

And How Are the Children?

**Recommendations for Improving the
Well-Being of Children with Disabilities
in Texas**

for

House Bill 1478

**Submitted to
Texas Legislature
&
Don Gilbert, Commissioner
Texas Health and Human Services Commission**

by the

**Children's Policy Council
September 1, 2002**

CHILDREN'S POLICY COUNCIL

Susan Murphree, Chair

Colleen Horton, Vice-Chair

September 1, 2002

Dear Texas Legislature and Commissioner Don Gilbert:

The Children's Policy Council (Council) respectfully submits to the Texas Legislature and Commissioner Don Gilbert, Texas Health and Human Services Commission the attached recommendations, per our charges in House Bill 1478 (77th Texas Legislature).

The Council focused on the charges required in legislation and on its mission to promote and advocate for public policies that support children with disabilities to grow up in families, to be an integral part of their communities, and to meet their potential. For a full list of our charges, please see Appendix A.

It has been an honor to serve as appointees to the Council. We acknowledge and value the expertise and ideas contributed by our ex-officio members and stakeholders and the wisdom and support of the state agency staff.

We appreciate your consideration of these recommendations for the benefit of Texas children with disabilities and their families.

Sincerely,

Susan Murphree

Susan Murphree, Chair

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And How Are the Children?

Among the most accomplished and fabled tribes of Africa, no tribe was considered to have warriors more fearsome or more intelligent than the mighty Masai. It is perhaps surprising then to learn the traditional greeting that passed between Masai warriors. "Kasserian ingera," one would always say to another. It means, "*and how are the children?*"

It is still the traditional greeting among the Masai, acknowledging the high value that the Masai always place on their children's well being. Even warriors with no children of their own would always give the traditional answer, "All the children are well." Meaning, of course, that peace and safety prevail, that the priorities of protecting the young, the powerless are in place, that Masai society has not forgotten its reason for being, its proper functions and responsibilities. "All the children are well" mean that life is good. It means that the daily struggles of existence, even among poor people, do not preclude proper caring for its young.

I wonder how it might affect our consciousness of our own children's welfare if in our culture we took to greeting each other with this same daily question: "*And how are the children?*" I wonder if we heard that question and passed it along to each other a dozen times a day, if it would begin to make a difference in the reality of how children are thought of or cared for in this country? I wonder if every adult among us, parent and non-parent alike, felt an equal weight for the daily care and protection of all the children in our town in our state, in our country.... I wonder if we could truly say without any hesitation, "the children are well, yes, all the children are well."

What would it be like...if the President began every press conference, every public appearance, by answering the question, "*And how are the children, Mr. President?*" If every governor of every state had to answer the same question at every press conference: "*And how are the children, Governor? Are they all well?*" Wouldn't it be interesting to hear their answers?

**Excerpt from a speech by the Rev. Dr. Patrick T. O'Neill,
First Parish Universalist Church in Framingham, MA*

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Executive Summary

Many children with disabilities in Texas are thriving in families, attending community schools, and participating in all types of typical childhood activities. Many others, however, are residing in large congregate institutions or are at risk of institutional placement due to their inability to obtain sufficient community supports. Over the past two years, the Children's Policy Council has attempted to identify the support needs of families caring for children with significant disabilities and to develop recommendations that could improve access to services for children. The primary goal of the Council has been to help move the system toward more family and child-centered services that could enhance the opportunities for children with disabilities to grow up in nurturing families, which is in alignment with state legislation and policies.

BACKGROUND

House Bill 1478 (77th Texas Legislature) provides the statutory authority for the Children's Policy Council. Through this legislation, the Council is required to assist the Health and Human Services Commissioner and health and human services agencies in developing, implementing, and administering family support policies and related long-term care and health programs for children.¹ The Council's work is based on the following mission:

To promote and advocate for public policies that support families of children with disabilities, enabling their children to grow up in families, be an integral part of their communities, and meet their potential.

House Bill 1478 directs the Council to study and make recommendations in the following topic areas: funding, transition, collaboration, permanency planning, enforcement of regulations, services and supports to families, and the provision of Medicaid services.²

IMPORTANT DEFINITIONS

This report refers frequently to the provision of long-term services and supports. Senate Bill 374 (76th Texas Legislature) defined long-term care services to mean "the provision of personal care and assistance related to health and social services given episodically or over a sustained period to assist individuals of all ages and their families to achieve the highest level of functioning possible, regardless of the setting in which the assistance is given."³ Because of children's need for attachment and nurturance, the optimal setting for long-term supports to achieve maximum developmental potential is within the context of a family.

The term "family support" is also used frequently in this report and refers to the services that help families care for children in their homes. Essential elements to a system of family support can be categorized into three areas:

¹ House Bill 1478, 77th Texas Legislature, 2001.

² Ibid.

³ Senate Bill 374, 76th Texas Legislature 1999.

- Individual services – health and social care services for the personal needs of children such as medical services, home nursing care, personal attendant services, mental health services, counseling and mentoring, transition services, independent living skills, and case management.
- Assistive products – tangible supports such as durable medical equipment and assistive technologies, and home modifications for children with disabilities.
- Family services – support for the whole family, including information and referral, respite care, alternate family care, family income supports, crisis services, sibling support and parent training.⁴

Overlap exists between the two definitions. Often, long-term care refers strictly to the services provided to the individual with disabilities. Family support, however, while it includes long-term services and supports is intended to support the family unit for the benefit of the child. It is widely recognized that supporting the family greatly increases the health and well being of the entire family and increases the likelihood that the child with disabilities will remain at home.

PROGRESS IN SUPPORTING CHILDREN AND FAMILIES

Under the direction of the Texas Health and Human Services Commission, much work has been done to identify barriers families encounter when trying to access supports and services and to develop strategies to improve the systems of family support. Through various agency/stakeholder workgroups, areas such as case management, permanency planning, and transition have been thoroughly evaluated and recommendations are in various stages of implementation. The Commission is also beginning to implement Senate Bill 36 (77th Legislature) that requires cross-agency training for caseworkers, although lack of funding has limited implementation activities. This training, when fully implemented should enhance the ability of staff to provide quality information to families.

In cooperation with the Texas Education Agency, health and human services agencies have developed a proposed Memorandum of Understanding created to address the needs of individuals transitioning from children's services to adult services. This is of vital importance as many families express serious concerns about their inability to obtain information and access community services for their child when he or she ages out of children's services and public school.

