

**Aging
with
Developmental
Disabilities:**



**The
Texas Project**

*Funded by the Texas Council for Developmental Disabilities
and the Texas Department on Aging*

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Aging with Developmental Disabilities

Texas Council for Developmental Disabilities ★ Texas Department on Aging



The Texas Project

Chapter 1

Executive Summary

1.1 Genesis of the Texas Project

Growing concerns around issues involving aging people with developmental disabilities (DD) and their aging caregivers prompted Texas to join the quest for solutions. In 1996, the Texas Department on Aging (TDoA) submitted a proposal to the Texas Council for Developmental Disabilities (TCDD) for a five-year project to develop pilot projects in a minimum of four communities to increase community integrated services for aging individuals with developmental disabilities, or for aging caregivers with dependents having DD.

TCDD awarded TDoA \$1,057,951 over a five year period from October 1996 and through May 2001. An additional \$600,000 which represents cash and in-kind contributions was also provided to assure adequate funding and continuation of supports and services across the state.

1.2 Year One: October 1996 through May 1997

TDoA's first activity in 1996 was creating a statewide consultant committee to guide the development and implementation of the project. The members of this committee were asked to bring their expertise and experience, not only in the areas of aging and developmental disabilities, but in other areas critical to a well-balanced approach for the project, including self-advocacy skills, insurance matters, financial and estate planning, life planning, and legal issues.

Initially, this group worked with TDoA to develop the project plans, and to develop and disseminate a request for proposal to the Texas Area Agencies on Aging (AAAs) for developing model local projects. The committee believed that it could be possible to expand this project beyond the four pilot projects required by the TCDD, and might even be possible to construct the project so that all 28 AAAs could become involved.

Beginning in 1997, TDoA planned to fund up to seven area agencies on aging (AAAs) each year for four years. Each AAA was to receive \$37,500 over a two-year period. Funding for the third year and beyond would be the responsibility of each local project and AAAs were instructed in their initial proposal to address their plan for supporting their local project. By the fourth year, TDoA hoped to have most AAAs participating in the project.

1.3 The Next Four Years

In June 1997, funding was awarded to seven AAAs to launch their local projects. These AAAs represented both urban and rural service areas. In June 1998, five more AAAs joined the project, and in June 1999, one additional project was added.

At this point it became apparent that the initial plan for funding seven new projects each year was not feasible for a variety of reasons. Therefore, the plan was revised to continue funding to the initial seven projects. For 1999, only one AAA submitted a proposal to launch a new project.

1.4 The Texas Money Management Project

As a result of the Texas Council for Developmental Disabilities' (TCDD) approval of the TDoA's amended work plan for the final two years of the grant, a contract was entered into with the Texas Money Management Program (TMMP) through the Health and Human Services Commission (HHSC). This contract was to provide technical assistance to AAAs and local communities in the development and maintenance of local money management programs as a less restrictive alternative to guardianship.

The Texas Money Management Program is a non-profit technical assistance program designed to prevent financial abuse, neglect and exploitation of low-income older adults and adults with disabilities who are at risk of losing their independence due to an inability to manage their finances. The program assists local communities in the development of money management programs and provides technical support for existing sites around the state. It provides a less restrictive alternative to guardianships by assisting those who would otherwise have their rights taken away.

1.5 Local Projects

Over the course of the project, a total of 13 AAAs joined the effort. Of these, nine projects were still in operation in May 2001. Each local work group approached the task a bit differently, and the outcomes reflected both the

differing approaches as well as the impact of circumstances that arose during the course of the project. A case study on each of these nine projects is presented in Chapter III.

1.6 Best Practices

Chapter IV discusses the best practices to have emerged from the project. These are categorized into three broad categories: collaboration, outreach, and capacity building. While the overall goals of this project have been relatively simple and straightforward, the process of achieving it's goals has not.

1.6.1 Collaboration

Obviously when creating a new collaborative initiative, it is important to find ways to bring key stakeholders to the table. Many funding agents today stipulate that the projects they fund must have a collaborative aspect. However, simply mandating collaboration and then making it happen are two different things. In order for collaborative initiatives to truly succeed, it is important that the collaborative relationships become a by-product of the planning process for other aspects of the initiative.

We believe that one of the most important factors in determining the success of a collaborative initiative is that the community must have an identified need that generates a strong sense of urgency, which, in turn, brings key stakeholders together for problem solving.

1.6.2 Outreach

In order for a new community effort to reach its target audience (in this case older people with DD and their aging caregivers), it's crucial to communicate its existence and purpose widely to the general public. The best outreach practices used by the Texas project included

- holding resource fairs,
- distributing resource guides through the local newspaper,
- inserting flyers in utility bills, and
- using internet websites.

1.6.3 Capacity Building

Once the key stakeholders have agreed to work collaboratively, it is important to start building capacity - first within the members of the collaborative work group, and second within the larger group of providers, consumers, and other local stakeholders. This is an ongoing process that requires a number of approaches, including cross training staff of the local provider organizations, and education and training of the larger group of stakeholders and consumers.

Some of the best practices to have emerged from the Texas project included:

- Cross-training tours
- Brown bag lunch seminars
- Cross-training video
- A Regional Learning Collaboration
- The Access Center for the Elderly (ACE) Project
- The Community Resources Coordination Group for Adults (CRCGA)
- The FRAGILE Populations Emergency Response System Registry and Volunteer Network

1.7 Linking Across Distances

What is a great paradox in this information age? What is a common complaint among members of any organization or group? What tends to keep people from taking advantage of all of the opportunities that are open to them?

The simple fact is that despite the widespread availability of information today, getting the needed information to the right person in a format that he or she will understand and utilize is a huge challenge.

When linking people across a state as large as Texas, technology can play a vital role in making sure that all players have the necessary information to carry out their roles. Some techniques that have been helpful for the Texas project include:

- Utilizing e-mail and listserves
- Audio conferencing
- Web conferencing
- Video conferencing

1.8 Lessons Learned

At the conclusion of this project, we have learned many lessons, including some that would lead us to approach this project differently had we the chance to start over again. The most important of these lessons included:

■ It takes more than two years.

In our initial plan, we had thought that two years of funding was sufficient to launch these projects in the local communities. However, at this point we are seeing that a minimum of three years duration for a project of this type is necessary with this level of funding. It takes time to introduce and develop new concepts with staff in public agencies to effect change. The level of funding is adequate for a part-time effort, which, when spread out over three years in small doses is more readily acceptable and therefore more likely to succeed.

■ Hire an independent contractor for project coordination.

An independent contractor for the project is preferable to an in-house coordinator at the AAA for the following reasons:

- ◆ AAA staff availability and expertise in working with people with disabilities may be limited.
- ◆ A partnership between a AAA and a disability organization demonstrates to other agencies the effectiveness of a collaborative model.
- ◆ Funds were consistently utilized because an independent contractor operates on a performance-payment (fee for service) basis.
- ◆ Contracting out provided an opportunity for an AAA to expand its' sphere of influence beyond the "box" of other state/ public agencies and in particular to include new and necessary relationships with disability organizations.
- ◆ Disability organization(s) in non-advocacy/fragmented communities benefit from the coat tails of a compatible organization that can lend credibility to disability issues to the community at-large, directly impact the development of a disability system similar to a successful AAA model, and provide a source of much-needed funding to sustain disability advocacy/organizing efforts.

■ **Concentrate on a few model projects.**

The initial plan in Texas was to spread the funds out in small amounts over the entire state. As we saw during the course of the project, not all areas of the state were interested in participating in this project, and in later years, the project was reduced to a few key locations where there was sustained interest. In hindsight, it may have been more effective to offer a larger amount of funding to fewer pilot projects from the beginning.

Aging with Developmental Disabilities

Texas Council for Developmental Disabilities ★ Texas Department on Aging



The Texas Project

Chapter 2

Overview of the Texas Project

2.1 Background Information

The 20th Century has seen an unprecedented increase in the life expectancy of the average American. As the life expectancy of the average American has increased, so has the life expectancy of the average American with developmental disabilities (DD). As recently as the 1960s the median life expectancy for people with DD was just 35 - 40 years. Today the life expectancy for those with mild and moderate impairments is approaching that of mainstream adults.

This increased life expectancy has created a new dilemma for both service providers and the families/caretakers of these individuals.

- For the first time, DD service providers are finding themselves faced with aging clients. The DD service system has not been prepared for this, as the DD system has largely been built on a pediatric model. Further, the DD service system is a bit fragmented, with the different disorders under the DD umbrella (mental retardation, visual impairments, hearing impairments, autism, traumatic brain injury, epilepsy, cerebral palsy) tending to have separate service systems.
- For the first time, providers of traditional aging services are being asked to serve people with DD. The aging network grew out of strong advocacy on behalf of mainstream elders, promoting the quality of life for these individuals. Consequently, this system has been reluctant to integrate with services for various health problems and disabilities. In fact, some advocates for older people insist that to serve this group would be tantamount to implying that aging is a disabling process.
- For the first time, professionals who have worked in the fields of DD and those who have worked in the area of gerontology are finding themselves needing to find a way to bridge their services.

- For the first time, older caretakers of people with DD are finding that there is a very real possibility that their loved ones may outlive them.

A further complication is the fact that many older adults with DD have lived their lives in the community with their families, and have not been part of ongoing service systems. In many ways these people are hidden from view. These individuals typically turn to formal service systems only when their existing support system is no longer able to provide for them. Often, this happens rather abruptly, following the death or incapacitation of the primary caregiver.

Precise prevalence rates for developmental disabilities in the United States are not available. Factors contributing to the difficulty of arriving at hard numerical estimates include:

- The case definitions for developmental disabilities often rely on clinical examinations and clinical judgment rather than on results from laboratory reports.
- Historically, standards for defining specific types of developmental disabilities have been defined state-by-state, without the benefit of having a national standard.

Nevertheless, the Centers for Disease Control estimate the prevalence of developmental disabilities among 10-year-old children in selected study areas at 2.22%. Developmental disabilities are life-long conditions, and it is not unreasonable to believe that a minimum of 2.22% of the adults age 60 and over have a developmental disability.

These issues are forcing both families and service providers to consider new ways to meet the needs of these individuals as they age.

2.2 Genesis of the Texas project

Growing concerns around these issues prompted Texas to join the quest for solutions. In 1996, the Texas Department on Aging (TDoA) submitted a proposal to the Texas Council for Developmental Disabilities (TCDD) for a five-year project to develop pilot projects in a minimum of four communities to increase community integrated services for aging individuals with developmental disabilities, or for aging caregivers with dependents having DD.

TCDD awarded TDoA \$1,057,951 over a five year period from October 1996 and through May 2001. An additional \$600,000, which represents cash and in-kind contributions was also provided to assure adequate funding and continuation of supports and services across the state.

Over the five-year course of the project, the following TDoA staff served as Project Director:

- Christy Fair (October 1996 - January 1999)
- Jeannie Boatman (January 1999 - July 1999)
- Gary Jessee (October 1999 - May 2000)
- Ray Bryant (June 2000 - May 2001)

In addition, TDoA contracted with the following individuals for project coordination:

- Jim Stone, Third Age, Inc., Lexington, KY (October 1996 - May 1999)
- Linda Fulmer, Fulmer & Associates, Fort Worth, TX (June 1999 - May 2001)

2.2.1 Similar projects in other states

The reauthorization of the Older Americans Act of 1987 and the Developmental Disabilities Act and Bill of Rights of 1987 placed requirements on the state agencies responsible for aging services and developmental disabilities services to seek to serve the aging and older populations who qualified under the definition of severe disabilities. The Assistant Secretaries of the Administration on Aging and the Administration on Developmental Disabilities encouraged state agency participation in cooperative efforts between aging and developmental disabilities by signing memorandums of understanding for collaboration and cooperation to serve this targeted group across the country. However, as late as 1993, less than 1/3 of all the states (15) had developed a memorandum of understanding between these two state agencies. The memorandum called for the review of each agency's annual plan by both agencies to see what services and programs would be available to the population with developmental disabilities who are aging. The Developmental Disabilities Councils were to provide for a representative member of aging services to be a member of the Council.

To further this process, the reauthorization of the Older Americans Act in November 2000 (Public Law 106-501), established an important new program, the National Family Caregiver Support Program (NFCSP). Developed by the Administration on Aging, this program was modeled in large part after successful long term care programs in several states and after listening to the needs expressed by hundreds of family caregivers in discussions held across the country.

The program calls for all states, working in partnership with area agencies on

aging and local community-service providers to have five basic services for family caregivers, including:

- Information to caregivers about available services
- Assistance to caregivers in gaining access to supportive services
- Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities
- Supplemental services, on a limited basis, to complement the care provided by caregivers

The statute requires states to give priority consideration to

- persons in greatest social and economic need (with particular attention to low-income, minority individuals); and
- older individuals providing care and support to persons with mental retardation and related developmental disabilities.

In developing its own project, Texas sought to expand on the base of knowledge developed by similar initiatives in other states. The following is a summary of these other initiatives.

2.2.1.1 New York

New York led efforts to initiate collaborative efforts to benefit older people with developmental disabilities. The state sponsored a pilot project under the leadership of Matthew Janicki and Philip LePore that funded four counties (two rural and two urban) to

- identify the needs of the target population,
- map the availability of services, and
- focus on educating the DD service staff on how to access aging services.

Outcomes of this project included information and materials on the techniques used to initiate and operate the projects during the funding period.

2.2.1.2 Maryland

Maryland's approach, called "Partners", was coordinated by Edward Ansello and Iris Gordon. The project focused on educating and sensitizing staff members of the aging and DD systems by having representatives to work in the other agency for two or three days. The hope was that this would give staff a perspective of what was going on and the resources available for serving the aging and older population. Local people were recruited as aging / DD specialists to assist in opening the service systems of both agencies to the target population.

2.2.1.3 Ohio

Under the leadership of Ruth Roberts and her staff at the University of Akron, the Kennedy Foundation funded a five-year project entitled "Friends". This project promoted the use of older mainstream volunteers as mentors for older people with developmental disabilities in the Akron area.

Through the project a limited number of older people with DD were involved in community activities for a few hours each week, and were accompanied by a mainstream companion. The project funds were used to cover mileage expenses, insurance for the volunteers, and small stipends if necessary.

This project set the stage for the collaboration of a multi-site university research project (seven in six states) to create the first Rehabilitation Research and Training Center (RRTC) on Aging and Developmental Disabilities funded by the National Institute on Disabilities and Rehabilitation Research beginning in 1988.

2.2.1.4 Illinois

The state of Illinois project focused on moving people with developmental disabilities from skilled nursing homes into community residences. Alan Factor and Tamar Heller were instrumental in assisting the planning and assessments of needs.

Both are faculty members at the Institute for Human Development at the University of Illinois at Chicago and have been involved in a longitudinal study of 300 older families caring for adults with DD since the mid 1980's.

2.2.1.5 Kentucky

The state of Kentucky has funded model aging projects in rural areas that focused on person centered planning and accessing the available and current resources of the local communities. These models are still operating and providing individualized options and supports in four of eight sites.

Kentucky's DD Council funded two series of demonstration projects in 1988-91 and 1992-94. A statewide needs assessment was conducted in 1993-94 where more than 200 older people with disabilities and their aging caregivers had the opportunity to voice their needs and concerns in 18 public forums across the state. In addition, more than 800 agencies and staff members were involved in education and awareness training of the impact on aging and DD, and the needs of this target population. Jim Stone, CEO of Third Age, Inc. was the person who directed these activities.

2.2.1.6 Florida

The state of Florida conducted joint planning sessions among the aging and developmental disabilities service agencies during a two-year period.

2.2.1.7 Colorado

In 1990-91 Colorado launched an effort to fund specific aging support services for older people with DD who were ready for typical retirement activities. Selected staff attended the Lexington Conference on Aging and DD in 1991 with the charge to bring back information that could be adapted to the state systems.

2.2.1.8 Mississippi

Under the leadership of Paul Cotton, Mississippi has sponsored an annual state conference between aging and MR/DD service providers for more than a decade. Older people have moved from institutional environments to small group homes accessing senior centers or other available activities.

