is expected to increase to approximately the \$100,000-115,000 range.
- The complex state regulatory system and administrative process augment the difficulty that ESC has in administering the program.

Texas Respite Resource Network

The Texas Respite Resource Network [TRRN] works to foster the development of respite care that adequately meets the need of all Texans in need of respite services. The TRRN functions on multiple levels: at the state, county and community levels.

- The TRRN, in conjunction, with the ECI, works to obtain more federal funding, as well as examining policy to see how they can become more user-friendly for local respite-care providers.
- In San Antonio, the TRRN helped start the Respite Care of San Antonio and Respite Care Station at Santa Rosa. The TRRN has also worked to create community-based coalitions for the advocacy of respite care.
- The TRRN is federally funded through the Disabilities Council which is given to states who then distribute the funds at their discretion.

CAMP

CAMP has served children afflicted with serious development related disabilities in Bexar County and the outlying counties for 20 years. Started in 1979 as a camping program, CAMP has evolved to expand its service to meet the needs of their clients. In 1991, CAMP initiated a complete respite care program.

- CAMP operates a 350-bed facility located outside of Kerrville used for camping and respite care.
- In San Antonio, CAMP is currently exploring the development of a new facility.
- CAMP provides many options to its clients, and its clientele has expanded due to the efforts of the advocacy of TRRN. Yet, CAMP's funding has not kept pace with the client increase, creating a situation in which potential clients are placed on a waiting list.
- Offers in-home pediatrician and nursing services.

Respite Care of San Antonio

Started as a model program by the state for in-home care of adults and children 12 years ago, Respite Care of San Antonio [RCSA] offers out-of-home respite care services, a respite house and other respite services in other facilities around the city.

- Last year, RCSA received licensing to become a crisis center for homeless children.
- RCSA has a large client waiting list as it is unable to provide care without increased funding.
- RCSA charges on a sliding-ability-to-pay scale, but many of the clients that they serve are unable to pay anything.

Issues

In understanding the state of respite care in Texas, it is necessary to understand the situation of their clients. Respite care is based on the idea that families are the best caregivers of developmentally disabled children, and thus, the importance of establishing a network of support services designed to keep families together cannot be underscored strongly enough. Developmentally delayed children require great attention and care, many of which families are not prepared or able to sufficiently provide. The great emotional, financial and physical sacrifice exacted from the family often leads to divorce, insufficient care, abuse/neglect of the child and ultimately, to the institutionalization of the child. Providing support services such as respite care better equips families to cope physically, emotionally and financially with the task of raising the child. Disregarding emotional considerations, preservation of the family unit ultimately proves to be more cost effective to the state over the child's lifetime because families are better suited to care for the child and cheaper than costly state institutions.

- Despite this, respite care has failed to garner the attention of the State Legislature. In spite of ECI's attempt for the past 12 years, only now has funding been allocated for the development of respite care, and even then, ECI's conservative request (given the projected need of respite care services in Texas) of \$8 million, the legislature appropriated only \$1 million over the next two years.
- For years, respite care providers were told that funding would not increase because of budgetary constraints. However, this year, the Texas Legislature had a budget surplus, in addition to money from the tobacco settlement, and even with that, Health and Human Resources received very little.
- State agencies have not been very aggressive in attempting to augment federal funding. The federal government determines allocations by a scale in which the government matches (dollar for dollar) the amount of money a state is willing to offer for a service. The state is particularly poor in taking advantage of this opportunity, in part because many of the agencies are unwilling to cooperate and pool sources to earn more money because of turf rights.
- Many believe that respite care is overlooked because of its lack of political clout. A majority of those served through respite care programs are poor, and those respite care advocacy attempts are undermined by the lack of a voting block. In addition, the overall lack of money precludes lobbying for more support.
- The perceived lack of importance that respite care seems to suffer from may be due to the misperceptions about what it actually is. Many equate respite care with babysitting.

- Texas ranks 48-50th in funding for health and human services in the United States. In addition, many states have increased funding of community-based services for individuals with disabilities instead of segregating them into institutions. Some states have closed all of their large congregate institutions, but Texas still spends more on institutional care than on community-based services and has only closed two large institutions.
- In San Antonio, there are three community-based programs that provide high quality respite and support services to families, however, they are constantly seeking funding to keep their programs alive and cannot meet the needs of all the families who need respite care.
- The Center for Health Care Services has mismanaged funds, wasting money that could have been used to provide more or better services. Their inefficiency may be part of the reason that Bexar county has not received better funding. Respite Care of San Antonio has had to threaten legal action for payment of services contracted with the center.
- Families in rural areas have a harder time because there are very few respite care providers in the outlying counties.
- With improved medical technology, these developmentally delayed children are living longer than they had in previous years. Many times, they outlive their parents, leaving them with an uncertain future. Where these children go and at what cost is quickly becoming an issue that needs to be addressed.
- Eligibility for Medicaid children's services ends at 21 years of age. There are fewer services under Medicaid for adults and so many families face reduced services for their family members as they get older.
- The need for respite care in the area is high. There are waiting lists for all the programs, and providers have to consistently deny people who need service.
- The situation will probably become worse before it gets better because a majority of funding for community providers comes from private sources in the community, which many think are fast tiring of funding. Recently, USAA and Diamond Shamrock, two large corporate donors, have reduced the amount of money contributed to the community.
- If the community respite care providers close their doors, the problem will become worse as many of the children will be transferred to state institutions which do not meet the needs of the child.

Future Directions

- Although much progress has been made in the availability of state/federal funding for respite services over the past 10 years, the current level of funding is far below the level of need for this service.
- The state agencies and the community providers need to collaborate on finding cost effective ways of utilizing available funds. There is a realization from the state level that this is the goal for the future and the state agencies are being required to work with local communities to reduce fragmentation and red tape.
- There is a need to ensure that providers are trained properly in safety.

- The system must be reformed. Many providers are leaving/retiring because they are frustrated with attempting to cope with the inefficiency of the system. The system needs to enfranchise the families with a proactive role in the securing of services.
- There is a need to develop a flexible, affordable respite system that meets the needs of families and that addresses both the planned and crisis aspects of respite. Respite is the most cost effective family service and respite can prevent families from falling apart.
- Advocacy groups have urged the state to develop a single point of entry for services and some progress has been made in the formation of a long-term care agency during this past legislative session. However, the time frame to change the system will be extensive and the system remains fragmented for families. Models from other states are being reviewed.
 - In Texas, families are often left to their own devices to earn the money needed.
 - Tennessee and Kansas both have similar models and rank near the top in providing respite care to their citizens.

Parting Thoughts

- Currently, there is not enough respite care to meet the need of the community.
- Respite care providers must find a way to develop flexible funding sources.
- Collaboration among providers equals maximization of services.
- The most effective system of respite care is to provide a single-entry point through which everyone is directed to providers.
- Respite care is a proactive way to serve families.
- A small increase in funding would affect a large difference for families.
- Respite care is investment in family.
- Providers must find a way to eliminate the waiting list.
- Prevention is the key to respite care.