Also accomplished during the past biennium was the study and report on the issue of single case management. This report, developed by the School of Social Work at the University of Texas, included strategies for the development of a comprehensive, single case manager model based on: best practices, analyses of nine state programs, information obtained from focus group

⁴ Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. II: Current Services and Future Policy*. Austin, TX, 2001, p. 18.

meetings with family members, and review of literature. The study emphasized the need for on-going family involvement to ensure access to quality information.⁵

A significant step toward improving the system of care for children with disabilities was the passage of Senate Bill 368 (77th Legislature). This legislation directed the creation of a stronger system of permanency planning for children residing in institutions, as well as the development and implementation of a system of family-based options for children in institutions in a pilot project area. Both components of this legislation were aimed at addressing support gaps in the current systems of care for children with developmental disabilities. The primary purpose of the new permanency planning requirements is to address the urgency of the developmental needs of children with disabilities and how those developmental needs are affected by institutionalization. In a study performed by the Lyndon B. Johnson School of Public Affairs at the University of Texas at Austin, the effects of institutionalization were characterized as follows:

Numerous studies have been performed on the effects of long-term institutionalization on children, and virtually all of them describe slowed social and cognitive development for these children...Negative effects appear to be correlated to the length of time a child lives in an institutional setting, as well as with ages at which a child enters a facility...Most western psychologists have held that despite trained staff and good standards of hygiene, institutional care of very young children is likely to severely and probably permanently damage the development of a wide range of functions.⁶

Through the process of permanency planning, state policy planners are learning about the circumstances that lead families to consider out-of-home placement for their child. As a result, the state will be able to begin focusing on more family-centered supports that when implemented, can often prevent institutional placements. In addition to the urgency reflected in the research on institutionalization of children, the magnitude of this issue and the need for systemic changes is validated by the large number of children residing in institutions, and the significant number of individuals waiting for community services. The tables below depict the most recently available statistics for Texas.

Type of Facility	Number of Children
Nursing Facilities	231
State Mental Retardation Facilities (state schools)	257
Intermediate Care Facilities for the Mentally Retarded	697
Institutions for the Mentally Retarded Licensed by DPRS	76
Group Homes (Waiver Homes)	291
Total	1,552

Source: HHSC, June 2002

Note: Number of children includes those 21 years and younger

⁵Busch, N., Ruffing, T., Rudenick, J., Sullivan, H., and Meimeyer,. "Exploring a Single Case Manager for Children with Disabilities, Final Report for the Texas Health and Human Services Commission." October 2001, p. 1-20.

⁶Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. II: Current Services and Future Policy*. Austin, TX, 2001, p.9-10.

Home and Community-Based Services	Number Served	Number on Waiting/Interest List
Home and Community-Based Services (HCS, HCS-O, MRLA waivers at MHMR)	1,063 ages 0-21	17,591 total 6,305 children ages 0-17
Community Living Assistance Supports and Services (DHS)	1,492 adults & children	8,094 total 6,172 children
Community-Based Alternatives (DHS)	30,040 adults 21+	41,198 adults 21+
Medically Dependent Children's Program (DHS)	911 under 21	3,087 under 21
Children w/Special Health Care Needs (TDH)		
<i>Family Supports</i>	5	319
<i>Health Benefits</i>	5,289	1,146
<i>Case Management</i>	49,370 (fy 01)	0
Consolidated Waiver Program	up to 100adults up to 100 children	Draw from other wait lists
In-Home and Family Support (MHMR)	2,944 Children	434 Children
In-Home and Family Support (DHS)	3,199 adults & children	11,364 adults & children
Deaf/Blind Multiple Disabilities	116 adults	47 children

Source: DHS, August 2002, HHSC, August 2002, MHMR, August 2002, TDH, August 2002

SYSTEMIC BARRIERS

While significant progress has been made, many major barriers continue to exist that impede a family's ability to obtain the supports and services they need to care for their child with disabilities at home. Current system barriers include: fragmentation in the system, families' inability to obtain comprehensive and accurate information, inability to access waiver services due to extensive waiting lists, shortages of quality direct care workers in the community, lack of sufficient alternatives to institutional care, lack of sufficient funding for community services, high turnover rates for both agency and direct service staff, lack of flexibility and family-centered practices, inconsistencies among agencies with respect to application and eligibility requirements, limited knowledge of cross agency programs at the local and regional level, and more. Some of the current policy barriers are the same as those identified in various reports on long-term services for more than a decade. In 1992, the Governor's Committee on People with

Disabilities recommended strategies for reducing fragmentation and maximizing opportunities for accessing community services.⁷ Many of these recommendations remain valid today.

Contributing to the barriers mentioned above is the difficulty in identifying and addressing the unique needs of children with a variety of disabilities. With the large number of children with disabilities in the state, identifying and prioritizing the services and supports needed presents many challenges. While much commonality exists among children needing long-term services, various disabilities can present the need for specialized services. For example, very little has been done to identify children in Texas with traumatic brain injury (TBI). This can result in under-identification and misdiagnosis. As a result, children with TBI are often placed in classrooms with children with emotional disabilities and often do not receive the services they need. The inability of these children to access the appropriate neurological assessments and treatments can significantly impact their potential for progress. Another example of gaps in specialized services is the need to identify and make available positive behavioral supports to families caring for children with significant emotional and behavioral disabilities. Often, the lack of behavioral supports and services for children with significant disabilities can result in out-of-home placements. More and more frequently Council members are becoming aware of families who are forced to relinquish custody of their children because they cannot get the mental health services their children need.

The recommendations included in this report were developed to provide possible solutions to existing barriers. Many children and families are in desperate need of services and developing children do not have time to waste. Each day in an institution or each day without the needed community services and supports is opportunity lost for the child.

CODE RED – THE KIDS NEED HELP

The Children's Policy Council has spent the past two years analyzing the current status of the systems of long-term care and family supports that are available to children in Texas. While many programs exist that can provide services, many children cannot access those services due to insufficient funding or various administrative policies and procedures. The recommendations are numerous, which indicates a substantial unmet need. Many of the various recommendations can be categorized into a small number of overarching themes.

OVERARCHING THEMES

Children Belong in Families

First, Texas continues to have more children residing in institutions than any other state and continues to allow the institutionalization of young children. If the state is to make meaningful strides at reducing the number of institutionalized children in Texas, concerted effort of time and commitment of resources will be needed. This problem was decades in the making and will not be reversed in a few short years. Implementation of several recommendations in this report is critical if progress is to be made and the quality of life for these children is to be improved. The

⁷Governor's Committee on People with Disabilities. *Moving From Institutions to the Community: A Blueprint for the New Texas*. Austin, Tx., 1992, p. 12-13.