2.3 In the Beginning: 1996 - 1997

TDoA's first activity in 1996 was creating a statewide consultant committee to guide the development and implementation of the project. The members of this committee were asked to bring their expertise and experience, not only in the areas of aging and developmental disabilities, but in other areas critical to a well-balanced approach for the project, including self-advocacy skills, insurance matters, financial and estate planning, life planning, and legal issues. The committee included representatives from:

- Other advisory committees to the Texas Department on Aging
- Texas Department of Mental Health Mental Retardation

- Social service agencies
- Guardianship groups
- Texas Department of Health
- Texas Department of Insurance
- Public advocacy groups
- ADAPT and other self-advocacy groups
- Aging citizens with DD and their older family caregivers
- University Aging Research Centers
- Arc of Texas
- Arc-United States

Initially, this group worked with TDoA to develop the project plans, and to develop and disseminate a request for proposal to the Texas Area Agencies on Aging (AAAs) for developing model local projects. The committee believed that it could be possible to expand this project beyond the four pilot projects required by the TCDD, and might even be possible to construct the project so that all 28 AAAs could become involved.

The committee developed a point system for reviewing each proposal and recommended approval, disapproval, or approval with specific conditions to the Texas Board on Aging, which accepted the recommendations of the committee. The committee reviewed project reports and recommended action for continuation of projects to the Texas Board on Aging. These responsibilities were major functions of the group, which was called the TDoA-DD Project Consultant Committee.

2.3.1 The Initial Plan

Beginning in 1997, TDoA planned to fund up to seven area agencies on aging (AAAs) each year for four years. Each AAA was to receive \$37,500 over a two-year period. Funding for the third year and beyond would be the responsibility of each local project and AAAs were instructed in the initial proposal to address their plan for supporting their local project. By the fourth year, TDoA hoped to have most AAAs participating in the project.

To keep the project manageable, each AAA that received funding agreed to address the following:

Year One Objectives

1. Develop on-going cooperation and collaboration relationships between the aging and developmental disabilities service agencies at the local level.
2. Identify gaps in the support system and interagency training requirements in the local project areas and develop local plans of collaboration.
3. Orient and cross train key local aging and DD personnel to understand and react to the support needs of aging people with DD.
4. Conduct local needs assessments, to identify support needs and gaps in service delivery.

Year Two Objectives

1. Continue on-going cooperation and collaboration relationships of the work group.
2. Include private advocacy groups and others to support the public agencies/service-integration goals.
3. Develop and refine steps to create individual support plans for older people with disabilities and older caregivers that will help them achieve the highest possible level of independence and social autonomy.
4. Work to mainstream older people with DD and older caregivers into the existing aging programs now available (i.e. senior centers, meal sites) and other age appropriate services available in the local community, including the existing disabilities programs.
5. Recruit volunteers and find available community resources to assist for their aging relatives who have disabilities.

Because each local area is unique, local projects were given considerable latitude. The ultimate hope was that each project would create an environment where any person growing older with DD or anyone caring for such a person could easily access all appropriate aging and disabilities services.

From 1996 through May 1999, the TDoA contracted with Jim Stone, Third Age, Inc., Lexington, KY as the state project coordinator with the responsibilities to initiate and develop the project, to provide technical assistance and training for local projects, and to manage the grant. In June 1999 TDoA contracted with Linda Fulmer, Fulmer & Associates, Fort Worth, TX as the state project coordinator to complete the five-year initiative, evaluate the local projects and write the final report.

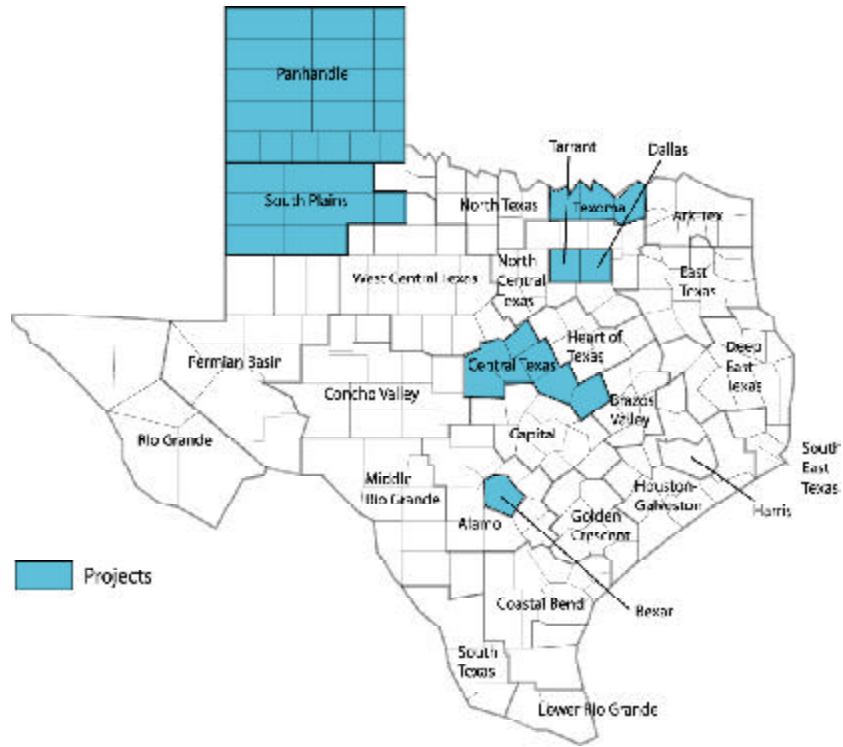


Figure 1. Local Projects from June 1997 through May 1998.

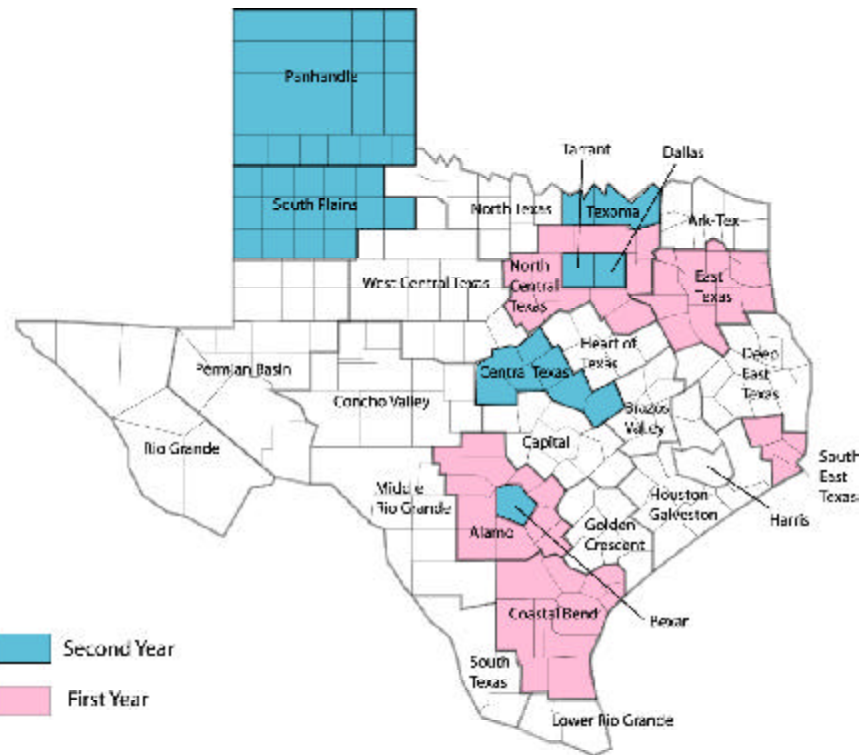


Figure 2. Local Projects from June 1998 through May 1999.

2.4 The Next Four Years.

In June 1997 funding was awarded to seven AAAs to launch their local projects. These AAAs represented both urban and rural service areas:

- Bexar County AAA, based in San Antonio and serving Bexar county.
- Central Texas AAA, based in Belton and serving the largely rural counties of Bell, Coryell, Hamilton, Lampasas, Milam, Mills, and San Saba.
- Dallas county AAA, based in Dallas, and serving Dallas county.
- Panhandle AAA, based in Amarillo and serving the entire panhandle of Texas. This sprawling area includes Armstrong, Briscoe, Carson, Castro, Childress, Collingsworth, Dallam, Deaf Smith, Donley, Gray, Hall, Hansford, Hartley, Hemphill, Hutchinson, Lipscomb, Moore, Ochiltree, Oldham, Parmer, Potter, Randall, Roberts, Sherman, Swisher, and Wheeler counties.
- South Plains AAA, based in Lubbock and serving the largely rural counties of Bailey, Cochran, Crosby, Dickens, Floyd, Garza, Hale, Hockley, King, Lamb, Lubbock, Lynn, Motley, Terry, and Yoakum.
- Tarrant County AAA, based in Fort Worth and serving Tarrant county.
- Texoma AAA, based in Sherman and serving Cooke, Fannin, and Grayson counties.

In June 1998, five more AAAs joined the project from the following AAAs:

- Alamo AAA, based in San Antonio and serving the counties surrounding Bexar county and including: Atascosa, Bandera, Comal, Frio, Gillespie, Guadalupe, Karnes, Kendall, Kerr, Medina, and Wilson counties.
- Coastal Bend AAA, based in Corpus Christi and serving Aransas, Bee, Brooks, Duval, Jim Wells, Kenedy, Kleberg, Live Oak, McMullen, Nueces, Refugio, and San Patricio counties.
- East Texas AAA, based in Kilgore and serving Anderson, Camp, Cherokee, Gregg, Harrison, Henderson, Marion, Panola, Rains, Rusk, Smith, Upshur, VanZandt and Wood counties.
- North Central Texas AAA, based in Arlington and serving Collin, Denton, Ellis, Erath, Hood, Hunt, Johnson, Kaufman, Navarro, Palo Pinto, Parker, Rockwall, Somervell, and Wise counties.
- South East Texas AAA, based in Beaumont and serving Hardin, Jefferson, and Orange counties.

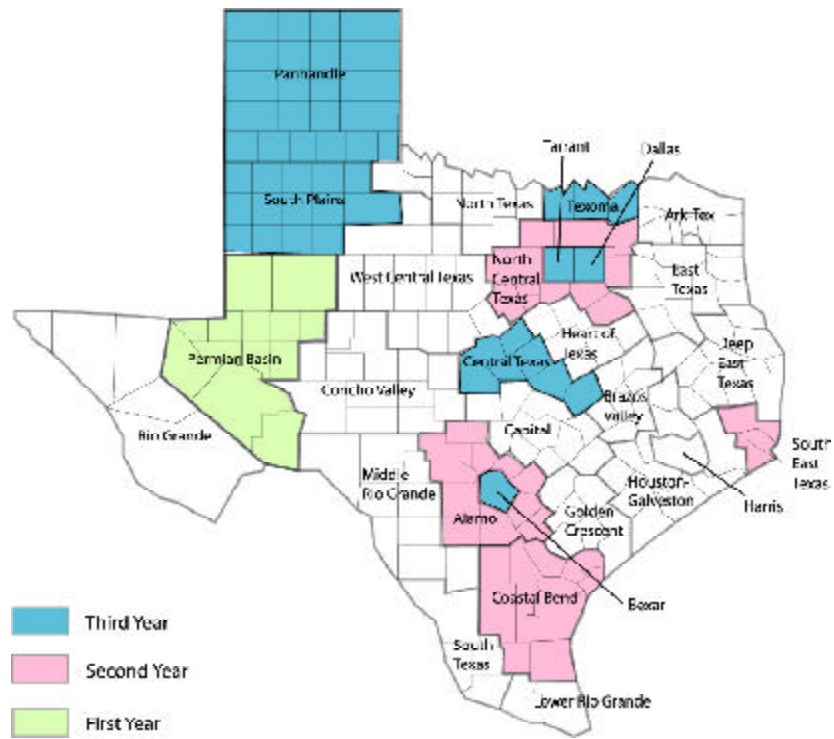


Figure 3: Local Projects from June 1999 through May 2000.

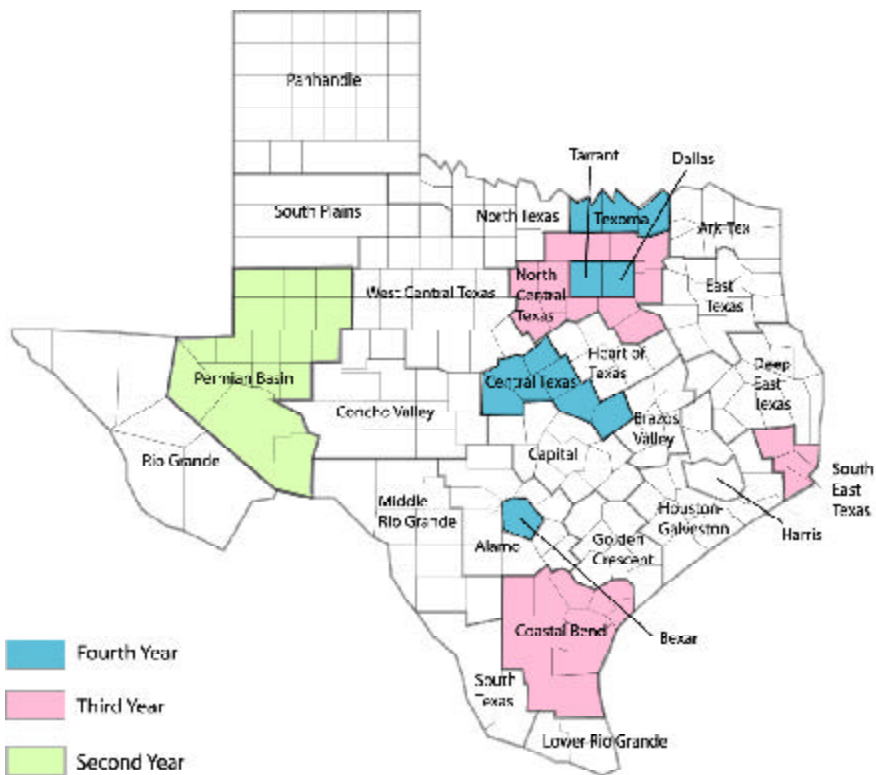


Figure 4: Local Projects from June 2000 through May 2001.

At this point it became apparent that the initial plan of funding seven new projects each year was not going to work - there simply were not enough AAAs willing to apply for the funding to make this happen. Therefore, the plan was revised to continue funding to the initial seven projects. For 1999 only one AAA submitted a proposal to launch a new project:

- Permian Basin AAA, based in Midland and serving Andrews, Borden, Crane, Dawson, Ector, Gaines, Glasscock, Howard, Loving, Martin, Midland, Pecos, Reeves, Terrell, Upton, Ward, and Winkler counties.

In June 1999, TDoA contracted with Linda Fulmer, coordinator for the Tarrant County AAA project from 1997 to 1999. A quarterly meeting for staff of all of the local projects to increase cross-project sharing was established. This was intended to offer new ideas to projects struggling to find their footing, as well as to build the network between staff in disparate parts of the state.

By May 2000 it became clear that some of the local projects had not met the objectives of the project and were no longer funded. Thus, for the final year the local projects map changed again, as illustrated in Figure 4.

2.5 The Texas Money Management Project

As a result of the Texas Council for Developmental Disabilities' (TCDD) approval of the TDoA's amended work plan for the final two years of the grant, a contract was entered into with the Texas Money Management Program (TMMP) through the Health and Human Services Commission (HHSC). This contract was to provide technical assistance to AAAs and local communities in the development and maintenance of local money management programs as a less restrictive alternative to guardianship.

2.5.1 Background

The Texas Money Management Program is a non-profit technical assistance program designed to prevent financial abuse, neglect and exploitation of low-income elderly and adults with disabilities who are at risk of losing their independence due to an inability to manage their finances. The program assists local communities in the development of money management programs and provides technical support for existing sites around the state. It provides a less restrictive alternative to guardianships by assisting those who would otherwise have their rights taken away.

At the beginning of this project, there were six local programs located in Austin, Beaumont, Corpus Christi, Dallas, Lubbock, and Waco. Of those, Beaumont

was in need of a new permanent sponsoring agency to take over the program from its temporary home with the Social Security Administration, and Guardianship Services of San Antonio (which was the local sponsor for money management) had just closed. TMMP has been successful in expanding the number to ten, including new sponsors for Beaumont and San Antonio.

During this time period, a total of 316 low-income older adults or adults with disabilities across Texas were assisted in maintaining their independence by receiving money management services. Fifty-six percent (56%) of those served were elderly.

The next sections detail the requirements as outlined in the Health and Human Services Commission contract with the Texas Money Management Program and the activities that have been accomplished during this period.

2.5.2 Continue Program Focus on the Development of Money Management Services Throughout Texas

The Texas Money Management Program's purpose is to advise, support, guide and promote the expansion of local money management programs to as many areas of the state as possible. Twenty-five presentations were made to various groups in an effort to acquaint communities with TMMP, including:

- Four presentations to individual organizations
- Eleven workshops at conferences
- Ten presentations to state-wide and local initiatives
- Ongoing technical assistance to all local sites

2.5.3 Aging and Developmental Disabilities Coalitions

TMMP staff made a presentation on the Program to the local site directors of TDOA's Aging and DD Coalitions. As a result, the AAAs that received grant funding from TDoA received the following services from TMMP staff:

- **Bexar County AAA:** Worked with Family Service Association of San Antonio, Inc., (FSASA) to take over TMMP sponsorship from Guardianship Services. Guardianship Services lost its contract with both Bexar County and Adult Protective Services, resulting in the dismantling of that agency.
- **Central Texas AAA:** Worked closely with Friends for Life (FFL) in Waco to expand into three counties within this area. Initiated two meetings between the AAA and FFL to facilitate a joint project. As a result, the AAA is providing office space and \$6,000 to assist with the expansion into these additional counties. This joint effort was successful in its expansion efforts and received a grant from the Guardianship Alliance of Texas.

- **Coastal Bend AAA:** This area already had a money management program in place at Lutheran Social Services of the South. Continued to provide technical assistance to the staff there. This program has expanded from Nueces County into Jim Wells, Kleberg, and San Patricio Counties. Arranged for an AARP recruitment for the new counties.
- **Dallas AAA:** Established a money management component of the Guardianship Program within the Senior Citizens of Greater Dallas, Inc., to serve Dallas County. Received a Guardianship Alliance of Texas grant.
- **North Central Texas AAA:** Worked with the AAA to establish a local program. The AAA has subcontracted with REACH, an independent living center in Dallas, to run this program in Denton and Collin Counties. This program received a Guardianship Alliance of Texas grant.
- **Panhandle AAA:** Have met with the AAA, which has expressed strong interest in establishing a money management program in Amarillo and is in the process of completing the needs assessment survey. Estimated date for program to begin is Fiscal Year 2002.
- **Permian Basin AAA:** Met with and provided program materials to the AAA. This AAA has expressed great interest in establishing a program, however, development of a money management program there had to be delayed due to time constraints for the staff.
- **South East Texas AAA:** The AAA developed a seminar entitled, *"Guardianship and Money Management: an Introduction"*, and invited TMMP to participate. As a result of this seminar, the Golden Triangle Retired Senior Volunteer Program (RSVP) is the new sponsor (taking over from the Social Security Administration) and has expanded into all three counties: Jefferson, Orange, and Hardin. This program has received a Guardianship Alliance of Texas grant.
- **South Plains AAA:** Established a money management program within the AAA. This program serves Lubbock, Hockley, and Dickens Counties. Due to staff turnover, this program evolved slowly, but volunteers have been recruited and trained. Staff is now in the process of seeking client referrals. This program received a grant from the Guardianship Alliance of Texas.
- **Tarrant County AAA:** Discussions with the AAA resulted in TMMP staff being referred to Guardianship Services of Fort Worth, the AAA contractor. Several meetings have been held with Coleen Colton, who is the Director of Guardianship Services in Fort Worth. An application and letter of agreement have been received from Ms. Colton to start a money management program for Tarrant County. Anticipated date for establishment is June, Fiscal Year 2001.

■ **Texoma AAA:** A new money management program was established within the AAA to provide services to all three counties: Cooke, Fannin, and Grayson. An AARP volunteer recruitment was conducted and trainings were held in all three counties in December of 1999. This program works through the AAA's Benefits Counseling program, which serves as a resource to the program. This program received a grant from the Guardianship Alliance of Texas.

2.5.4 Local Guardianship Programs

Of the ten current money management programs, all but one either receives or has received funding from the Guardianship Alliance of Texas (GAT). The coordination between GAT and TMMP has resulted in the addition of six new programs, including some with new, more stable sponsors. The TMMP gives first preference to programs receiving funding from the Guardianship Alliance of Texas and which wish to add money management as a less restrictive alternative to guardianships.

2.5.5 Special Focus: Aging and Developmental Disabilities Coalitions Combined with Local Guardianship Programs

Priority has been given to those local sites that have both an Aging and DD grant from TDOA and a grant from the Guardianship Alliance of Texas. Of the ten current programs, nine of them either have guardianship programs, or plan to transition money management services into the development of a guardianship program. Those include: Central Texas AAA, South Plains AAA, Dallas AAA, Texoma AAA, North Central AAA, South East AAA, Bexar County AAA, Concho Valley AAA, and Capital Area AAA.

2.5.6 Coordination efforts with Guardianship Alliance

Priority in the development of local money management programs is given to those entities that receive grants from the Guardianship Alliance of Texas and which have been identified by the Guardianship Advisory Board as a priority area.

The State Advisory Council for the TMMP has stated that money management services are one of the most effective alternatives to guardianships, thus local guardianship programs are the most desirable sites for money management programs followed by non-profit organizations with experience in effective volunteer management.

2.5.7 Technical Assistance

Technical assistance has been provided to 12 sites during this time period. This technical assistance has included, but is not limited to, fundraising, program

materials, development of a new sponsoring agency, technical questions, volunteer recruitment, income guidelines, and reports.

2.5.8 Co-location

HHSC provides office space, computer, and phone service at no charge to the program. The office space is located adjacent to the Guardianship Alliance of Texas office. This co-location has been the key to the success of the collaborative effort between the Guardianship Alliance of Texas and the Texas Money Management Program and has resulted in a savings to the program of approximately \$16,000 per year. The cooperative working relationship that has developed between the two entities has resulted in the growth of this less restrictive alternative to guardianships.

Aging with Developmental Disabilities

Texas Council for Developmental Disabilities ★ Texas Department on Aging



The Texas Project

Chapter 3

Local Project Case Studies

Differing Approaches and Varied Outcomes

In this chapter we will present a case study prepared by staff from each of the nine local projects that were launched during this five-year endeavor that continued to function through May 2001. Each local work group approached the task a bit differently, and the outcomes reflected both the differing approaches as well as the impact of circumstances that arose during the course of the project.

3.1 Bexar County AAA

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Project Coordinator:

- July 1997 - May 2000: Kim Sheffield, Family Services Association
- November 2000 - May 2001: Carol Zernial, Bexar County AAA

The Bexar AAA joined the project in July 1997. The Bexar AAA is sponsored by the Alamo Area Council on Governments and serves Bexar County, an urban county whose primary municipality is San Antonio.

The AAA contracted with the Family Services Association for project management. Family Services Association assigned Kim Sheffield to manage the project from July 1998 through May 2000. After Sheffield was reassigned, the AAA decided to bring project management back in-house for the remainder of the grant. Carol Zernial was hired in November 2000 to take over the project.

In a nutshell, the project systematically devised a plan each year that enabled

it to competently address all required goals and objectives. During its first year, the project developed its Special Needs Network for Aging Persons (SNNAP) as an umbrella for all activities. During early 2000, the project took the lead in developing a regional access plan, which gave all players an added incentive to remain active.

3.1.1 Challenges Facing the Project

A primary challenge that this project experienced was staff turnover at participating agencies. Turnover results in collaborative projects losing momentum as newer participants continually need to be brought up to speed.

3.1.2 Model Selected

The project's model has changed each year; however, the process appears to be replicable.

During Year 1, SNNAP developed three separate work groups to address the core goals. This provided the high number of individuals initially interested a forum through which to work. The larger group would hear the reports from each of the three work groups, but did not meet as frequently.

During Year 2, SNNAP began merging work groups into a central group as the less closely involved members begin to drop off.

Finally, in Year 3 the project chose to consolidate the work in a central leadership group. Year 4 activities are focusing upon interdisciplinary case review, outreach, and cross training of aging and DD providers. Sustainability will be achieved through the work of the Regional Access Plan that links aging and DD providers via the Internet with a common referral process and shared client database. Meetings of SNNAP will continue through a volunteer network of members who share the associated costs.

3.1.3 What Worked

Having a consistent project coordinator through the first three years was invaluable in providing the project with steady momentum. Having members take turns hosting the meetings provided an opportunity to learn about the other providers facilities and services as well as share costs. Defining clear goals for each of the committees resulted in the completion of the related objectives. Developing memorandums of understanding and a common referral form laid a good foundation for continued interagency cooperation.

3.1.4 What Didn't Work

Losing the project coordinator in June 2000 caused the project to lose a bit of momentum. Decentralizing the work of the project into committees without consistent feedback to the group as a whole resulted in a loss of enthusiasm generated by sharing a common vision. Staff turnover among the member organizations created repetition of information at each meeting resulting in a loss of interest. SNNAP members would have preferred to lead the training activities rather than have an outside trainer brought in who did not fully utilize the depth of expertise among the group.

3.2 Central Texas AAA

Richard McGhee, Director

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Project Coordinator:

· July 1997 - May 1998: K. Whisnant Turner, Ph.D, University of North Texas

· June 1998 - May 2001: Lucinda Harman, Ph.D., Combridge, Inc.

The Central Texas AAA joined the project in July 1997. This AAA provides services in a seven-county area that is largely rural. The initial work group was brought together by the combined efforts of the AAA Director and the United Way Executive Director with the goals of developing interagency awareness and leadership that would result in joint aging/developmental disability staff training, problem/barrier identification/resolution, practical agency coordination, and the sharing of local resources. The initial steering committee included two outside facilitators/mediators from the University of North Texas and from Texas A&M University.

The steering committee also included representatives from county governments, local offices of state agencies, and local private providers. Over the course of the project the people representing many of these organizations changed; however, many of the same organizations remained involved. Also, during year two, members from the consumer population were recruited and added to the steering committee.

During the first active year of the project, two cross-training sessions were developed and held with positive responses from the rest of the committee. By the end of the first year the initial project coordinator ended his work, and a local independent contractor was retained to serve as the project coordinator.

Because of the zeitgeist of the times, several other coalitions formed in the area to address parallel issues. Due to duplication of activities, several of these joined forces under the umbrella of the Central Texas Partners in Health (CTPH), which has become the permanent home for the aging & DD initiative.

The initial purpose of CTPH was for the non-profit health care providers to conduct a region wide needs assessment. However, since becoming an umbrella for several initiatives, the focus expanded to include intervention and community development. This has provided the mechanism for sustainability of the work of the initial steering committee.

From the regional assets and needs assessment, five CTPH task forces were formed:

- Access to health care and services
- Affordability of health care and services
- Education
- Recreation
- Aging and Disability groups

The Aging and Disability task force and the Access task force were the designated areas for the original steering committee to place their efforts. From these two task forces, the three major endeavors emerged:

- The Central Texas Long-term Care Access committee that was formed in response to Texas SB374. This resulted in a major proposal and implementation plan for the seamless delivery of services to all people, regardless of age and income, which have long-term care needs.
- The Fragile Population Emergency Response Registry and Volunteer Network. This was developed in preparation for Y2K and has continued as a means of developing safety nets for people with disabilities in times of storms or other power outage problems. This project has become the vehicle for the delivery of additional services and supports that allow individuals with disabilities and their aging caregivers the ability to remain in their own homes and to become more valued members of the community. It is also training young people in the efforts of community service and educating them in both aging and disability issues.
- Developing a regional independent living center (ILC) with the state mandated services of information and referral, peer counseling, advocacy, and life skills training.

In addition, the Central Texas ILC planning group had four other major goals:

- Develop housing capacity and home ownership for people with disabilities.
- Develop transportation that is readily available and affordable for people with disabilities and their aging caregivers or families.
- The hiring, training and brokerage of personal attendant care for people with disabilities.
- Develop an insurance fund to provide the personal attendants and the families of people with disabilities with affordable health insurance.

In summary, even though the outward complexion of the coalition changed significantly and became more comprehensive, the goals of this coalition are in the process of being met in highly sustainable ways. Combining the forces of multiple collaborative working groups has been very successful, and is highly recommended for communities where the same individuals are called on to serve on numerous projects.

3.2.1 Challenges Facing the Project

The primary turf issues that emerged were surrounding the silo arrangement of the Health and Human Services Commission in terms of funding streams, eligibility, target populations, and confidentiality issues. These issues appeared to be almost insurmountable in the initial stages of the project. However, many of these issues were circumvented with the merging of CTPH and the coalition.

The community needs assessment through CTPH was the vehicle that pulled the entire group together. There still exists some turf problems with respect to the funding streams, and these are addressed in the Central Texas Long-term Care Access proposal. The Fragile Population Project and the Independent Living Center cross all turfs and do not require any administrative approval from the various agencies as both work directly with the consumers.

In addition, many of the people involved in the coalition were also involved in other collaborative efforts. Merging into CTPH was a time and energy relief for all involved.

3.2.2 Model Selected

If a model could be determined, it would have to be classed as a “just-in-time” model with high visibility leadership. The collaborative work group moved from planning into action spurred by

- a health summit sponsored by CTPH,
- the potential disaster of Y2K, and
- the passing of Texas SB374.

The outcomes for the coalition include:

- FRAGILE Population Registry and Volunteer Network
- The Central Texas Long-term Care Access proposal and implementation plan
- The biannual meetings, entitled “Lattice”, for front line workers involved in client service and referral, cross-training of the providers for the two target populations
- The Health Summit and the Mental Health Summit, both sponsored by CTPH
- The formation of the independent living center

The sustainability of the coalition efforts is proceeding with grant writing and collaboration with all of the partners of CTPH.

3.2.3 What Worked

The AAA Director allowed the project coordinator free reign to manage the project, and to bring him in as needed for consultation. An outside consultant from Texas A&M was very helpful in providing educational presentations and assisting with political issues and turf issues.

Having a project coordinator who is both a trained professional and a person with a disability assisted in communicating effectively with both providers and consumers. Furthermore, contracting project coordination through an independent, non-profit organization decreased the turf issues for each of the coalition members.

Using the collaboration with CTPH as the vehicle for sustainability was paramount to the success of the coalition efforts. This minimized duplication of efforts and time of the individuals involved, and provided a much better foundation for seeking additional funding.

Maximizing the timing of various events with respect to project development and media coverage was very helpful. The passing of the SB374 and the Y2K event spurred activity at a highly efficient pace. The media coverage of the Y2K related activities was amazing and occurred on about a weekly basis during the last eight weeks of 1999. This coverage included newspapers, radio, and television.

3.2.4 What Didn't Work

The primary thing that did not work was trying to maintain the coalition as a totally separate entity from other collaborative efforts in the community. Moving toward a larger, umbrella collaboration was far more effective.

3.3 Coastal Bend AAA

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Project Coordinator:

Judy Telge, Accessible Communities, Inc. (formerly ACARE, Inc.)

The Coastal Bend AAA serves a 12-county area. Other than Corpus Christi, the area is largely rural. The Aging and DD (A-DD) Project of the Coastal Bend was initiated in 1997 through conversations between the Area Agency on Aging Director and the Director of (then) ACARE, Inc., a cross-disability non-profit organization, about the issues in common of aging individuals and people with disabilities. AAA Director Betty Lamb, with the assistance of Judy Telge, ACARE Executive Director, pursued funding from TDoA for the A-DD Project in 1998. AAA determined that contracting to ACARE the coordination of activities of the A-DD would be the best approach for this Project.

Lamb and Telge identified others to serve on the initial core work group from the City of Corpus Christi Senior Services, and Nueces County MHMR Center to create a Core Work Group of four members. Mailing lists of senior center coordinators, AAA providers, disability organizations and agencies were compiled to form a network of nearly 100 individuals in the early stages of the project. This list was utilized to announce meetings and trainings, and to disseminate surveys and information about the project.

The four original players did not change over the life of the project; however, others were added as the need to involve rural counties was evident and as additional opportunities were presented. In the second year of the project,

representation from the rural counties around Nueces was added from a rural seniors' site and the Coastal Plains MHMR community center.

During the second year, the Regional Access Planning Project (RAPP), a result of Texas SB374 encouraging simplified access and combining aging and disability long-term care services, provided further evolution of the A-DD Core Work Group into being the basis for the RAPP Steering Committee.