Children's Policy Council strongly recommends that work begin immediately to implement the following recommendations:

1. Children with disabilities age 12 and under should not be admitted to any institution, as defined by Senate Bill 368, 77th Texas Legislature (*Rec. 1.2, Promoting Families*).
2. Remove the responsibility for permanency planning from the facility where the child resides in order to eliminate the conflict of interest created when the facility that receives funding for having the child occupy a bed is also responsible for seeking opportunities for family-based options (*Rec. 2.1, Promoting Families*).
3. Continue and expand the existing family-based alternatives project (*Rec. 3.1 & 3.2, Promoting Families*).
4. Prioritize children who are in institutions. Children under age 18 residing in institutions as defined by Senate Bill 368 should be prioritized for funding that supports children moving into families in the community.
 - (a) This may be accomplished by providing waiver slots for all requesting transition to families, or by allocating 50% of appropriated slots.
 - (b) Expand the Rider 37 concept to allow funding to follow the child to the community for children residing in any LTC facilities as defined by Senate Bill 368 (*Rec. 1.4 & 1.5, Promoting Families & 1.1, Funding*).
5. Fund agency permanency planning efforts.
 - (a) Fully fund DHS appropriations request to continue permanency planning efforts in nursing homes;
 - (b) Fully fund HHSC's appropriations request to continue funding permanency planning training and monitoring;
 - (c) Fully fund MHMR's appropriations request to ensure permanency planning in ICF/MRs and state schools (*Rec. 1.3, Funding*).

Families Need Support

A second overarching theme in this report addresses the need for a stronger system of family supports. Families need help. They are often physically and emotionally exhausted, extremely frustrated, and at times left with a feeling of hopelessness. The knowledge that waiver services may not be available for their child for at least five to ten years leaves many feeling desperate. At times families are forced to relinquish custody of their child to Child Protective Services in order to get the services their child needs. Families need respite (a break for the caregiver), they may need equipment, they may need home modifications, and other services. Families want to care for their children and typically go for many years with little or no help. In order to promote the physical and emotional health of families caring for children with disabilities the state should make children with disabilities a priority and immediately implement the following recommendations.

1. Create a position for a parent of a child with a disability as liaison at state agencies, and designate an existing position at regional levels to be a parent liaison contact. These positions should be valued at professional salary levels and should be created at following agencies - Texas Department of Human Services (DHS), Texas Department of Health (TDH), Texas Department of Mental Health Mental Retardation (TDMHMR), Early Childhood Intervention (ECI), Texas Department of Protective and Regulatory Services (PRS), and Texas Education Agency (TEA) (*Rec. 1.4, General Family Supports*).
2. Maintain access for children to all current and future Medicaid waivers using eligibility criteria based on child's income (*Rec. 2.3, General Family Supports*).
3. Actively solicit parents of children with disabilities as applicants for case management positions and employ parents and other qualified, experienced family members as case managers for children and adults with disabilities who are not their own family member (*Rec. 5.1, Case Management*).
4. For families whose children have multiple case managers, identify a lead case manager and use consultative case management for expertise in certain subject areas while working toward a single case manager model (*Rec. 2.2, Case Management*).
5. Conduct cross agency case management education and training summits in each HHS region. New funding and/or blending current training budgets will be necessary:
 - (a) Training should be based on each regions assessment of their needs and an update on new programs and policies. Needs assessments must include input from families receiving services and families waiting for services; and
 - (b) Include parents in all aspects of planning the summits and have parents as equal participants in the summit - as trainers and as learners (*Rec. 3.1, Case Management*).
6. Require middle and high school level teachers to participate in in-service training on transition, person-centered planning, and advocacy as part of their required number of state days of training. Improve the quantity and quality of transition training in the Comprehensive System of Professional Development. Parents and parent groups should be invited to attend trainings (*Rec. 2.1, Transition*).
7. Direct Texas Rehabilitation Commission to implement a presumed-capable policy for eligible transition age students and provide access in a timely manner, based on 1) the person having a disability, and 2) the belief that the services will benefit the person in terms of employment. TRC should:
 - (a) Begin serving students with disabilities earlier, not beginning at their senior year with an assessment.
 - (b) Increase opportunities for extended evaluations for employment services and extended supports by ensuring adequate provider base, particularly in rural areas and
 - (c) Increase opportunities for timely supported employment (*Rec. 2.2, Transition*).
8. Include long-term care information in Texas Education Agency parent manual (*Rec. 2.6, Transition*).

9. Each waiver should provide flexible family support services to meet the unique needs of each family.
 - (a) Families should be able to mix and match support services to meet the unique needs of the family. Waiver policy should embrace individualized solutions and move away from "one size fits all" solution for children and families. For example, eliminate service type caps such as the 150 hour supported employment cap in the Home and Community Services (HCS) program at the Texas Department of Mental Health and Mental Retardation.
 - (b) Expand access to consumer directed services options
 - (i) Expand consumer directed services to all 1915 (c) waivers where they can hire caregivers directly and not be required to use a home health state agency, regardless of the agency administering the waiver program.
 - (ii) Expand the type services available in the consumer directed services models
 - (c) Allow flexibility in the authorization and scheduling of private duty nursing to allow families to use the services in a manner that best suits their needs.
 - (d) Extend to six months the authorization for private duty nursing in the Comprehensive Care Program (Rec. 3.2, Medicaid Waivers).

Families caring for children with disabilities face many challenges in their daily activities. For those without support, the responsibility can become overwhelming. Families do, however, recognize the many rewards associated with raising a child with disabilities. As reported in a recent article in *Health Affairs*, "many caregivers reported that their experiences had a positive influence on their life and their relationships with those they care for."⁸ Families want to keep their children at home, but at times, circumstances require them to seek help.

AND HOW ARE THE CHILDREN?

While some children with disabilities are doing well, many are not. While some families are able to care for their children on their own with extended families and other natural supports, others are left alone with little support and children at risk. The Council looks forward to the future when we can say, "all the children are well." The information and recommendations contained in this report are designed to identify areas needing change and propose various methods for improving the system of long-term services and supports for children in Texas. By continuing to address the problems, strategize potential solutions, and implement essential recommendations, Texas will continue to move in a direction that will improve the quality of life for many children with disabilities and their families.