In the third year of the A-DD Project, the RAPP leadership expanded to include a parent and a provider of services to children with disabilities, the United Way InfoLine Director, and a person with a disability from the Mayor's Committee for People with Disabilities, all identified through A-DD activities. The Core Work Group of the A-DD Project in the third year included AAA, the Contractor, Corpus Christi Senior Services, Nueces County and Coastal Plains MHMR Centers, a rural senior center, and the United Way InfoLine.

The players were brought together primarily by having a vehicle in the form of the A-DD Project, driven by a contractor representing the disability community, and a willing provider in the form of the AAA. If these elements had not been present **or funded**, the Project would not have begun, nor continued. The other members of the Core Work Group became involved because they were identified by AAA and the Contractor as being in key positions and responsive to collaborative efforts. The Contractor, a trustee on the local MHMR Board, facilitated the MHMR involvement. The Core Work Group members brought suggestions from their organizations that met the parameters of the A-DD Project and the RAPP. Because respective issues were addressed through a collaborative process, there was a reason for continued involvement on the part of members.

There were fizzles in the first year of the Project, which may have been due in part to the minimal amount of funding for the Project. Once a new Project Coordinator was hired, communication improved to both the AAA Director and Contractor in frequency and directness; a supportive and instructive environment for the Project was evidenced; and a connective-ness with other Texas Projects occurred. Until then, the AAA Director was connected to other AAA Directors who were involved in similar projects, but the Contractor, responsible for day-to-day activities, had no similar connection.

An increase in funds for the second and third years helped prioritize the Project, and pay for/justify time spent on the RAPP, a natural fit with the A-DD Project. The A-DD network mailing list was a baseline utilized in bringing together interested parties for the RAPP.

Throughout the second and third years of the Project, the AAA Director assured that the Contractor was involved in senior center staff trainings. These opportunities provided the stage for sensitivity training for workers at senior centers to receive education about disability issues, the Americans with

Disabilities Act (ADA), accessibility, and identifying correlation between disability and aging. This ongoing effort was extended to the Ombudsman training in the third year and dovetailed with a pilot project transitioning individuals with disabilities from nursing homes to the community coordinated by the Contractor.

Cross training was held in the form of a Consumer Help Day in the first year, a half-day resource fair for both aging and disability providers. In the second year, cross training provided more specific information about collaborative efforts, permanency planning and the Community Resources Coordinating Group (CRCG) process. The third year cross training spotlighted a national speaker addressing aging and developmental disability providers about permanency planning. Opportunities for families to participate in the process were provided, as well.

3.3.1 Challenges Facing the Project

A primary challenge facing the Core Work Group was time constraints. Beyond the Core Work Group, other key stakeholders had challenges including the distance to travel and the time it takes to attend activities beyond the daily routines that might be cited for reasons of non-participation, and/or lack of an identified aging population with developmental disabilities.

Because of the geographic spread in the Coastal Bend, trainings were offered in locations outside of Corpus Christi, with the best attendance in the first year in Alice (northwest). Two trainings in Bee County (north) were poorly attended, with one attracting only adult day care providers and family members. Several attempts have been made to provide training in Kleberg County (west) without success. However, training was planned in conjunction with the ombudsman training in early 2001.

Initially, there was difficulty in moving forward, because of the time it took to figure out what to do. Although the Contractor is very knowledgeable about the local issues and is well connected relative to persons with disabilities, and the AAA has an excellent reputation in the aging community, attempting to get the providers together to figure out what to do was a challenge.

With any new venture, there is reluctance to buy in if continuation is not permanent or if a new way of doing business is being presented and lacks specific parameters, or mandates. Lack of a disability advocacy community (fragmentation) in the Coastal Bend hampered progress. There seemed to be an uncertainty on the part of disability advocates as to whether their particular issues would be addressed or possibly diluted in this venture. The sensitivity training to the disability community was managed through one-on-one contacts regarding the realities present in this geographic area.

Initial resistance from some of the disability community segments was replaced with involvement over time, with repeated requests for participation from the Contractor. The A-DD Project began to demonstrate that a collaborative model is a recognized and viable vehicle locally, with the capability and flexibility to evolve in order to meet the current and changing needs of the communities it serves.

3.3.2 Model Selected

Planning for the Project was minimal except in the stages that involved developing the RAPP. Goals in the first year A-DD Project were not clear nor were they realistic. Focus, direction and goal setting improved in the second and third years, with each year building upon the previous. The Core Work Group attempted to meet quarterly, with the best planning occurring at each year's final meeting, when the group could retrospectively assess Project status, then plan for the following year.

Implementing plans was not a problem in the second and third years, other than making the time to do all that was identified as needed, and narrowing expectations on a limited budget.

The outcomes of the A-DD Project were far beyond expectations and exceed initial planning, partly because the opportunities that arose were unanticipated. Outcomes realized to date:

- A vehicle is in place in the Coastal Bend to address aging and disability issues as a collaborative effort.
- A resource guide for persons with disabilities of all ages has been initiated and disseminated throughout the Coastal Bend.
- The formation of a Community Resources Coordinating Group for Adults.
- A regional plan for a long-term care access system for persons with disabilities and those who are aging is being implemented in the Coastal Bend, with an Access Center housed at the same location with the AAA possible in early 2001.

3.3.3 What Worked

The Project was legitimized because authority backed it. Specifically, having TDoA, the AAA, and the state legislature launch the initiatives gave the request

for involvement by the Contractor a degree of urgency and legitimacy that could have been lacking otherwise.

Additionally, the collaboration by a State Representative and the diverse mix of the communities, particularly in Nueces County, proved beneficial.

3.3.4 What Didn't Work

What didn't work about this project can be summed up as follows:

- Focus groups (one-on-one surveys and using training time worked better due to time constraints).
- Assumption that the Project's focus would be accepted by all communities at the same level as Nueces County.
- Hesitancy on the part of some AAA affiliates to include private providers in trainings (adult day care is seen as a competitor of senior centers in some communities).
- Inability to undertake consumer/family interviews or follow up with family contacts. The contractor frequently answered consumer requests for services with "no defined resource exists to meet all your needs, however, have you tried this ...?" Information has been collected from these one- on-one contacts but due to time constraints, not compiled nor followed up. An interview survey was adopted by the Core Work Group in the second year, but was not implemented.

3.4 Dallas AAA

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Project Coordinator:

· July 1997 - May 1998: Arc of Dallas

· June 1998 - May 2001: Garnett Grevelle, Senior Citizens of Greater Dallas

In 1996 a group of Dallas professionals came together to address issues that were being raised by parents of adults with developmental disabilities and agencies serving clients with DD. These professionals were from the fields of aging, mental retardation, and other developmental disabilities. The questions centered on the needs of people with DD who were growing

older. The original agencies represented included:

- The Arc of Dallas
- Community Homes for Adults, Inc. (CHAI)
- Dallas Area Agency on Aging
- Dallas Center for Developmentally Disabled
- Dallas County Mental Health/Mental Retardation (currently Dallas Metro Care Services)
- Dallas County Nutrition Program (now the Dallas County Older Adults Service Program)
- Senior Citizens of Greater Dallas

On April 30, 1996, an all day *"Symposium on Aging & Developmentally Disabled"* was held at the Jewish Community Center. Over 100 people attended this event.

The Special Interest Group on Aging and Developmental Disabilities met on June 24, 1997, and agreed to become a coalition with expanded membership from other aging and disability providers.

Activities directly related to the formation of the coalition commenced on July 25, 1997. The first meeting, a planning session, was devoted to cross-agency familiarization and the organization of a plenary session and luncheon that would be held on August 28, 1997. Twenty-nine invited participants attended this first meeting with nearly equal representation by aging and developmental disability agency personnel.

The initial challenge was to sell the systems approach to a service oriented group of providers. The term "plan" became the operative term. After much discussion, the group has been able to envision services for older people with DD in a schematic sense as opposed to the immediate hands-on direct service approach.

In addition to establishing the priorities and expectations for building the coalition, a survey was conducted to assess the extent of existing inter-relationships between the providers of aging and DD services in order to determine whether or not any form of information coordination existed between them.

The results of the survey confirmed that there had been little inter-agency communication or any formal or informal attempt to coordinate the delivery of services for this unique sub-group of older people with DD whose needs

fell into the scope of both types of providers. In short, the survey indicated that if the older people with DD were to be adequately served, it would be necessary to establish formal linkages between the aging and DD providers, as well as creating a permanent, active and continuously engaged coalition committed to the coordination and expansion of the service delivery system.

In the summer of 1997, the Dallas Area Agency on Aging subcontracted with The Arc of Dallas to have the Associate Director use part of his time to coordinate the coalition. In the summer of 1998, the subcontractor became Senior Citizens of Greater Dallas and a person was hired to work on the coalition and a feasibility study of a Gatekeeper Program for Dallas.

Outcomes of four-year project have included:

- **Cross-Training Tours.** Two sets of cross-training tours have been held. Each set consisted of two tours. One tour took staff from aging providers to visit DD provider agencies, while the other tour to staff from DD service providers to visit agencies that serve older people. With each tour, participants had an opportunity to visit four agencies providing a first hand experience with colleagues working in a different area of human services.

- **Access Center for the Elderly (ACE) Program.** Formed in 1978, the ACE Project established a network of human service agencies to address the needs of older adults and their families through the maze of social services in order to maintain their independent lifestyles. The overall goal seeks to eliminate or reduce premature *institutionalization* of this population in an attempt to support and improve non-institutional long-term care. The ACE Program offers an opportunity to modify an existing, successful program to help people who are aging with developmental disabilities.

- **Resource Fairs.** Two resource fairs have been held. The first was held at the Arc of Dallas and the second at University Park United Methodist Church. Twenty-one agencies had representatives at the first resource fair. Twenty-seven agencies had representatives at the second fair and talks and informal discussions were held on Medicare, Social Security, and Supplemental Security Income (SSI). Attendance was much better at the second fair because of a feature article about the fair that appeared in *The Dallas Morning News* the morning of the fair.

- **Brown Bag Breakfasts and Lunches.** "Brown bag" breakfasts and lunches were held to present material to the front-line workers (and any other interested parties). Each lasted approximately one hour to reduce time away from their direct care duties.

- **Pamphlet.** A tri-fold color pamphlet titled *Making a Difference* was designed, produced, and distributed in settings where caregivers might see it.
- **Directory of Services.** *A Directory of Services for Persons with Special Needs and Persons Responsible for Their Care* was developed and published by the Aging Information Office of the Community Council of Greater Dallas and the Dallas Area Agency on Aging. It was developed with input from members of the Dallas County Coalition on Aging and Developmental Disabilities and selected providers of services and was funded in part by the Texas Department of Aging and the Texas Planning Council for Developmental Disabilities. This has been distributed by affiliates of the coalition to their clients and to participants at resource and health fairs.
- **A Gift from the Caregiver.** An instrument (presently called *A Gift from the Caregiver*) has been developed for the caregiver to record likes and dislikes, everyday routines, and other details about their loved one with developmental disabilities. This is to be passed on to the successor caregiver to be used to comfort and ease the way of the person being cared for. A great deal of interest has been shown for this tool, especially on the part of caregivers.

3.4.1 Challenges Facing the Project

The biggest issue to emerge through the functioning of this coalition was over the intended use of the grant funding. During the first two years of the project, many shared the common misconception that the grant was intended to provide direct services instead of for systems change. On one side of the issue, the Dallas Area Agency on Aging believed very strongly that a system should be developed so that it would continue the work of the coalition after the grant funding was gone. The provider agencies were hoping to see the funding put into services for their clients.

It was not until the third year that the intentions for use of grant funding was clarified, and work began on developing systems approach to services for older people with DD in a schematic sense.

3.4.2 Model Selected

At the plenary luncheon (with the catchy title: *Sometimes You Are Invited To LUNCH. Sometimes You Are Invited To CHANGE THE FUTURE. On Thursday, August 28 You Are Invited To Do BOTH.*) on August 28, 1997, Jim Stone, TDoA's Project Coordinator for the Texas Aging and Developmental Disabilities Project, provided remarks about his experiences in Kentucky and encouraged the coalition to

develop a Dallas model for service integration. There were 49 persons in attendance, representing 42 agencies.

An affiliation agreement was distributed and plans for building the coalition were presented. The affiliation agreement provided assurance that members would work collectively in developing a coordinated system of services that is relevant to the needs of aging persons with developmental disabilities and provides support to caregivers of such individuals. The affiliates agreed to meet monthly and discuss concerns and obstacles.

During the September monthly meeting, three work groups were established to develop strategies to accomplish the goals of the coalition. Co-Chairs from aging agencies and developmental disability agencies were appointed to each work group. The groups met regularly and provided progress reports at a successful and well-attended meeting on February 12, 1998. The three work groups are:

- **Needs Assessment Work Group**, charged with developing strategies and tools for assessing the needs of the target population, caregivers, and service providers.
- **Interagency Training and Education Work Group**, charged with developing a curriculum for specialized staff orientations and strategies for disseminating information.
- **Outreach and Community Awareness Work Group**, charged with identifying strategies to be used in locating the target population and assisting with referrals.

3.4.3 What Worked

Two programs that have worked very well are the cross-training tours and the resource fairs. These events have been beneficial not only in their intended purposes, but they have also provided opportunities for informal networking and greater understanding of the roles of the various agencies for the professionals involved. These programs are described above.

3.4.4 What Didn't Work

The administration of the survey was somewhat irregular. Apparently, some of the people administering the survey did not have a clear understanding of what a developmental disability is. Better training for people working within the aging area is needed concerning developmental disabilities. This is being looked at again.

3.5 North Central Texas AAA

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Project Coordinator:

- June 1998 - December 1999: Kim Mathis-Voelker, UNT Student Intern
- January 2000 - May 2001: Zanda Hilger, Z-Quest

The North Central Texas (NCT) AAA joined the project in June 1998. The AAA provides services to the 14 counties surrounding the Dallas Fort Worth Metroplex. While most of these counties are rural, their proximity to the urban area and the presence of the University of North Texas in Denton adds resources that might otherwise be lacking.

In the first year, projects were established in three AAAs with contiguous service areas. This gave the North Central Texas AAA an ideal opportunity to observe their partners' work during the first year, noting other projects' successes and challenges and planning their own proposed approach.

Selecting partner agencies was an easy task. The AAA had been in discussions with REACH Independent Living Center and the University of North Texas regarding interagency initiatives. Both institutions embraced the Integrated Services Project and expressed a willingness to serve as co-sponsors. REACH played a critical role in enlisting the support of disability providers, understanding disability issues, and identifying disability resources. The University of North Texas brought to the project expertise in conducting research and designing educational programs. In addition, the University provided critical human resource support. It selected a student intern to serve as project coordinator during the first 18 months of activity, who was caring for two family members with developmental disabilities while pursuing a graduate degree in gerontology.

Once the cosponsor agencies were selected, the partners jointly defined the scope of the project and set goals and objectives. They realized that the vastness of the AAA's service area would make it difficult, if not impossible, to have a significant impact throughout the entire region. Therefore, they systematically selected two counties in which to pilot the project:

- Denton County — a more urban county with a well-developed provider network. In addition, it is home to the University and to a REACH satellite office.
- Johnson County — a more rural county with an active provider network. Since these two counties are not adjacent, the partners decided to sponsor parallel activities as opposed to joint activities.

3.5.1 Challenges Facing the Project

The greatest challenge facing this project was apathy, and this issue was most pronounced in Johnson County.

During the first few months, the coalition sponsored a free workshop offering Continuing Education Units (CEUs) for participants, and held two coalition meetings in Johnson County. None of these activities drew more than six outside participants. No MHMR employees attended any activities, even though one of them was held at the Johnson County MHMR offices.

To reassess local interest, the coalition made arrangements to host the Johnson County provider network meeting. They made a presentation on the project, and then asked participants who were willing to support it in any way to sign an interest list. Only two individuals did so. At that point, project leaders decided to concentrate their efforts elsewhere and perhaps revisit the area after acquiring more project experience.

Response in Denton County was much more positive. The kick-off workshop was well attended and received. Although the coalition meetings did not set attendance records, they consistently had broad representation and enthusiastic involvement from MHMR staff and other agency representatives.

This is not to suggest that all participants were clear on the concept. Coalition leaders encountered confusion about what constitutes a developmental disability. Some of the providers were unable to distinguish a developmental from a physical disability.

Once terms were defined and clarified, the coalition experienced challenges from participants who were looking for specific services not currently available. They were disappointed to learn that the project could not fund direct client services. As a result, project leaders dealt with undercurrents of: "If you can't do what I want, what *do* you do?" Project staff found it necessary to constantly orient coalition members to the purpose of the project, namely to provide training to professionals and build community awareness of support services.

They also worked through some tensions regarding outreach. The group recognized that the majority of eligible persons were not taking advantage of formal services. However, some providers were reluctant to engage in case finding when they were having difficulty managing current caseloads. As the project proceeded, professionals became more comfortable with the idea that the intent was to provide them tools to enhance their client services and were in no danger of flooding their waiting rooms.

Ironically, a greater challenge was in locating unserved persons. The coalition wanted family members who were sole providers to join them for coalition meetings and workshops. They wanted their input regarding unmet needs.

They wanted to offer them resource materials. In an attempt to get the word out, they distributed press releases, ran public announcements on cable TV, and disseminated program brochures through the public libraries, doctors' offices, and other venues. While they had limited success in reaching caregivers, most of those identified were already connected to one or more service agencies.

3.5.2 Model Selected

The coalition's work plan emphasized research, education, outreach, and resource coordination during the first year. During the second year, they maintained their first year priorities and began to develop some new resources. During the third year, they made education a primary objective and expanded their focus from Denton County to the entire region. In addition, they designed a new system for delivery of long-term care services.

The commitment to education was evident from the beginning. The coalition introduced the Project in both Denton and Johnson Counties with a workshop, entitled *"Bridging the Gap between Aging and Developmental Disabilities."* Jim Stone helped participants understand what a developmental disability is, what kinds of supports persons with developmental disabilities may need, how aging may affect those needs, and what kinds of community resources are available to meet those needs.

Shortly after forming the coalition, the project coordinator surveyed members regarding their training needs and began planning educational programs to address these needs. During the first several months of program activity, the coalition sponsored programs on guardianship, the Americans with Disabilities Act, the Older Americans Act, person-centered planning, and services for aging persons with developmental disabilities. When they joined efforts with Tarrant County during the third year, they cosponsored innovative programs on a monthly basis that drew providers who work with both adults and children with developmental disabilities.

In the early stages of the project, project leaders were reminded that diverse groups such as the coalition are often well suited for planning but less adept at doing things and taking care of details. Participation in the coalition varied from meeting to meeting, which helped generate new ideas but made follow up difficult. For this reason, they hired a project coordinator who could keep the coalition and its activities on track. In addition, they formed three subcommittees that were assigned specific tasks:

- Assessment
- Training
- Resource coordination

The assessment subcommittee, with the guidance of a UNT faculty member, developed different assessment tools for:

- Persons with developmental disabilities
- Caregivers
- Providers

In addition, this subcommittee developed a plan for gathering assessment data.

The training subcommittee analyzed assessment data pertinent to training needs and developed educational programs to meet these needs. The resource coordination subcommittee included a provider who had developed a directory of aging resources. This subcommittee gathered data on aging and disability resources, and the coordinator compiled the data into a comprehensive directory.

To reach a broader audience, the project not only printed hard copies of the resource directory but also posted the information on the Internet. They created a web page on aging and developmental disabilities which contained resource information, information on project meetings, and upcoming educational programs, needs assessment data, and links to many other related sites.

3.5.2.1 New Directions

The Integrated Services Project laid the foundation for the introduction of a new money management program and redesign of the AAA's system for delivery of long-term care services.

Project staff analyzed both primary and secondary needs assessment data, and determined that there was a significant need for money management services. Since project funds could not be used for direct services, they applied for and were awarded funding through the Texas Guardianship Alliance to launch a new money management program. They piloted the program in Denton and Collin Counties and assigned trained volunteers to clients who required either bill payer or representative payee services. One of the first clients served was an older woman with mild mental retardation.

Through the Integrated Services Project, the coalition explored ways to better integrate aging and disability services for persons of all ages. They capitalized on these experiences as they explored ways to better integrate long-term care services for persons of all ages through the Regional Access Project (RAP). The AAA brought together providers and consumers from throughout the region (including members of the Integrated Services Project coalition) to create a new service delivery system. This initiative was launched in direct response to Texas SB374 , which created an opportunity for entities such as area agencies

on aging to design and implement comprehensive, community-based support and delivery systems for long-term care services. The AAA has submitted a RAP proposal to the Texas Health and Human Services Commission. Although the proposal has been approved, no funds have yet been allocated for its implementation.

3.5.3 What Worked

The partners have realized a number of positive benefits from participation in the Integrated Services Project. They believe that they have accomplished their goals of developing on-going cooperation and collaboration between aging and disability service providers, identifying gaps in the support system, cross-training aging and disability providers, and developing volunteer and community resources to assist families with aging adult children with developmental disabilities. As a result, they have become more aware of community needs and resources and more widely recognized as a source of aging and disability information. Their project experiences have better prepared them to help younger persons with disabilities access long-term care services, per SB374.

But more significant are the benefits the community has realized. Consumers can more easily access resource information. Professional and lay caregivers can more easily access resource information and receive affordable, practice-oriented training that addresses their unique needs.

Following is a summary of what worked:

- *Coalition-building*: Over 30 agencies participated in Denton County Integrated Services activities. As they joined efforts with the Tarrant County Area Agency on Aging and supported the establishment of the Regional Learning Collaboration, they saw a dramatic increase in the number and diversity of partner agencies.
- *Coalition meetings*: Providers became more aware of available services. In addition, they gained personal contacts to help them advocate and obtain services for clients with multiple, complex needs.
- *Resource directories*: While this project did not invent Denton County resource directories, they did prepare the first directory that focused exclusively on aging and developmental disabilities. They quickly exhausted the supply of 1,000 directories. Although these were widely distributed, the largest number went to MHMR. MHMR requested full boxes of the directories to distribute to both staff persons and consumers.
- *Web page*: The coalition has received a number of Internet inquiries from agencies that needed information for clients or had new information they wanted to share with providers and consumers.

- *Agency-specific training and technical assistance:* The coalition had the opportunity to design and conduct in-service training for providers who were dealing with unique challenges. For example, they worked with volunteer Chaplains at the Denton State School who were ministering to aging residents with Down's Syndrome and Alzheimer's Disease.
- *Aging and disability curriculum:* They developed an interactive, informative curriculum designed to heightens providers' awareness of aging and disability issues and increase their sensitivity.
- *Partnership with educational institutions:* As they partnered with the University of North Texas, they involved gerontology and rehabilitation faculty members and students in coalition programs. In a more formal partnership with Tarrant County College, the project's community education and professional development programs were offered through the school's Continuing Education Department. These associations were valuable in terms of sustainability. Further more, they allowed the project to reach students and give them tools for enhanced practice. This is a critical audience when working toward systems change.
- *Large-group training:* On a monthly basis, the Regional Learning Collaboration sponsored innovative programs that educated, created a forum for networking, and identified resources. Topics included essential lifestyle planning, service coordination, dual diagnosis, community emergency response and assistance for special needs individuals, and the spectrum of autism. Regular attendees included rehabilitation counselors, probation officers, MHMR workers, and special educators.
- *Experience in improving system design:* As project leaders looked at gaps in the service network and institutional barriers to service delivery, they better understood how to design a new access system that is sensitive to the needs of a diverse consumer base.

3.5.4 What Didn't Work

Although few of the project's initiatives failed, some did not achieve the desired level of effectiveness. Following is a brief summary of under-performing activities:

- *Coalition development in Johnson County:* As mentioned earlier, the project did not attract a critical mass of providers in Johnson County. Perhaps these difficulties are related to the more rural nature of the community.
- *Outreach to unserved persons:* The project encountered ongoing

challenges in locating and serving aging persons with developmental disabilities who were not connected to one or more service agencies. Despite efforts to widely publicize public hearings and holding them at various times of the day to accommodate caregivers' schedules, they did not have any participants. In addition, the coalition widely distributed information on project activities and invited family members to attend, yet no more than a handful did so.

■ *Consistent representation at coalition meetings:* Each time the coalition held a meeting, they spoke to a different audience. This had both positive and negative implications. Project leaders and coordinators enjoyed introducing new persons to the project but were disappointed they didn't have a larger corps of regular attendees. At times, the coalition meetings were very small. Nevertheless, the discussions were always valuable.

The coalition would have liked to fill all of their programs to the rafters. Alas, this was not to be. Even with well-attended coalition meetings and training events, members could identify a number of key agencies that were not represented. They realize, however, that numbers are not always the best measures of program effectiveness. More meaningful indicators are quality of information imparted, received, and degree to which it improves client services. Coalition leaders and coordinators are pleased with the participant feedback they've received.

3.6 Permian Basin AAA

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AAA Grant Coordinator:

· June 1999 - August 2000: Susan Crenshaw

· August 2000 - May 2001: Jeanne Daniel

Project Coordinator:

· Jerry Lee Jones, DPA, Midland Business Center

The Permian Basin AAA provides services to a sprawling 17-county region in West Texas. The major municipalities are Midland and Odessa, with the balance of the region being a sparsely populated rural area.

In the Spring of 1999, Susan Crenshaw approached Midland Business Center to help administer the project. Permian Basin AAA joined the project in June 1999.

Dr. Jerry Lee Jones, Midland Business Center, and Susan Crenshaw attended a meeting in Fort Worth in August to find out exactly what the grant was about and what direction the Permian Basin should take.

Following the meeting, plans went forward with setting up a coalition of persons from different agencies. In developing these plans, the project was able to benefit from advice offered by the other 12 projects that had started in previous years.

The first meeting of the coalition took place on October 15, 1999. The purpose of the meeting was to share about the grant and to get acquainted with one another. Each agency representative was asked to sign a Statement of Agreement. In addition, four subcommittees were set up:

- Point-of-Entry
- Coalition
- Needs Assessment
- Training

All of the committees met in the days following the coalition meeting. Through the work of the committees, it became clear that a survey should be distributed to gather some information about the Permian Basin region and the needs of those with DD.

A survey was developed, and a rough draft was presented at the coalition meeting in December 1999. Several revisions were made, and the most effective ways of distribution were discussed. The finished surveys in Spanish and English versions were given to coalition members at the following meeting. Each of the participating agencies distributed the survey in the way they thought most appropriate.

The coalition also decided to develop and produce a brochure. Agencies that wanted to participate were to bring descriptions of their agency for inclusion.

A meeting was held on March 14, 2000 to receive descriptions of agencies for brochure. Pat Jones of Midland Business Center oversaw the compilation, design and printing of the brochure. This was the second primary project of the Coalition for 1999-2000.

Several cover designs were reviewed by the coalition, their assistance was solicited in proofing, and they made the final decision for the cover prior to printing. It was decided that 5,000 copies would be printed for distribution.

Distribution was ongoing throughout the second year, and because it included information about the purpose of the coalition and the various agencies who may provide services, it was used for a variety of purposes.

The coalition was encouraged to participate in open meetings in Midland and Odessa regarding public transportation. Susan Crenshaw made a report during the April 25 meeting. Possible projects mentioned at that meeting were training for receptionists regarding point of entry; caregiver training, and a common release or memorandum of understanding.

The coalition met on May 31, 2000, to receive the completed copy of the survey and its report. During the first year, some 30 persons were on the mailing list for invitations to meetings and received copies of minutes or other material that the coalition published. The Area Agency on Aging made application for a grant for a second year. Midland Business Center was again retained to administer the grant.

In August 2000, Susan Crenshaw announced that she would be leaving the Area Agency on Aging and Jeanne Daniel was named as her replacement.

The project goals for the year were divided among the four committees. Three projects are well underway at this time. These included

- a resource directory,
- a common intake form for the agencies, and
- an attempt to encourage senior centers to mainstream seniors with disabilities.

A fourth project involved training the trainer of caregivers.

Updated participant lists were distributed with updated addresses and contact information. Committee lists were likewise updated on a frequent basis.

3.6.1 The Model Selected

The model selected by this project was that of a typical collaborative work group. The AAA elected to contract with an outside agent for project management, and the collaborative work group established subcommittees to handle the details of specific projects.

3.6.2 What Worked

The project was able to benefit immensely from the accumulated knowledge developed by the twelve projects implemented in earlier years.

3.6.3 What Didn't Work

Because this project did not begin until the 4th year of the 5-year project, it had only have two years to become established before the end of the grant.

3.7 Southeast Texas AAA

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Project Coordinator:

· October 1998 - May 1999: Sandy Brannan, Southeast Texas AAA

· May 1999 - May 2001: Bonnie Loiodice, Southeast Texas AAA

The Southeast Texas AAA's contracted program coordinator, Sandy Brannan, assembled the original work group. Brannan sent invitations to local social service providers, and advocacy groups. The initial group was comprised of representatives from the local independent living center (SETLIFE), the Southeast Texas mental retardation authority (Beaumont State Center), the Texas Department of Human Resources, a home health agency, the Golden Triangle NAMI representative, and a hospital social worker.

The AAA entered the project in the second quarter of the fiscal year (10/98). Beaumont State Center, TDHS, and SETLIFE have participated in all the activities of the group. It is interesting to note however that TDHS initially sent a different worker to each event or meeting. These people acted primarily as observers. The project was in its second year before a TDHS worker was identified who sincerely wanted to fully participate. This TDHS worker has become a very important contributor to the project. She provided the project with a critical link to managerial and supervisory personnel at TDHS.

This group was brought together by their desire to expand the capacity of Southeast Texas social services providers to include the specific needs of older persons with developmental disabilities. The original group developed a list of 11 major concerns. The work group decided to have forums and conduct an agency assessment of area resources to identify resource gaps and consumer priorities.

Subsequent meetings revealed that the work group members were unfamiliar with the services already available to persons with disabilities in Southeast Texas. To address this problem, the group decided to produce a training/informational video showcasing four agencies. Each agency that participated in the video project was also provided with a directory of regional social services. The participating organizations provided informational literature which was assembled in a 'Coalition on Aging with Developmental Disabilities' folder, and given to anyone who views the video. A specialty directory of regional agencies that provide services to those persons with developmental disabilities is also included in the folder.

Consumer legal and financial matters, including guardianship, were topics that repeatedly surfaced at work group meetings. The information provided at the project quarterly meeting by the Texas Money Management Program helped the work group choose their next project. In August 2000, the workgroup hosted an educational event, *“Guardianship and Money Management: an Introduction.”* A second purpose was served by sponsoring this event. The Retired Senior Volunteer Program at the Southeast Texas Regional Planning Commission used this forum to introduce the AARP Texas Money Management Program to the community as a whole.

Throughout the project, some things fizzled and some took off. The April 1999 workshop provided some focus. The topics that emerged were long term planning, transportation and caregiver concerns. The rate of return on the survey assessing area resources and priorities was terribly low. A second survey was attempted yielding an 8% return. Dr. Martha Sabin, of the Beaumont State Center, presented a written report on this survey.

The Spring 2000 video project was an exciting collaborative process. The process helped the group define itself. Independence and participation in community life was the concept of this training/educational video. The video and the accompanying literature are now an important training resource for agencies in the region. It has also been used to recruit volunteers, train volunteers, and inform community groups.

The money management and guardianship event attracted supervisory and managerial personnel from across the region. Several individuals from Houston and Galveston also made the trip to Beaumont to hear presenters from the Guardianship Alliance of Texas, the Texas Money Management Program, and the Jefferson County probate court. A video recording was made of this event.

3.7.1 Challenges Facing the Project

The consumer advocate representatives became disillusioned when they found that this project was not intended to provide direct services. This issue surfaced repeatedly. Once the advocates realized that everyone needed more information to identify area resources, the direction was clear.

3.7.2 Model Selected

This project created a collaborative work group that focused on building consensus before taking action. For example, in the first meeting with the video production company it became apparent that the coalition had not communicated their ideas clearly to the production coordinator. The work

group met, brainstormed, voted on a concept for the video, and began writing the individual scripts. The outcome was that each agency took responsibility for its own section of the video, while still focusing on the concept that was agreed upon.

3.7.3 What Worked

What worked best for getting responses to the survey was making them available at resource fairs and community events. The coalition obtained booth space in order to make the survey available to those in attendance.

3.7.4 What Didn't Work

The project did not have success in gathering information with the surveys that were distributed by mail.

3.8 Tarrant County AAA

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Project Coordinator:

- August 1997 - May 1999: Linda Fulmer, Fulmer & Associates
- June 1999 - May 2001: Zanda Hilger, Z-Quest

The Tarrant County AAA joined the project in July 1997. This AAA serves Tarrant County, an urban county whose primary municipality is Fort Worth.