⁸Donelan, K., Hill, C., Hoffamn, C., Scoles, K., Feldman, P., Levine, C., and Gould, D. "Challenged to Care: Informal Caregivers in a Changing Health System." *Health Affairs*, (July/August 2002), p. 228-229.

Promoting Children in Families Through Permanency Planning

INTRODUCTION

Over the past two years, Texas has undertaken several initiatives to promote the ability of children with disabilities to live in families. In spite of these efforts, Texas continues to institutionalize many of its children. In the year 2000, there were approximately 1,253 children with disabilities under the age of 21 living in state mental retardation facilities (state schools), intermediate care facilities for the mentally retarded, nursing facilities, and institutions for the mentally retarded licensed by the Department of Protective and Regulatory Services. As of June 2002, there were approximately 1,245 children in the same facilities. (Health and Human Services Commission, 6/02) Consequently, while various initiatives have begun and attention is being paid to these children, there is still much work to be done. As a state we continue to allow very young children to be placed in a variety of institutions. Once placed in facilities, children rarely have the opportunity (the supports and services needed) to return to their birth families or to transition to alternate support-families.

Both the Children's Policy Council and the Senate Bill 367 Task Force on Appropriate Care Settings for Individuals with Disabilities have strongly endorsed the need for increased family supports and the development of family-based options for children residing in Texas institutions. Research has shown that institutionalization of children negatively affects all aspects of development including cognitive, physical, emotional, and psychological growth.⁹ Families suffer tremendously when forced to consider institutional placement for their children. The inability to access adequate supports and services affects entire families, not just the children with disabilities.

Permanency planning is meant to be an ongoing process with the objective of providing children with the opportunity to grow up in families. To ensure effective permanency planning, the Council believes there must be an understanding across agencies that permanency planning is not meant to be a review of the child's placement, but is meant to evaluate the system's response to the support and service needs of the individual child and family. To meet these objectives, comprehensive training should be provided to those responsible for permanency planning activities. Training should be based on best practices, should include parents of children with disabilities who have resided in institutions, and should provide incentives for those participating. Permanency planning should be included in the cross-agency case management training required by Senate Bill 36 (77th Texas Legislature) and should also target physicians, hospital staff, and other providers serving children with disabilities. As appropriate, reports submitted to the Texas Legislature and federal agencies by state human service agencies should provide data, on children in facilities as well as current agency permanency planning efforts.

⁹Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. II: Current Services and Future Policy*. Austin, Tx., 2001, p.9.

The State of Texas should strongly affirm and promote its belief that children belong in families and that no child should be left behind, including children with disabilities. This can be accomplished by removing the barriers and implementing the recommendations identified in this section.

PROGRESS

During the past two years, many state agency staff, disability advocates, legislative staff, and parents of children with disabilities have worked cooperatively to develop public policies that promote the right of children with disabilities to live in families. While the actual number of children living in institutions has not decreased, the Council believes that continuing the initiatives, most of which are in the first six to twelve months of implementation, and intensifying efforts to support children and families will result in significant opportunities in the near future for these children. Current initiatives include:

- Passage of Senate Bill 368 (77th Texas Legislature) which enhanced permanency planning requirements for children in institutions and directed the Health and Human Services Commission (HHSC) to contract for the development and implementation of a system of family-based alternatives to institutional care;
- Development of inter-agency permanency planning standards.
- Implementation of Texas Department of Human Services (DHS) contracts for permanency planning for children in nursing facilities;
- Development and distribution of a permanency planning guide designed for parents whose children reside in institutional settings;
- Creation of two staff positions at the Health and Human Services Commission to conduct permanency planning training and review permanency planning data collected from agencies;
- Award of contract to EveryChild, Inc. to develop and implement a system of family-based alternatives for children in institutions in a 12-county, central Texas area. These alternatives may include shared parenting between birth families and newly recruited families; and
- Collection of data across agencies on children in institutions as a result of Senate Bill 368. These data will be evaluated on an on-going basis to improve permanency planning efforts.

PROMOTING CHILDREN IN FAMILIES RECOMMENDATIONS

Implementation of the following recommendations will increase opportunities for children to grow up in families.

Recognize the urgent developmental needs of children when addressing long-term care services.

- 1.1: Prioritize children who are in institutions. Children under age 18 residing in institutions as defined by Senate Bill 368 (77th Texas Legislature) should be prioritized for funding that supports children moving into families in the community. This may be accomplished by providing waiver slots for all requesting transition to families, or by allocating 50% of appropriated slots for children.
- 1.2: Children with disabilities age 12 and under should not be admitted to any institution, as defined by Senate Bill 368, 77th Texas Legislature.
- 1.3: Require appropriate state health and human services agencies that provide long-term care services and supports to include in agency strategic plans that will prioritize decreasing the population of institutionalized children in Texas based on the impact of institutionalization on childhood development.
- 1.4: Continue DHS Rider 37 that allows funding for long-term services and supports for children residing in nursing facilities to be used to purchase community waiver services.
- 1.5: Expand the ‘funding following the child’ concept of DHS Rider 37 to include children with disabilities who are publicly funded and reside in any institutional setting.
- 1.6: HHSC should work with agencies to identify funding resources for children at risk of institutionalization due to a family crisis, a change in their support needs, or other emergency situations.

Rationale

Many of the children currently residing in institutions were initially placed due to the inability of their families to access adequate community supports and services. To move children out of institutions and into families, funding must exist to provide the individualized services that these children require. Rider 37 currently provides a funding stream for children leaving nursing homes to purchase those needed services. Expanding the ‘funding following the child’ concept of Rider 37 to include children living in ICF/MRs and Medicaid eligible children living in acute care hospitals would provide a funding stream to purchase similar services for children leaving these facilities.

When a family is in crisis and requires immediate out of home placement for their child, often the only option available is "temporary" placement in a facility. Many times, these temporary placements turn into long-term placements. Developing funding to provide temporary out-of-home support in family-based settings would reduce the likelihood that the temporary care would result in institutionalization of the child.

Ensure effective permanency planning implementation.