With a vision of integrating services for older people with developmental disabilities and older caregivers of persons with developmental disabilities, the Area Agency on Aging of Tarrant County formed a partnership with a core group of ten aging and disability service agencies and organizations. The group included a spectrum of public agencies, not-for-profit agencies, the corporate for-profit industry, and a university.

The initial Coalition included the public agencies Mental Health and Mental Retardation (MHMR) of Tarrant County and the Texas Department of Human Services' Aged & Disabled Services. The not-for-profit agencies included the Easter Seals Society which also serves those with epilepsy; United Cerebral Palsy which provides respite care to both populations; Ability Resources, Inc., which provides housing; the Handicapped Resource Association; YMCA/Urban Services Branch, which provides special transportation; and the Alzheimer's Association. The corporate for-profit entity, Colonial Southwest, provided adult

day care and assisted living. The university partner was the University of North Texas' Center for Studies in Aging. Area Agency on Aging advisory council volunteers represented AARP, the Texas Silver-haired Legislature and other senior groups.

The need for integration of services was evident based on:

- the number of people with disabilities and aging caregivers needing service,
- the traditional "separateness" of the aging and disability service providers,
- the need for advocacy to ensure continued services with decreased availability for funding for services, and
- the need to reduce duplication of effort across service providers.

The work group formed committees to study various issues. An early assessment identified fragmented services as well as services that were needed. The work group also determined a lack of understanding about services and issues across the service disciplines. Families needed information about financial planning and lifetime assistance planning for their dependent family members.

The last two years of the grant in Tarrant County was marked by a lack of consistent attendance at the Coalition meetings. Although many of the original coalition member agencies remained involved to some degree, the personnel changes within those agencies contributed to this sporadic attendance.

One parent of an aging individual with developmental disabilities continued to actively participate in the Coalition but was discouraged by the many challenges which seem to have no satisfactory answers, especially regarding issues she has with policies of the Social Security Administration.

Although monthly training programs focusing on needs identified by families, such as guardianship and lifetime financial assistance, were marketed through brochures, agency and organization newsletters, and the Community Events section of the *Fort Worth Star Telegram*, few family members participated in educational activities.

Continued engagement of Coalition members was maintained through the formation in early 2000 of the Regional Learning Collaboration (RLC), which was the main focus of the last year of Tarrant County Coalition activities. The RLC included not only Coalition members, the North Central Texas Area Agency on Aging Coalition, and Tarrant County College but was expanded to include a total of 24 service and educational entities. Tarrant County College Department of Continuing Education provided the training site, refreshments, and administrative supports while the grant provided funding for the Coordinator's activities.

3.8.1 Challenges Facing the Project

Tarrant County human service agencies have enjoyed a tradition of networking, collaborating to solve community problems, and advocating for change. Some agencies have always served both the populations that are aging and populations that have disabilities. However, fragmentation of services was more of a problem than duplication as indicated through assessment of needs, during Coalition meetings, and in planning and implementing services.

Identifying the number of people with mental retardation who are older or who have aging parents or caregivers was a challenge within the scope of the Coalition. The proposed initiative to integrate aging and disability services was a new endeavor. The federal and state policies and funding regulations for aging services have encouraged “separate but equal” services. Nevertheless, most human service agency staff realize that with decreasing federal funding, the need to create new ways to deliver services is essential to survival.

A common challenge for community providers and professionals is what has been termed the ‘silo effect’ (providers know their own target population and services, but lack current and relevant information on other services and needs). This is also exhibited through the manner in which many federal and state funding sources designate the use of their funds. Some providers are generalists or trained in a specific field of service, program, or functional area rather than to a specific population; some providers are specialists in either aging or disabilities; some have particular personal or professional commitments to advocacy for one group or another; some will come from bureaucracies whose policies and regulations have shaped staff thinking, views, and attitudes regarding who can or cannot be served by certain programs or funding streams. Some members will come with theoretical learning, others with years of practical experience. Some have worked within one system’s available resources while others have had to develop or search out resources from non-traditional sources to address clients’ needs. The diversity of the stakeholders presents challenges.

One of the challenges of cross training with the diversity of disciplines and needs occurs frequently when developing educational programs through the RLC. The Coordinator would talk with a speaker about the program requested and follow up with written information and the brochure, which specifically details the target population. During the program, however, many of the speakers had difficulty ordaining their presentations outside of their usual scope of practice. For example, someone talking about case coordination with people with developmental disabilities needed prompting to include needs specific to the aging individuals or families.

3.8.2 Model Selected

The Tarrant County model began as a multi-stakeholder collaborative work group that also created sub-committees to address specific projects. The project hired an independent contractor from the start to provide a degree of consistent focus on the project.

Over time, and as the grant began its final year, the model evolved into the RLC described above. This is believed to be the best way to continue to expand awareness and provide meaningful educational opportunities in a way that is sustainable.

3.8.3 What Worked

The Coalition complemented numerous initiatives already underway, including a coalition of case managers mobilizing home health agencies to develop standards for the home health care industry; guardianship services; a AAA Aging Initiatives Fund to provide small grants to innovative projects; the development of additional education courses and support groups for caregivers (such as the 6-week *As Parents Grow Older* course); and the Arlington-based Handicapped Resource Association consortium of aging and disability providers which developed a resource guide and a shared equipment closet for that city.

A goal of the training provided through the grant is that of cross training to enable participants to learn in areas different from their main field of practice. Initial training during the early years of the grant focused on the grant itself and its service and integration philosophy. This approach evolved into an emphasis on developing skills in providing services to the target populations and forming partnerships through networking at the training programs. The largest attendance for training was two programs on accessing and using community resources.

3.8.4 What Didn't Work

The greatest difficulty centered on engaging active involvement and support from one of the larger provider organizations in the area.

3.9 Texoma AAA

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The Texoma AAA serves a three-county area in North Texas. Sherman and

Dennison are the primary municipalities in the area. The service delivery network in the area is comprised of a close-knit team of long time employees that have learned to work collaboratively over many years.

In May, 1996, the Texas Planning Council for Developmental Disabilities announced funds for a project that would “result in an increase in community integrated services from Area Agencies on Aging and other state agencies to individuals with developmental disabilities who are aging or whose parents are aging.” The Texoma AAA prepared the proposal to initiate this project as a pilot or model for the state; however, the award was given to the Texas Department on Aging, which had submitted a five-year proposal for a state-wide project.

In March 1997, TDoA released a request for proposals to the AAAs that encouraged them to work toward assisting Texans with developmental disabilities and their caregivers. The Texoma AAA submitted another proposal for this project, and in May 1997, was awarded a \$25,000 grant for the first year of the project. Due to preliminary planning efforts completed in 1996 to prepare the original proposal, the AAA that became the core of the local Aging-Developmental Disabilities Coalition had already identified many local partners. These organizations were asked to identify other key leaders in the community including family caregivers and consumers who could contribute toward this initiative.

In August 1, 1997, the first collaboration meeting was conducted. Sixteen participants attended the first meeting. The end of 1999 had actively involved over 100 individuals and agency representatives involved in the Coalition efforts, during this two-year period.

Coalition meetings were conducted on August 1, 1997, October 17, 1997, and January 16, 1998. The Coalition identified four major goals to achieve during the first year. The part-time staff supported by the grant spent significant time during the months of November and December researching materials provided by the TDOA consultant to provide resource information to Coalition members to identify courses of action to address these goals:

- Cross training for all agency personnel on sensitivity training, service access, barriers to service access, available resources in the community, eligibility and referral protocols, appropriate housing options, guardianship and surrogate decision making, health care proxies for the mentally retarded, and financial planning.

- Outreach strategies to identify older people with DD and their families; and the completion of needs assessment activities to identify the concerns and desires of older Texans with developmental disabilities and their family caregivers.

- Training for older adults with DD and their families on the issues they identify as most critical in planning for long term care and life transitions.
- Effective system integration among provider organizations to promote easier access to a coordinated array of services which are responsive to the needs of adults with DD.

Based upon the input received during Coalition meetings, the AAA staff worked one-on-one with individual Coalition members to clarify specific topics that should be addressed and to identify the best experts on these subjects. A survey compiling these suggested topics was mailed to Coalition members in November 1997. From this input, a training program, entitled, "Bridging Systems to Better Serve Older Adults with Developmental Disabilities and Their Caregivers," was developed. This program consisted of three unique sessions offering a total of nine Continuing Education Units.

During year one, coalition members collected data to identify the existing service delivery infrastructure serving all persons with developmental disabilities. The resource information was compiled into a booklet specifically designed for family caregivers and older adults with developmental disabilities. The publication was intended for distribution during the final transitional planning meeting with teachers and mental retardation professionals as adult children exited the school system's services. Another tool, a *Lifecare Planning Checklist*, was also developed to guide families through the decision-making steps that must be completed in planning for future care for their adult child in case of their own incapacitation or death. The *Aging-DD Resource Guide for Texoma* was distributed to all participants attending the "Bridging Systems" programs.

The Texoma Aging - Developmental Disability Service Provider Network conducted a Strengths, Weaknesses, Opportunities, Threats (SWOT) assessment during the first year among provider organizations throughout the region. All responses clearly stated that persons with DD and their aging family caregivers in Texoma were not adequately prepared for life transitions.

The AAA Director also met regularly with families of the Tri-County Alliance for the Mentally ill to identify service gaps and needs of these family members.

Finally, during year one, the Texoma project was notified of the opportunity to participate as a research site for a possible National Institute of Health clinical trial to study the efficacy of Vitamin E in the treatment of dementia in persons 50 years of age and older with Down Syndrome. The grant application was completed by the International Consortium on the Treatment of Dementia in persons with Down Syndrome. The AAA contacted Austin College coalition representatives to determine their interest in this project as well as the local neurologist to determine the number of current patients he serves over the age of 50 with Down Syndrome. The college and coalition enthusiastically supported the opportunity to participate in this research endeavor. Letters of

support were collected from the Coalition, and the grant was ultimately awarded.

During year two, significant staff time was focused on the development of a new regional advocacy organization to promote awareness of resources and services and to enhance educational opportunities on topics relating to developmental disabilities. Prior to this time there were no formal advocacy groups for persons with developmental disabilities established in the region prior to the grant.

On January 26, 1999, the AAA held its first exploratory meeting and on February 16, 1999, the official organizational meeting was conducted. On March 9, 1999 the new chapter of the Arc of Texoma adopted the Articles of Incorporation, Constitution, and Bylaws, and a board of directors was established. A staff member from the Arc state office attended an April 1999 meeting to conduct new board member orientation. Monthly meetings were conducted at the offices of the AAA since the inception of the new chapter. The AAA staff also provided assistance in the design of the new brochure for The Arc of Texoma.

Finally, during year two of the project, the AAA received a supplemental grant award to prepare a replication guide entitled *"Caring for Adults with Developmental Disabilities and Their Families - A How To Manual for Area Agencies on Aging to Design Cross-Systems Training."* This guide contained 500 pages of resource information collected by the AAA during its first year of funding and provided examples of the agendas, assessments, surveys, correspondence, handout materials, speakers, brochures, outreach letters, created by the Texoma AAA. Over fifty manuals were distributed to agencies and organizations across the state.

The third year of the project was one in which the prior years of planning and networking resulted in very tangible results. After the close of the 1999 Legislative Session, SB374 encouraged a planning process at the local level to enhance service access by elderly citizens and persons with disabilities. The Aging-DD Coalition evolved into the Texoma Regional Access Work Group. In August 1999, a subcommittee met to discuss additional membership representation that needed to be recruited on the access work group. Five four-hour meetings were conducted between November 1999 and February 2000.

In March 2000, the AAA completed and submitted the *Texoma Regional Access Plan* for enhanced access by elderly consumers and persons with disabilities to the Health and Human Services Commission (HHSC).

As the Regional Access Work Group evolved, new members were brought into the existing Coalition to strengthen representation by a wider range of providers (both public and private), parents of children with disabilities, elected officials, older consumers, community leaders, law enforcement, and consumers with disabilities.

Upon completion of the plan, the Coalition remained enthusiastic to continue progress on their work. Although HHSC indicated that an appropriation request would be developed in Fiscal Year 2001 to support implementation of access plans across the state, the AAA staff began researching funding opportunities to support immediate implementation efforts. A proposal was developed and submitted to the Texas Department of Health on April 14, 2000, requesting \$200,000 to develop the infrastructure for the proposed Access Center. In June 2000, the AAA was notified of its TDH Innovations Grant Program award for a 14-month period.

In addition, the Regional Access work group and the AAA took over the operations of the Texoma Council for the Deaf, which had lost its funding. Through the strong support of the AAA, the Texoma Council for the Deaf has been revitalized and continues to operate.

Toward the end of 2000, new Bylaws were drafted to make the Regional Access Work Group a formal standing committee to the Texoma Council of Governments.

The coalition leaders truly believe none of the accomplishments described above would have occurred without the seed money provided by the Texas Department on Aging for their five-year grant from the Texas Council for Developmental Disabilities. Although the original concept of a Disabilities Access Center was submitted to the DD Council in the original 1996 proposal, the final product is stronger because of the grassroots planning and consensus building carried forth by the members of the Aging--DD Coalition over a three-year period of time.

3.9.1 Challenges Facing the Project

The only true challenge that this project has faced has involved the difficulty in moving forward due to lack of funding. This is the only challenge that has kept the project from fully realizing all of its goals more quickly.

3.9.2 Model Selected

Planning for model design began in 1999 and was published in a regional access plan to the HHSC.

The outcome was a successful concept accepted by HHSC and an approved grant of \$200,000 from the Texas Department of Health to initiate the new concept.

3.9.3 What Worked

Everything worked as detailed in the plan; although, not all components are fully in place at this time. Technology is being explored for linkage with other agencies. Common intake forms being explored. IRIS software was purchased and is currently implemented. Training curriculum for personnel in the Access Center has yet to be fully developed and standardized statewide.

3.9.4 What Didn't Work

It has all worked! Thanks to dedicated Coalition members who believe that service access must be improved for elderly persons and persons with disabilities. The Regional Access Work Group has a long way to go, but members have an excellent plan to follow and fall back on.

Aging with Developmental Disabilities

Texas Council for Developmental Disabilities ★ Texas Department on Aging



Chapter 4

Best Practices

Collaboration, Outreach, Capacity Building

In this chapter we will discuss the best practices to have emerged from the project over the past five years. These are broken into three broad categories: collaboration, outreach, and capacity building. While the overall goals of this project have been relatively simple and straightforward, the process of achieving those goals has been quite a winding road.

4.1 Collaboration

Obviously, when creating a new collaborative initiative, it is important to find ways to bring key stakeholders to the table. Many funding agents today stipulate that the projects they fund have a collaborative aspect. However, simply mandating collaboration and seeing it happen are two different things. In order for collaborative initiatives to truly succeed, it is important that the collaborative relationships become a by-product of the planning process for other aspects of the initiative.

In many communities across the United States today both public and private providers are struggling with the fragmentation and gaps that exist in most human service systems. Increasingly, providers are being asked to tighten their eligibility criteria, and to serve more people with fewer resources. Thus, in many communities, a number of collaborative initiatives have been launched to examine and to (hopefully) resolve the issues created by these gaps.

Member representatives of these groups are often one-and-the-same and include key health and human services agencies and staff operating in the local area. Other local non-profit organizations, Mayor's Committee for People with Disabilities, and other disability-specific agencies join major state agencies

and the local Area Agency on Aging. Private for-profit entities are essential to the mix as they often are the only resource for people with disabilities with multiple needs in some areas. Individuals with disabilities and family members with disabilities are also involved.

With so many of the same people being asked to serve on multiple collaborative initiatives, what differentiates those that actually gel and produce outcomes from those that fizzle? We believe that one of the most important factors in determining success of a collaborative initiative is that the community must have an identified need that generates a strong sense of urgency that brings key stakeholders together for problem solving.

In the sections on outreach and capacity building we will discuss in more detail some specific activities that can result in excellent collaboration building, as well as provide an example of a local issue that generated such a sense of urgency that the outcome produced a lasting systems change.

4.2 Outreach

As we touched on in Chapter II, many older adults with DD have lived their lives in the community with their families, and have not been part of ongoing service systems. In many ways these people are hidden from view. These individuals typically turn to formal service systems only when their existing support system is no longer able to provide for them. Often, this happens rather abruptly following the death or incapacitation of the primary caregiver.

In order for a new community effort to reach its target audience, older people with DD and their aging caregivers, they need to get the word out about the initiative to the general public. The best outreach practices used by the Texas project included:

- Holding resource fairs.
- Distributing resource guides through the local newspaper.
- Inserting flyers in utility bills.
- Using internet websites.

4.2.1 Resource Fairs

Resource fairs can be held as stand-alone events for a specific population, or integrated within larger community events, such as community-wide festivals or celebrations.

The basic steps in planning a resource fair are outlined in Table 1.

Table 1. Basic Steps for Planning a Resource Fair

Key Step/Decision	Why
<p>Assemble a diverse, collaborative planning committee that includes:</p> <ul style="list-style-type: none"> ■ Governmental partners; ■ Public and private providers; ■ Equipment vendors; ■ Local business leaders & philanthropists; ■ Representatives from the target population. 	<p>There is strength in diversity. Including representatives from these core groups can open doors to people and services necessary to the success of the project, and to developing a plan that appeals to the target population.</p>
<p>Determine your target audience.</p>	<p>You need to know who you are wanting to reach in order to determine the resources and presentations you want to showcase.</p>
<p>Determine when to hold your event.</p>	<p>To avoid conflicts with other events likely to attract your target audience</p>
<p>Determine a location for your event</p>	<p>You will want a location that is convenient and accessible to your target audience, and also that will draw the general public to your resource fair.</p>
<p>Decide whom you want to invite to make presentations, and get the invitations out early.</p>	<ul style="list-style-type: none"> ■ Speakers who are in demand are often booked several months in advance. ■ A high profile keynote presenter can draw attendees who might otherwise not make the effort to be there.
<p>Ask local vendors and organizations to set up and man exhibits.</p>	<p>You will want to have plenty of exhibits and resources for attendees to visit with and learn from.</p>
<p>Arrange for logistical support for the Resource Fair.</p>	<p>A short list of logistics includes:</p> <ul style="list-style-type: none"> ■ Developing a floor plan for exhibits and presentations; ■ Arranging for tables, chairs, microphones, electrical outlets, modem hook ups, name tags for presenters, table signs for the displays, enough space for presenters to put up backdrops, sign-in lists, extension cords, refreshments, greeters and bags so everyone can take home the information they collect; ■ Arranging for exhibits to be set up the day before the fair; ■ Recruiting and coordinating volunteers to manage the flow and troubleshoot problems on the day of the fair; ■ Arranging to return everything you borrowed to the right people in good condition. ■ Sending thank you notes to everyone who helped to make the fair a success.
<p>Plan your advertising/promoting campaign.</p>	<p>If you don't advertise sufficiently, no one will know about your Resource Fair, and they won't come. Options for getting the word out include:</p> <ul style="list-style-type: none"> ■ Press releases to the local media; ■ Flyers posted in public areas; ■ Having members of the planning committee publish notices in their newsletters & offices;
<p>Evaluate what worked and what didn't work.</p>	<p>This can help you make your next Resource Fair more successful.</p>

A number of excellent books have been published on how to plan and manage special events such as resource fairs. Books generally available through retail and online bookstores include:

Event Planning: The Ultimate Guide to Successful Meetings, Corporate Events, Fundraising Galas, Conferences, Conventions, Incentives and Other Special Events by Judy Allen.

Special Events: Best Practices in Modern Event Management by Joe Jeff Goldblatt.

Additional resources are available through professional organizations for association and meeting planning professionals such as the American Society for Association Executives (ASAE). One of their publications is:

Special Events: Proven Strategies by Alan L. Wendroff.

These books and other publications may be purchased by contacting ASAE by phone at 202-626-2723, by TDD at 202-626-2803 or by fax at 202-371-8825. Publications may also be ordered online at www.asaenet.org.

4.2.2 Resource Guides

Many of the local sites in the Texas Project developed resource directories that combined listings of providers and resources for both people with DD and for people who are growing older. While many of these directories were distributed to people caring for people with DD, one project was able to gain extra exposure from the effort by partnering with the local newspaper for publication and distribution.

The Coastal Bend Project partnered with the United Way InfoLine and the area's major newspaper (*Corpus Christi Caller Times*) to produce the first annual Resource Guide for Persons with Disabilities of All Ages. Modeled after the Senior Services Director compiled annually by aging organizations in the area, the Guide was an insert in the newspaper on October 20, 2000, and recognized Disability Employment Awareness Month. This production literally took information about services and resources into homes and businesses and onto the newsstands throughout the Coastal Bend. The Guide was also submitted to the Texas Governor's Committee on People with Disabilities as a nominee for the Barbara Jordan Media and the Martha Arbuckle awards. If selected for either of these prestigious awards, the Resource Guide for Persons with

Disabilities of All Ages will be replicated throughout Texas via Mayor's/County Committees for People with Disabilities.

4.2.3 Distributing Flyers in Utility Bills

Another way to reach people who may be difficult to find is to work with a local utility company to include an informational flyer in the regular monthly mailing of their utility bills. After all, even families who do not subscribe to the local newspaper are likely to have a utility bill delivered to their mailbox at least month.

4.2.4 Internet Websites

A number of projects expanded their exposure through Internet websites. The Tarrant County project's website has generated inquiries from people as far away as San Diego, California, and CNN in Atlanta. An unsolicited comment from one website visitor was:

"Of these sites, I feel that the Area Agency on Aging of Tarrant County has the best website. Although the primary focus is on the elderly and their related concerns, it applies to every single person alive and is especially pertinent to the disabled population. . . . The web site itself is easy to read and easy to access. The format is simple; not too busy or cluttered. Subject headings and topics are easy to locate. . . . The section on The Aging and Developmental Disabilities Coalition contains links to additional resource sites, information on community education opportunities and professional development programs. I was delighted to find that the Coalition's interactive manual for human services professionals, Lifetime Permanency Assistance Planning for Persons With Disabilities, a family planning notebook, is included for use with clients. A section with links to area services expands with links to National organizations, Texas organizations, and Tarrant County organizations. Additional reference sources and published materials are also available."

4.3 Capacity Building

Once the key stakeholders have agreed to work collaboratively, it is important to start building capacity - first within the members of the collaborative work

group, and second within the larger group of providers, consumers, and other local stakeholders. This is an ongoing process that requires a number of approaches, including cross training staff of the local provider organizations, and education and training of the larger group of stakeholders and consumers.

4.3.1 Cross Training

A number of cross training models emerged during the course of the Texas Project, including:

- Cross-training tours
- Brown bag lunch seminars
- Cross-training video

4.3.1.1 Cross Training Tours

Cross training tours can be an effective way to familiarize local providers with the operations of their colleagues providing other types of services. This can be much more effective than simply hearing about a program in a seminar, because it adds the visual and experiential dimension to the learning.

Each set of cross-training tours should actually consist of two tours:

- One tour taking staff that work in aging services to visit providers that serve people with developmental disabilities.
- A second tour taking staff that work with people with DD to aging service providers.

4.3.1.2 Brown Bag Breakfasts and Lunches

“Brown bag” breakfasts and lunches can be held to present material to the front-line workers, as well as other interested parties, whose job duties prevent them from being able to travel off-site to attend longer seminars. These should last 30 minutes to one hour and be scheduled during regular meal breaks. Because these are short, each presentation should be very specific and focused, with the training objectives limited to one key concept.

4.3.1.3 Cross Training Video

While programs such as the cross training tour described above can be very dynamic, many providers are unable to free front line staff frequently enough

to enable them to attend live training. To counteract this problem, a professionally produced cross training video can be helpful. With this, a group of providers work together to showcase each of their services and provide a video tour of their operations.

During the project, the South East Texas project worked with a local television station on the production and moderation of the video. It has proven to be an invaluable tool in educating not only staff, but also the community about resources that are available.

4.3.2 Regional Learning Collaboration: Community Education and Professional Development Programs

Two of the local projects found that educational programming proved to be the strongest priority of the project. By the third year of the project, the Tarrant County and North Central Texas projects had formed a partnership to maximize educational resources. The coordinator proposed forming a partnership with other service providers and Tarrant County College and gave this collaboration a unique identity that became the Regional Learning Collaboration (RLC).

4.3.2.1 Co-sponsors

Over the course of the project a total of 24 co-sponsors were identified. These included organizations providing services not only to the aging and people with developmental disabilities but also to organizations that serve a wide spectrum of age groups and disabilities. The primary qualification for an entity as a co-sponsor was an agreement to publicize each program internally to its staff and consumers. This cut down on the expense of marketing the programs.

4.3.2.2 Topics

Program topics were identified through a focus group at Tarrant County College and through discussions and recommendations from Coalition meetings. Some of the topics were intended primarily for professional development needs of providers, while others were targeted more to meet the needs of consumers and caregivers.

4.3.2.3 Marketing

A brochure listing all RLC programs plus a "shell" brochure to print monthly community education and professional development programs was designed

and published by the North Central Texas Coalition and jointly distributed with the Tarrant County Coalition. 500 of the generic brochures were distributed and another 500 are distributed monthly for each program.

As part of the agreement with sponsor organizations, educational programs were published in newsletters and announced to staff. Announcements are also sent monthly to the local newspaper.

In addition, the coordinator developed a relationship with the Special Education Specialist of Region XI Educational Service Center who disseminated information to all school district special education departments in the region.

The brochure identifies the following target audience for this series and answers the following questions:

“Who can benefit from this program?”

If you provide services to or live with individuals with developmental disabilities or those growing older, you can benefit from these programs:

- **Parents and guardians**
- **Service coordinators and case managers**
- **Caregivers**
- **Professionals**
- **MHMR workers**
- **Senior workers**
- **Nurses**
- **Special education professionals**
- **Rehabilitation counselors**

Why these programs?

As a result of improvements in medical care, people with special needs are living longer and healthier lives and need specialized services throughout each stage of their lives.

The **Regional Learning Collaboration** recognizes the challenges facing our community and its member agencies are joining together to sponsor programs that educate, create a forum for networking, and identify resources.”

4.3.2.4 Benefits

The RLC provided benefits to service providers, caregivers, and consumers in many ways, including:

1. Educational programming in areas where there was identified need
2. Reduced tuition for co-sponsoring service providers
3. Continuing education credit for licensed staff of provider organizations
4. An open forum for networking and resource sharing

4.3.2.5 Expertise/Cross Training/Networking

Speakers for these programs were recruited from the communities they serve and providers of services to the target population. They not only know their discipline but the intricacies of their organizations and recommendations for accessing and using these services for the participants.

Unexpected cross training benefits emerged from RLC programs with attendance ranging from 12 to 36. The initial and traditional audience of people who provided services to or lived with people with developmental disabilities and the aging expanded. The audience began to include regular participation by

- special education teachers (often working with families, which include the aging and developmentally disabled),
- adult probation officers, and
- counselors and program specialists from the Texas Rehabilitation Commission and the area Housing Authorities.

The partnerships that have formed during these workshops and resource sharing sessions are expected to be invaluable in bridging many gaps in services.

4.3.2.6 Partnership with Tarrant County College

An additional best practice was the partnership with Tarrant County College (TCC) itself. The college was able to provide free training facilities, financial support for food and refreshments, additional administrative supports, and the credibility of the programs being provided through a publicly supported college.

Future plans include expanding the partnership with the college into their workforce development program and a more formal relationship with other local universities using the TCC model with support from the TCC Dean of Continuing Education providing anecdotal evidence of how the partnership has enhanced TCC programming while forming and strengthening partnerships with community service providers.

The biggest challenge with the TCC partnership is marketing programs through the continuing education catalog published three times a year. The deadline for this catalog is six months before a program and the RLC has been unable to provide adequate information about the scope of the program and presenters that far in advance for educational programming.

4.3.3 Additional Seminar and Workshop Resources

Organizations that may wish to replicate a program such as the Regional Learning Collaboration, or that may wish to hold a regional conference may find excellent background and how-to advice from a number of books available through retail bookstores or online sellers. These include:

How to Run Seminars and Workshops : Presentation Skills for Consultants, Trainers, and Teachers by Robert L. Jolles.

How to Develop and Promote Successful Seminars and Workshops: The Definitive Guide to Creating and Marketing Seminars, Workshops, Classes, and Conferences by Howard L. Shenson.

Additional resources are available through professional organizations for association and meeting planning professionals such as the American Society for Association Executives (ASAE). Two of their publications are:

Convention Liaison Council Manual: A Working Guide for Effective Meetings and Conventions, 6th Edition. This is a publication of the American Society of Association Executives, and has long been considered a standard guide for association meeting planners.

New Conference Models for the Information Age by Coleman Lee Finkel. This book covers techniques to turn a traditional conference into an interactive learning experience.

These books and other publications may be purchased by contacting ASAE by phone at 202-626-2723, by TDD at 202-626-2803 or by fax at 202-371-8825. Publications may also be ordered online at www.asaenet.org.

4.3.4 Integration of Older People with DD into Services

The Texas Project saw two models emerge that have been successful with integrating older people with DD into services: the ACE Program and the FRAGILE Population Registry. These will each be described in more detail below.

4.3.4.4 Access Center for the Elderly (ACE) Program and Community Resource Coordinating Group for Adults (CRCGA)

The Access Center for the Elderly (ACE) Project was planned, funded, and implemented by the Dallas Area Agency on Aging in 1978. The ACE Project established a network of human service agencies to address the needs of older adults and their families in navigating through the maze of social services in order to maintain their independent lifestyles.

ACE remains a network of voluntary human service agencies working together towards resolving difficult and multiple problems of older persons. Such problems are defined as:

- **Difficult:** situations where the problems have lingered over a period of time and continue to remain unresolved due to either a delayed response by the appropriate agency or lack of obvious resource availability.
- **Multiple Problems:** situations where individuals are plagued with unresolved issues affecting several areas of their lives (financial, physical health, housing) that impede the regular functioning of their lives.

In many ways, this approach is similar to that developed by the Community Resource Coordination Group (CRCG) programs that focus on children with multiple special needs. The overall goal seeks to eliminate or reduce premature *institutionalization* of this population in an attempt to support and improve non-institutional long-term care.

The ACE Program offers an opportunity to modify an existing, successful program to help people who are growing older with developmental disabilities, as well as their aging caregivers.

The Coastal Bend Project initiated the development of a CRCGA in Nueces County. The Community Resource Coordination Group for Adults will assist adults with complex needs that require interagency coordination of services. A

memorandum of understanding is in process of being signed between Nueces County MHMR, Texas Dept. of Protective & Regulatory Service, TDHS and the AAA. Accessible Communities, Inc., the contractor for the A-DD Project is one of the community groups involved and was instrumental in this local development.

4.3.5 FRAGILE Population Emergency Response System Registry and Volunteer Network

The FRAGILE Population Registry was developed by the Central Texas project, and it continues to be their most important project outcome. FRAGILE is the acronym for Friends Responding Across Generations for Independent Living Environments.

4.3.5.1 How It Began

FRAGILE began with the Healthcare Contingency Planning Work Groups for Y2K awareness and preparedness. The founding organizations included:

- Central Texas Partners in Health (Healthcare Contingency Planning Work Group and the Aging and Disabled Work Group)
- Central Texas Council of Governments
- Killeen and Temple HELP Centers
- Killeen Senior Citizen Centers
- Retired Senior Volunteer Program
- Scott & White Hospital
- King's Daughters Hospital
- Metroplex Hospital
- Darnall Army Hospital
- Veteran's Administration Hospital
- Local nursing homes and assisted living centers
- Local emergency services (fire/police) departments
- Bell County 911 and Emergency Management Coordinators
- Home health agencies

Supporting sponsors and their respective contributions included:

- Bell County Judge and Commissioners (\$3,000)
- Central Texas Area Agency on Aging (\$700 + support from the Aging & DD grant)
- Bosshard Radio Services (all 800 mhz radios for communication purposes during community wide emergencies)
- Scott & White Hospital (personnel and meeting rooms)
- Central Texas Workforce Development Board (survey design and PALADIN user interface)
- Combridge, Inc. (personnel time and contact telephone and post office box)

Initially, the project was designed to consist of two databases:

- One database registered those individuals who identified themselves as "FRAGILE" for events such as power outages.
- A second database listed volunteers who wished to assist during these events.