- 2.1: Remove the responsibility for permanency planning from the facility where the child resides in order to eliminate the conflict of interest created when the facility that receives funding for having the child occupy a bed is also responsible for planning opportunities for family-based options.
- 2.2: Re-convene the ad-hoc interagency permanency planning workgroup that developed the permanency planning standards to: a) evaluate the progress and effectiveness of the permanency planning process, b) identify ways to strengthen accountability measures, c) evaluate data collection tools and reporting requirements, d) ensure that children with various disabilities are identified, and that the unique support and service needs specific to those disabilities are assessed. Ensure continued participation of families in the interagency permanency planning workgroup.
- 2.3: Use a system of trained developmental disabilities specialists in each region at the Texas Department of Protective and Regulatory Services to:
 - (a) Assist and educate individual caseworkers for children placed, or at risk of placement by TDPRS in institutions, and
 - (b) Provide specialized designated case managers for children residing in the institutions for the mentally retarded licensed by TDPRS.
- 2.4: Designate one or more dedicated positions in each MHMR region, as well as a position in each DHS region with large numbers of children in nursing homes, to provide coordination, expertise, and technical assistance for permanency planning and relocation activities to ensure a successful transition from facility to community-based services.
- 2.5: Continue permanency planning efforts begun in HHS agencies.
 - (a) Fully fund DHS appropriations request to continue permanency planning efforts for children in nursing homes
 - (b) Fully fund HHSC's appropriations request to continue funding permanency planning training and monitoring
 - (c) Fully fund MHMR's appropriations request to ensure permanency planning for 300 children in ICF/MRs and state schools.

Rationale

While important steps have been taken to begin implementing new permanency planning requirements, there is a significant lack of understanding throughout the health and human services system as to the true meaning of permanency planning and the intended outcomes. In many cases, permanency planning is still viewed as a paper requirement designed to ensure compliance. Permanency planning should not begin, nor should it end, with filling out forms or complying with a predetermined set of activities. It is not considered a time-limited process of decision-making. Permanency planning should begin with a focus on an individual child and his or her family. It should be the building of long-term, trusting relationships. These relationships lead parents to identify their vision of the ideal combination of supports and services that will allow them to imagine the possibilities and facilitate the realization of their child's potential and quality of life.

Continue and expand development and implementation of a system of family-based options to institutional care of children.

- 3.1: Continue the existing family-based alternatives project.
- 3.2: Expand the family-based alternatives project to: a) at least two additional geographic areas with high populations of institutionalized children, and b) include children at risk of institutional placement in all project sites.
- 3.3: Create a six-year plan (timeline) for activities associated with the development of family-based alternatives (i.e., expansion phases, rollout, etc.). HHSC should request agencies to include these activities in their respective strategic plans.
- 3.4: Expand recruitment and public awareness activities to include all areas of the state to ensure opportunities for children to move to support-families in close proximity to their birth family, with special consideration for children in CPS custody for whom proximity may or may not be appropriate.
- 3.5: The Child Protective Services should work in conjunction with the Children's Policy Council to:
 - (a) Evaluate adoption policies and procedures for children with disabilities, and
 - (b) Identify and make recommendations to remove barriers that prevent or impede frequent adoption of children with disabilities.

Rationale

The process of developing a system of family-based options to institutional care requires a commitment of time and resources. The current 12-county project is in its infancy. The initial 16-month project period provides limited time to develop the infrastructure and begin the intensive activities involved in this project. To develop quality, family-based options to institutional care for children the state must support continuation of the initial project. To ensure that all Texas children residing in institutions will have the opportunity to grow up in families, the state must support continual expansion at a reasonable pace. The opportunity to earnestly address the large number of children in Texas institutions has begun. The state of Texas should continue its commitment to these children by pledging support to the development of a system of support-families and to the provision of services all families need when caring for a child with disabilities.

Adoption of children with disabilities is difficult due to the low adoption subsidies and lack of on-going support to the families. To enhance the opportunities for real permanency for children with disabilities, recommendations should be developed that would reduce the obstacles and improve the opportunities for children with disabilities to be adopted.

Develop and implement a system of accountability and monitoring of institutional placements of children.

- 4.1: Ensure that the specialized treatment and services appropriate for children are provided based on the individual needs of the child.
- 4.2: HHSC should develop and publish an annual state report card that includes: 1) the number of children in facilities (are numbers increasing or decreasing?), 2) the number of children waiting for community services (those on Medicaid waiver waiting lists and non-Medicaid waiting lists), 3) the number of parents relinquishing custody of their child in order to access services, and 4) comprehensive data on institutionalized children collected from permanency planning data elements. This annual report card should be included in the Texas Council for Developmental Disabilities State of the State biennial report to the Legislature.
- 4.3: Authorize and support the ability of the mental retardation authorities to access reports specific to children in institutions in their respective regions. These reports focusing on children will enable the local authorities to better monitor and support these children and their families and contribute to the efforts to reduce the number of institutionalized children in their regions.

Rationale

While permanency-planning statutes were first passed more than six years ago, implementation started in earnest only over the past 12 months. Permanency planning is new to Texas human services agencies and few service providers have a comprehensive understanding of what it is or how to do it. Monitoring the implementation and evaluating the data being collected will enable state agencies to determine what additional work needs to be done to ensure that those charged with the responsibility have the skills, knowledge and resources to do the task.

General Family Supports

INTRODUCTION

Although there have been several initiatives in the area of family supports for children with disabilities during the past two years, many of the barriers and recommendations cited in the September 2000 Council report remain. Families, as primary caregivers for their children, are the most important influence on their children's growth and development. Providing support to families prevents costly out-of-home placement and provides for the nurturing environment children need to maximize their potential. Families and service providers agree that the supports must be flexible to meet the unique needs of each family. Families should have the opportunity to determine what supports they need, to decide when and how the supports will be provided and to be able to choose who will provide the supports.¹⁰ To help prepare families to make these important decisions, and to improve agency staff's ability to help families make these decisions on behalf of their child, the Council supports:

- Expanding opportunities for families to participate on all state-level advisory committees making recommendation on family support services;
- Continuing to support the Traumatic Brain Injury Council and the Children with Special Health Care Needs Advisory Committee to ensure a voice for self-advocates as well as children and their families;
- Expanding opportunities and funding for families to learn self-advocacy; and
- Utilizing existing training and conference opportunities for families to educate staff on the importance of family supports.

Natural supports refer to the support families receive from organizations, family, and friends in their communities. Families who have children with disabilities have often exhausted these natural supports and need additional support from one or more state programs. Rather than supplant traditional supports, the publicly-funded services should, and often do complement existing strengths of the family and community. Working together, natural and publicly-funded supports assist children with disabilities and their families to remain active, valued participants in their communities.