The FRAGILE volunteers include:

- Amateur radio operators
- Bell County Operations Center (Fire Departments, Volunteer Fire Departments, EMS, First Responders, and Fire Department Reservists)
- Killeen, Temple, and Belton high school students
- Bell County Extension/4H, Boy Scouts
- Churches
- Individuals

Costs have included the printing of registration forms and revised registration forms (\$607), printing of buttons (\$525) and postage (\$315). The monetary expenditures total to \$1,447 leaving a balance of \$2,253 for additional mailings, printing of stickers and other costs associated with the project.

4.3.5.2 How It Works

Assistance was originally restricted to emergency situations. Today, FRAGILE is available for intervention upon specific request from a registrant, intervention in community emergencies, and general follow-up and social support. The

911 center provides coordination of efforts during any community emergency such as power outages from storms.

The populations that registered included residents of thirteen counties. The emergency needs and power dependencies, and local family support were all considered in the determination of priority of need. Each registrant was classified as high (n = 48), medium (n = 230) and low (n = 247) priority.

- The high priority included those individuals who only had hours to live if the power was lost.
- The medium priority category included those people who had several hours to one or two days if power was lost. These individuals were also classed as medium priority if they had no local support, had a cognitive impairment or a mental illness.
- Those classed as low priority were individuals with minimal electrical or potable water dependencies, had ample personal supports, and were cognitively and mentally stable.

The number of pieces of patient equipment registered was 1215 from the high and medium groups. This included 24 respirators/ventilators, 52 CPAP, BiPAP, and IPPB machines, 105 compressor nebulizers, 157 oxygen concentrators, and 69 power wheelchairs/scooters.

4.3.5.3 Finding the Registrants

In order to gain access to the individuals needing assistance, the work group requested assistance from the durable medical equipment companies, home health nursing agencies, and long-term care agencies. These groups agreed to the distribution of forms to their clients. Both the durable medical equipment agencies and the home health nursing agencies assisted individuals in completing the forms.

Area support groups were also enlisted in distributing forms and assisting people in form completion. Volunteers including active and retired nurses telephoned each registrant and verified information that was unclear. This was necessary as many people were unsure as to the type of equipment they were using.

Hospital discharge planners began using the FRAGILE forms during discharge planning with patients leaving the hospital when the planners thought it would be beneficial.

As of January 2001, 525 people have registered with FRAGILE and over 100 volunteers or groups have joined the Volunteer Network. Services provided included actual visits on New Years Eve (1999-2000) to assure that equipment was functioning and to reassure each individual that someone in the area knew about and cared for him/her.

4.3.5.4 Continuing Activities

Current activities include the following:

- Continue registration of people, specifically in the Central Texas Council of Governments area.
- Refine FRAGILE risk categories according to acuity, age, family support, and power dependencies.
- Establish the Volunteer Registry in schools, 4H, service and faith based organizations, and scouting programs.
- Train volunteers.
- Maintain follow-up.
- Continue providing interventions as necessary.
- Disseminate replication information.

The ultimate vision for the FRAGILE Registry and Volunteer Network includes the following intervention services or activities:

- Emergency Response
- Respite Care
- Money Management
- Transportation
- Leisure Activities
- Community Inclusion/Socialization
- Circle of Friends
- Telephone checks
- Multigenerational Interactions

4.3.5.5 Lessons Learned and Frequently Asked Questions

The lessons learned during the first year and four months of the FRAGILE project include the following:

- Maximize each situation for media coverage (your best allies!).
- Do not wait to enlist volunteers.
- Do initial triage using R.N.s and retired R.N.s.

- Obtain a second contact name and number for each registrant.
- Establish response protocols.
- Enlist school support during the pre-semester planning and no later than the second week of the semester so that the project can be integrated into community service times.

The questions most frequently asked about the registry and program included the following:

■ ***What will it cost me and will Medicare/Medicaid cover it?***

There is no cost to the recipient at all. This is a total volunteer effort and no insurance is billed. Furthermore, no services are absolutely guaranteed.

■ ***Who registered me/how did you get my name?***

You were provided a form by your durable medical equipment company or home health agency or doctor. Either you or a family member completed the form. Someone from your home had to have sent in the form for us to have your name.

■ ***Will anybody get my medical history?***

The only people with access to this information are the registry personnel and the 911 center. No one else has access to this information. The 911 Center only knows important information like oxygen present in the home or ventilator dependent.

■ ***What are liability issues for the volunteers?***

None under the Good Samaritan law. No services are guaranteed. No volunteer will transport anyone in an emergency. The 911 Center will provide all emergency transportation.

■ ***What are the liability issues for the data managers?***

None as a waiver is signed when the form is submitted. Again, all efforts are provided by volunteers and are not affiliated specifically with any hospital or agency. This lowers the liability substantially.

■ ***How will the information be kept confidential?***

No one but the assigned volunteer, the 911 Center, and the data managers have access to the information about any given registrant or volunteer.

The FRAGILE Population Emergency Response Registry and Volunteer Network have been well received in the Central Texas area. Several responses were made over the past year including assisting registrants with needs during small-scale power outages, referrals to additional services, and social support. Future

planning referrals were also provided. The Central Texas FRAGILE project has become a model for serving the needs of people who are aging and people who have various types of disabilities. This project will continue and eventually become a part of the Central Texas Independent Living Center program.

Aging with Developmental Disabilities

Texas Council for Developmental Disabilities ★ Texas Department on Aging



The Texas Project

Chapter 5

Outcomes and Lessons Learned

5.1 Dissemination of Information

What is a great paradox in this information age? What is a common complaint among members of any organization or group? What tends to keep people from taking advantage of all of the opportunities that are open to them?

The simple fact is that despite the widespread availability of information today, getting the needed information to the right person in a format that he or she will understand and utilize is a huge challenge.

Throughout the five years of the Texas project, an ongoing concern with all parties was sharing information with:

- Members of the collaborative work groups
- Major community stakeholders
- People growing older with developmental disabilities and their caregivers
- The general public.

In Chapter IV we discussed several methods for disseminating information to the general public and target population, including:

- Holding resource fairs
- Distributing resource guides through the local newspaper
- Inserting flyers in utility bills
- Internet websites
- Cross-training tours
- Brown bag lunch seminars
- Cross-training videos

In this chapter we will briefly discuss a few additional methods used for disseminating information among key players in the project statewide. These techniques can be especially helpful when trying to manage a project involving people located across long distances.

5.1.1 E-mail and Listserves

An increasing number of providers and members of the general public have access to e-mail for communications. It can be very effective and easy to send notices and news updates to a large group via a broadcast e-mail. This is generally handled either by

- setting up a group of e-mail addresses in your own e-mail address book, or
- by establishing an e-mail listserve.

In the past, establishing an e-mail list serve often involved purchasing specialized software and setting it up on an organization's in-house server. This often involved considerable expense for both the hardware and software and for the technical expertise needed to manage the system.

Today, organizations may set up an e-mail list serve at little or no cost through publicly accessible online services such as Yahoo! Groups (<http://groups.yahoo.com>). With these services, any group member may post a message that is automatically delivered to all other members of the group. Any reply is also automatically shared with all group members. Individual group members may specify whether they want to

- receive each message in an individual e-mail,
- have messages for a day combined into a single message and delivered at a set interval, or
- elect to read messages online at the group's website.

Through these services, one person functions as the group moderator. That individual may specify that the group is either closed (meaning that only invited people may join the group and that only group members may access messages) or open, meaning that anyone who can access the Internet may join the group and access its data.

Additional features of these services often include:

- "Chat" - which is a service that allows group members to have live online exchanges.

- Posting of reports, databases, or other files that may be accessed by group members.
- A calendar of upcoming meetings and events.

The service provider does not usually charge the group members for the service. Instead, they receive compensation from paid advertisers. All in all, this provides an excellent way for groups to stay in contact with each other.

5.1.2 Audio Conferencing

This is the simplest and most basic form of distance conferencing. Audio conferencing (also called “tele-conferencing” or “conference calls”) happens when all meeting participants are connected through voice telephone lines. All that participants require is a telephone. Standard options for audio conferencing include:

- **Operator Attended** - The service provider’s audioconference coordinator is available throughout your conference call to assist participants as needed. At your request, the operator can dial out and add participants to a conference, perform a roll call, break a large conference into smaller subgroups, facilitate polling and Q&A sessions and perform a host of other services.

- ◆ In the United States, competitive service providers will offer this service for as low as \$0.30 per minute per line (per person). More often, the cost is in the neighborhood of \$0.45 to \$0.50 per minute per line.

- **Unattended** - (also referred to as “Meet Me” or “Passcode”) This level of service allows participants to dial a phone number and enter a passcode to bypass an operator and join the conference automatically. If needed, operator assistance is always available at the touch of a keypad.

- ◆ In the United States, competitive service providers will offer this service for as low as \$0.15 per minute per line. More often, the cost is in the neighborhood of \$0.25 to \$0.30 per minute per line.

- ◆ Some service providers offer flat rate calls for as low as \$35 per hour for up to 10 callers. Typically, with this service each caller is responsible for covering any long distance charges through their regular long distance carrier.

Commonly provided *enhanced* (meaning-extra charge) audio conference services include:

- **Audio Streaming** - This service lets you add an unlimited number of listen-only participants to your audio conference via the Internet. To access the audio conference, participants log onto a particular web site and listen in via their multimedia PCs.
- **Communication Line** - The service provider can keep an open telephone line with the conference host to verify participant attendance, provide updates on the number of participants joined, or have other dialrelative to the conference that may be inappropriate to conduct in the conference itself.
- **Digital Replay** - The service provider can digitally record the conference and make it available for playback, 24 hours a day, for as long as required, so designated parties can access a recording of the conference at their convenience.
- **Electronic Q&A** - This service allows someone to conduct large meetings and take questions at appropriate times during a conference. The Q&A session can take place before, during or after the presentation, or any time, as many times as needed, during the conference. This operator-assisted service entails having all but the main speaker(s) in a "listen only" mode. Members of the listening audience who wish to ask a question simply press a button on telephone keypads.
- **Location Level Billing** - The service provider can set-up independent accounts and bill each participant for their portion of the call. Typically, companies register for this service while making their reservation, and usually a 24-hour notice is required.
- **Participant List** - Either during or at the conclusion of the conference call, the service provider can provide a list of conference participants via fax or e-mail.
- **Participant Pre-Notification** - The service provider sends a fax or e-mail reminder 20 hours in advance of the conference.
- **Polling/Voting** - While in "listen only" mode, participants can respond to questions by pressing codes on their telephone keypads. Tabulations and results are available either instantaneously or at the conclusion of the call.
- **Rebroadcast** - The conference can be recorded for playback at a later date or time, as scheduled during the initial reservation of the conference.

- **Recording** - Most service providers can record the conference on audiocassette tape or compact disc, and send recordings via regular or overnight mail. Additional copies can be sent to multiple locations.
- **Transcription** - The conference can be transcribed by the service provider, in its entirety, and provided in written format on diskette or via e-mail.
- **Translation** - The conference can be translated into most foreign languages and provided in a written format on diskette or via e-mail.

5.1.3 Web Conferencing

During a web conference, participants are able to view a presentation at their computer and provide verbal feedback through audio conferencing. Desktop applications can also be shared with conference participants with the ability to make changes in real-time. To participate, users require two common business tools: a telephone and an Internet-connected PC. All web conferences are password-protected to ensure security.

Most vendors offering audio conferencing services today will also offer web conferencing options.

5.1.4 Videoconferencing

Videoconferencing requires more equipment and set-up than either audio conferencing or web conferencing, and is also more expensive. For videoconferencing to work, all participants must have access to the appropriate video and audio hardware and software in place at their site. Most videoconferencing service providers will require that their company has certified each videoconferencing site in advance of setting up a videoconferencing account. Most universities have videoconferencing facilities available that may be rented.

Video-conferencing is an interactive audio/visual meeting channel to sites worldwide via high-speed telephone lines. Video-conferencing systems employ a "CO-DEC," which CO-mpresses audio and video signals into digital data and then DE-Compresses them at far end sites.

Video-conferencing can be "point-to-point" between two sites, or "multi-point," joining up to 20 sites on a voice-activated bridge. Typical video-conferencing systems include PictureTel, VTel, CLI, GPT, and British Telecom. These support international video and audio standards for inter-operability between systems.

Basic equipment required to conduct videoconferencing includes:

- **Codec** - Takes analog signals from equipment listed below, digitizes and compresses them, and sends them via telephone lines to other meeting locations. Similarly, it receives the same type of signal from other locations and reverses the process to display the visual images on monitors and deliver audio through speakers.
- **Television monitors** - One monitor allows you to see meeting participants at other locations, another monitor allows a speaker to preview the "video" sent to the other participants (e.g., yourself speaking, a pie chart).
- **Main camera and microphones** - Provides video and audio for the interactive face-to-face aspect of the meeting.
- **Document camera** - Allows presentation of overheads, charts, slides and other "hard-copy" materials. Can also serve as a peripheral camera when doing interactive whiteboarding.
- **Personal Computer** - Allows the sharing of computer files (e.g., graphics, multimedia presentations). Connected to SUNet for easy file access and transfer from desktop a desktop computer.
- **VCRs** - Allows meetings to be recorded on video tape for later playback.

5.2 What the Project Cost

The project was funded through a combination of grant funds from the Texas Council for Developmental Disabilities and match funds. A basic breakdown of the funding follows in Table 2.

Table 2. Project cost from October, 1996 to May, 2001.

Year	Grant Dollars	Match	Total
10/1/1996 to 5/31/1997	\$57,961	\$19,320	\$77,281
6/1/1997 to 5/31/1998	\$250,000	\$107,143	\$357,143
6/1/1998 to 5/31/1999	\$250,000	\$123,134	\$373,134
6/1/1999 to 5/31/2000	\$250,000	\$134,615	\$384,615
6/1/2000 to 5/31/2001	\$250,000	\$166,667	\$416,667
FIVE YEAR TOTAL:	\$1,057,961	\$550,879	\$ 1,608,840

Over the five-year period, the match requirement grew from 25% to 40%. Match included both dollars and in-kind contributions (i.e. such things as donated staff time and meeting space).

5.3 Sustainability Beyond the Grant

The projects that succeeded found a variety of methods to sustain the project beyond the term of the grant. These included:

- Securing additional grant dollars for specific initiatives. Grants have been obtained from federal, state, and private foundations by various local projects.
- Combining the grant-related activities with other program operations. For example, a number of the local projects will continue grant-related activities as part of their regional access plan implementation. Other examples include combining these activities with development of local independent living centers or community resource coordinating group activities.
- Developing activities that include a fee for service. Examples include charging registration fees for seminars and conferences, and creating an association that receives membership fees.

5.4 Lessons Learned

At the conclusion of this project, we have learned many lessons, including a few that would lead us to approach this project differently had we the chance to start over again. The most important lessons learned included:

- **It takes more than two years.**

In our initial plan, we had thought that two years of funding was sufficient to launch these projects in the local communities. However, at this point we are seeing that a minimum of three years duration for a project of this type is necessary with this level of funding. It takes time to introduce and develop new concepts with staff in public agencies to effect change. The level of funding is adequate for a part-time effort, which, when spread out over three years in small doses is more readily acceptable and therefore more likely to succeed.

■ **Hire an independent contractor for project coordination.**

Contract out the project rather than handle in-house at the AAA for the following reasons:

- ◆ AAA staff availability and expertise in working with people with disabilities can be limited.
- ◆ A partnership between an AAA and a disability organization role models to other agencies the effectiveness of a collaborative model.
- ◆ Funds were consistently utilized because an independent contractor operates on a performance-payment (fee for service) basis.
- ◆ Contracting out provided an opportunity for a AAA to expand its' sphere of influence beyond the "box" of other state or public agencies and in particular to include new and necessary relationships with disability organizations.
- ◆ Disability organization(s) in non-advocacy/fragmented communities benefit from the coat tails of a compatible organization that can lend credibility to disability issues to the community at-large, directly impact the development of a disability system similar to a successful AAA model, and provide a source of much-needed funding to sustain disability advocacy/organizing efforts.

■ **Concentrate on a few model projects.**

The initial plan in Texas was to spread the funds out in small amounts over the entire state. As we saw during the course of the project, not all areas of the state were interested in participating in this project, and in latter years the project was reduced to a few key areas that sustained an interest. In hindsight, it may have been more effective to offer a larger amount of funding to fewer pilot projects from the beginning.