To promote a stronger system of family support in Texas, the Council believes that the state should strive to:

- Expand funding for TDMHMR and ECI children's mental health initiatives to target early identification and family centered, community-based treatment of children with mental health or emotional issues and needs;
- Take advantage of the Family Opportunity Act (if passed) or any new funding opportunity available to expand waiver programs and/or Medicaid buy-in to prevent the institutionalization of children;

¹⁰ Busch, N., Ruffing, T., Rudenick, J., Sullivan, H., and Meimeyer. "Exploring a Single Case Manager for Children with Disabilities, Final Report for the Texas Health and Human Services Commission." October 2001, p. 1-20.

- Expand access to childcare for children with disabilities through the Texas Workforce Commission local childcare programs, and independent school districts' preschool and after school programs; and
- Ensure that agencies that provide residential care for children with disabilities facilitate timely family reintegration by identifying resources to help support the child in his or her family and community by blending, redirecting or refinancing, if necessary.

Public attitudes toward families who care for children with disabilities are all too often based on sympathy and pity with an expected outcome of drain on the state's resources. These perceptions are based on a lack of experience and knowledge about individuals with disabilities. Public awareness initiatives should stress not only the challenges but also the benefits of caring for children with disabilities and emphasize the need to treat all children with dignity and respect. The expected outcomes for children with disabilities must focus on inclusion and active participation in their community. Public education campaigns can assist in altering public perceptions by providing evidence of the contributions of people with disabilities to their communities and the rewards a child with disabilities brings to a family.

The state can provide many opportunities to promote positive attitudes and perceptions of children with disabilities growing up in families. Community outreach information developed and distributed by agencies should aim to change public attitudes on what it means to care for a child with disabilities. Outreach efforts should also be used as opportunities to provide information to families regarding resources available and how to access specialized services in their communities. These public awareness objectives could be met through a variety of venues including: organizing a speakers' bureau of parents of children with disabilities, publishing news stories that highlight successes, developing public relations materials and fact sheets, and by working with non-traditional community groups.

PROGRESS

During the last two years, various workgroups and advisory councils have addressed the topic of family support for families caring for children with disabilities. Further, the HHSC implemented the Texas Family Support Initiative, a federal grant from the United States Department of Health and Human Services, Administration on Children, Youth and Families, Administration on Developmental Disabilities. Through this grant, three pilot sites established local family support councils that have proven to be successful in mobilizing community resources to support families in their areas of the State. The pilot sites are located in Tarrant County, Fort Bend County and surrounding rural counties, and El Paso.

Another initiative in the early stages of implementation is the Texas Integrated Funding Initiative established by Senate Bill 1234 (77th Texas Legislature) to implement Systems of Care in Texas. Through this project, three local communities have implemented the Systems of Care (wrap-around services) philosophy, which includes the full partnering with families and the support of families with children who have serious emotional disturbance.

Additional activities underway that enhance the system of family support include:

- The Texas Interagency Council on Early Childhood Intervention recently adopted the family support principles endorsed by the Children's Policy Council;
- HHSC contracted for the development of family-based alternatives as a support for families who are not able to care for their child in the home on a fulltime basis;
- The CLASS waiver was amended to allow for consumer directed services, resulting in an opportunity of families to hire, train and manage their child's personal attendant and respite care providers. Parents have used this option to increase wages to direct care staff; and
- Texas has been awarded funding that will be used to develop local access pilots to assist individuals and families in navigating the complex system of long-term services.

GENERAL FAMILY SUPPORT RECOMMENDATIONS

Services to individuals under the age of 22 should be family-directed (person-directed for those 18-21) and family-centered.

- 1.1: Use the Council's family support principles to develop, modify, and evaluate program rules and policies so programs effectively support families.
- 1.2: Expand use of Consumer Directed Services as a mechanism for families to direct their child's services. Expansion includes types of service and number of programs where consumer directed services are available as an option.
- 1.3: Schools should include education and training in self-determination for students receiving transition planning through special education.
- 1.4: Create a state level parent liaison position for a parent of a child with a disability, and designate an existing position at regional levels to be a parent liaison contact. These positions should be valued at professional salary levels and should be created at following agencies - Texas Department of Human Services (DHS), Texas Department of Health (TDH), Texas Department of Mental Health Mental Retardation (TDMHMR), Early Childhood Intervention (ECI), Texas Department of Protective and Regulatory Services (PRS), and Texas Education Agency (TEA).
- 1.5: Family Support Services funded through DHS, TDMHMR, PRS, and TDH should include advocacy as a service and allow funds to be used for consumers and families to learn self-advocacy skills by participating in conferences and training.

Rationale

Numerous self-determination projects throughout the nation have provided evidence that family-directed (or person-directed) planning yields cost savings in the delivery of support services. Consumers and families need opportunities to learn the life skills involved in decision-making and self-advocacy. Self advocacy means developing skills in understanding best practices, accessing and managing essential services for ones' own child and other children in the community, and identifying and offering solutions to systemic issues. For special education students, self-determination should be included in the course of instruction to prepare students for transition from public schools to adulthood. Families should be able to purchase advocacy services or have opportunities to learn self-advocacy.

In recognition that family supports prevent costly out-of-home placements, preserve and continue to expand the existing system of family supports.

- 2.1: Expand, rather than reduce, non-waiver family support efforts such as In-Home and Family Support (TDMHMR and DHS), Children with Special Health Care Needs (TDH), ECI, and non-educational Community-based Support Services (TEA) that provides maximum flexibility by effectively utilizing general revenue funds.
- 2.2: Family Support Services funded through DHS, TDMHMR, PRS, and TDH should include flexible funding support for siblings as it relates to being a sibling of a child with a disability.
- 2.3: Maintain access for children to all current and future Medicaid waivers using eligibility criteria based on child's income.
- 2.4: Maintain the safety net for children who cannot access Medicaid, Medicaid waivers, or CHIP by maintaining a comprehensive Children with Special Health Care Needs Program that includes medical and family support services.
- 2.5: Mandate that all state regulated health insurance policies provide coverage for mental, emotional, and behavioral disorders in children equal to coverage provided for other medical conditions, without discrimination against the category of illness.

Rationale

There are examples in our state of excellent flexible supports for families who have children with disabilities. Other supports are limited and do not always address the total array of needs for some families. Texas should expand such efforts while also providing for the flexibility to include relevant support for siblings and the valuable family-to-family networking. Families are often the best mentors and support for other families as they share experiences and successes in navigating the system. Research supports early intervention with children with disabilities and their families as the best approach to positive lifelong outcomes as well as a long-term cost-saving mechanism.

Case Management

INTRODUCTION

A case manager is a qualified, knowledgeable, resourceful, culturally competent individual empowered to develop a relationship with the child and family and advocate for them to access services across systems and programs. Case management includes service coordination, advocacy, and resource development and may be called by a variety of terms, often depending on the scope of the responsibility in a given program. Other terms used to describe case managers are service coordinator, broker of services, and care coordinator. A case manager provides services beyond eligibility determination.

Individuals with disabilities and their families use case management services to identify, access, appropriately utilize, and coordinate services. Many family members develop case management skills through self-advocacy training and by experience of navigating the system on behalf of their family member. Some families are not able to access services for their child, due to the lack of a case manager, while others have multiple case managers involved in their child's care.

Council members identified critical training priorities for case managers around topics of: 1) Promoting Independence/Olmstead, 2) Medicaid and non-Medicaid program services and eligibility, 3) the value of parents as case managers, 4) the use of internet for information about programs, services and rules, 5) transition between programs, 6) advocacy versus gate keeping, 7) family driven systems of supports, and 8) communication with families in a sensitive, respectful manner.

According to *Out of the Emergency Room*, June 2002, "many parents of chronically ill children are unaware of case management."¹¹ Findings are from in-depth interviews of Texas parents who had Medicaid or CHIP coverage for at least one or more children and who had at least one child that received treatment in an emergency room within the previous six months for a condition that did not require hospitalization. The respondents who have children with chronic illness said, they have never heard of case management; in fact, the term 'case management' was unfamiliar to many respondent and researchers had to explain it. Parents desire information, but do not know where to get it. The desire for information in this population of parents, who are dealing under difficult circumstances with children who have chronic illness, is very great.¹²

The case manager is the backbone in a system of family supports for the child with disabilities. In general, case management includes a needs assessment for the family, service planning and coordination, monitoring, evaluating, advocacy for the services necessary to meet a child's specific needs, crisis intervention, and linkage and referral to service providers. The Council recommended in the September 2000 report, that case management services be provided as a

¹¹ Seton Health Care Network. "Out of the Emergency Room: Communicating Healthcare Options to Low Income Texans." Austin, TX, July 2002, page 37.

¹² Ibid.

function separate from the service delivery function of the service provider. This distinction is an effective means to preempt possible conflicts of interest.¹³

PROGRESS

In the September 2000 Children's Policy Council report to the Health and Human Services Commission, the Council made the recommendation to establish one competent case manager for each child/family (as opposed to multiple case managers). In June 2001 HHSC initiated a project on behalf of the Texas Family Support Initiative, to develop a single case manager model for Texas. The model was envisioned as a framework for developing a pilot and for achieving on an incremental basis optimal integration among the numerous case management programs now administered by the state. In *Exploring a Single Case Manager for Children with Disabilities*, a final report for the Texas Health and Human Services Commission, October 2001 was completed. The report provides the background on the issues, elements of the single case manager model, a summary of potential barriers, and recommended initial steps.

The passage of Senate Bill 36 (77th Legislature) required cross agency training of case managers employed by the Texas Department of Health, the Texas Department of Human Services and the Texas Department of Mental Health and Mental Retardation. Initial steps toward implementation have begun despite a lack of new funding. Although not required in legislation, the Texas Council on Early Childhood Intervention and the Texas Department of Protective and Regulatory Services have voluntarily agreed to participate in interagency efforts to implement cross training activities.

The Texas Department of Health provided limited grant funding to projects to expand the "Parents as Case Managers" model. Future funding is in jeopardy.

CASE MANAGEMENT RECOMMENDATIONS

Empower case managers as advocates for the child and family.

- 1.1: Continue to move to a system that separates the function of case management from the provision of direct services. As a priority, case managers responsible for permanency planning should not be on the payroll of the facility in which the child resides.
- 1.2: Restrict case managers from being assigned as utilization gatekeepers, since the gatekeeper role conflicts with the role of case manager as an advocate.

¹³ Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. 1: Lessons Learned from Other States*. Austin, Tx., 2001, p. 11.

Rationale

Families repeatedly express the value of case management services based in part on the ability of the case manager to serve as an advocate for the child and family. Advocacy by case managers can be enhanced with the separation of case management from the provision of direct services, manageable case load sizes, and a focus on positive outcomes for the child and family, rather than utilization review gate keeping.

Establish one qualified case manager for each child and family.

- 2.1: Collect data across agencies on children receiving case management services from multiple agencies. This data should include information on how many children are receiving case management from multiple agencies, which areas of the state these children reside, and what funding sources pay for these services.
- 2.2: For families whose children have multiple case managers, identify a lead case manager and use consultative case management for expertise in certain subject areas while working toward a single case manager model.
- 2.3: Assist families to develop a master plan of care when children are involved with multiple programs and support services. A master plan of care should prevent cost-shifting between programs and agencies and between the school and human services programs.
- 2.4: Caseload size should complement the complexity of the needs of the children and families served.
- 2.5: Ensure quality by ensuring choice among case managers within and across programs. Limits on the number of medical case managers per area of the state should not eliminate choice.

Rationale

Families and case managers provide anecdotal information of multiple case managers for some children/families, but no current data is available in Texas in order to evaluate the extent of the problem and any unintended service duplication. Designating a single case manager or a lead case manager as chosen by the family and developing a master plan of care are incremental steps to moving toward a less fragmented, simpler, more streamlined access system in Texas. For example, the most qualified lead case manager for a child who is blind or severely visually impaired would be one with specific expertise in vision services.

Educate case managers.

- 3.1: Conduct cross agency case management education and training summits in each HHS region. New funding and/or blending current training budgets will be necessary.
 - (a) Training should be based on each region's, assessment of needs and an update on new programs and policies. Needs assessments must include input from families receiving services and families waiting for services.
 - (b) Include parents in all aspects of planning the summits and have parents as equal participants in the summit as trainers and as learners.

- 3.2: Create a career ladder for case managers to encourage retention of qualified individuals.
- 3.3: Increase and improve the interface between Children's Health Insurance Program health plan case managers for children with complex special health care needs and community-based supports and services.

Rationale

Training, knowledge, continuity and collaboration will be improved as the state commits to educating and valuing case managers and supporting collaboration across programs and services, including health and long-term supports and services.

Define, Set Standards and Evaluate Case Management

- 4.1: Include information from people served in the performance evaluations for case management by creating a feedback loop, such as post-cards or customer satisfaction surveys.
- 4.2: Provide information to families about case manager tasks, performance and audit criteria for case management.

Rationale

Families appreciate the value of case management services and strive to develop a trusting, respectful relationship with those providing case management services. Families support the need for appropriate compensation for the valuable role a case manager plays in the life of a child with disabilities and his or her family. Individual and systemic quality improvement can only occur with feedback from families. Families need an opportunity to understand the requirements facing case managers so they can seek resolution of competing responsibilities and loyalties by seeking programmatic changes when needed.

Case management in Texas should:

- a) be based on common family support values, which result in positive outcomes for children;
- b) be available as needed - even on evenings and weekends, if necessary;
- c) incorporate skills and knowledge at a level to support families who must navigate through and between complex, fragmented service systems with a variety of eligibility criteria;
- d) pay similar wages for similar functions across agencies and programs, and
- e) pay wages sufficient to attract and retain qualified staff.

Expand family members as case managers.

- 5.1: Actively solicit parents of children with disabilities as applicants for case management positions and employ parents and other qualified, experienced family members as case managers for children and adults with disabilities who are not their own family member.
- 5.2: Hire qualified parents as case managers as one strategy to address turnover, based on experience in Texas with Parent Case Management programs. Develop case management

positions with qualifications based on training, formal education and/or experience. Amend agency rules when necessary.

Rationale

Family members of children with disabilities who have formal and/or experiential training, knowledge and abilities can benefit other families by serving in case management positions as well as at all levels within the service system. A parent and a parent case manager who share common experiences will often quickly develop a trust and connection, which can facilitate more effective case management. The system benefits from accessing first hand the knowledge and sensitivity of parents whose children have long-term support needs.

Transition

INTRODUCTION

For the purposes of this section, transition refers to the process where an individual with disabilities moves from children's services to adult services. In Texas, children with disabilities receive services primarily through the public school system and the State Medicaid program. The Individuals with Disabilities Education Act (IDEA) entitles all students to a free and appropriate public education in the least restrictive environment. Through IDEA, students are also entitled to receive related special education supports and services that are needed to allow the child to benefit from his or her education. This can include such services as therapy, adaptive aids, classroom aids, and more. In addition, children who are Medicaid eligible or who receive Medicaid waiver services, have access to a variety of health and long-term supports and services.

As children with disabilities age out of the school system and the children's Medicaid programs, families are often catapulted into crisis. Adult Medicaid programs typically do not provide the level of services many children need and waiver programs are not readily accessible. Individuals can wait five to ten years before receiving a waiver slot that will provide them access to needed services. As school services terminate, they are often not replaced by comprehensive employment services or further educational opportunities. Often, young adults remain at home, isolated and disengaged from their community. Parents may have to quit work to provide care or may seek institutional placement for their child.

A seamless transition process is important to provide children/youth with disabilities and their families with continuity that includes the appropriate amount, duration and scope of services. The fragmented service system requires families to hunt for services across many programs and agencies. Time limits on services run counter to needs-based services. A more seamless system would increase access for individuals and their families.

As children transfer to adult services, families must once again maneuver the complicated system. Often they become frustrated by the complex eligibility process, the fragmentation in service provision, and the gaps in care caused by the inability to maintain certain levels of services. Our state should strive to improve transition by developing long-term services and supports as a seamless system that allows children to transfer to adult services without the risk of significant reductions in the level of service. This includes:

- The ability for the individual to continue receiving services with their current providers. These are services provided by health and long-term care professionals that have knowledge of the individual's disability and have built a relationship over time that helps to support the individual and his or her family.
- Person centered planning that allows for flexibility in using support dollars to provide services needed by the individual.
- Opportunities for youth and young adults with disabilities to earn an income, purchase goods and services, pay taxes, and contribute to their communities without risking the loss of health and long-term services.

The state should develop a process by which each child and family has the opportunity to participate in a comprehensive, effective transition process. Effective transition planning should:

- Address all life domains including health care, education, employment, leisure, community living, and family.
- Focus on self-determination and allow the individual to make choices and take risks.
- Identify the skills the individual may need to acquire to help him or her maximize their self-sufficiency.

PROGRESS

An interagency *Memorandum of Understanding (MOU) on Transition Planning for Students Receiving Special Education Services* has been drafted and is in the review process. This MOU places an emphasis on the need to improve transition planning for young adults by attempting to bring the necessary participants to the table. As of the writing of this report, the MOU has not been finalized or agreed to by the various agencies. While the intent of the MOU is positive, there are serious questions as to how it will be implemented and who will be held accountable for ensuring effective implementation.

TRANSITION RECOMMENDATIONS

Enhance TEA Memorandum of Understanding (MOU) on Transition Planning for Students Receiving Special Education Services (Transition MOU).

The Council supports the concept of the Transition MOU but is concerned about the lack of accountability for its implementation.

- 1.1: Increase representation on any future TEA Transition MOU workgroups to include parents of students with disabilities and advocates for children with disabilities.
- 1.2: Include in the MOU that participating agencies having transition responsibilities participate in local community coalitions and that a percent of their local agency budget or provider contract be used to fund coalition recommended activities using a blended funding methodology. This fund would be developed to address barriers to successful transition and to develop and implement strategies for quality transition. The coalitions should be required to meet quarterly and submit reports to the local agencies they represent.
- 1.3: Develop a satisfaction survey to be completed by parents and/or students in transition meetings one year after implementation of the new TEA MOU. A state level stakeholder group, including parents of students with disabilities, should be convened to develop surveys. A statistically significant stratified random sample survey with outside analysis of results should be completed, with the results published on the TEA Web site.

Rationale

The Memorandum of Understanding (MOU) on Transition Planning for Students Receiving Special Education Services establishes the respective responsibilities of each agency for the provision of services necessary to prepare students enrolled in special education programs for a successful transition to life outside of the public school system. The proposed Memorandum of Understanding (MOU) clarifies and adds definitions, better addresses information sharing and agency participation, regional and local collaboration, cross-agency training, and dispute resolution. Other terms of the MOU provide for the MOU to be reviewed and considered for expansion, modification, or amendment at any time the executive officers of the parties agree or at least every four years. Thirteen Texas agencies are included in the MOU (TCB, TCDHH, TDH, TDHCA, DHS, TDMHMR, PRS, TEA, THECB, TJPC, TRC, TWC, TYC). Regional coordination meetings will be held to plan and coordinate efforts of the appropriate agencies; these meetings should be instrumental in addressing the issues identified in the MOU agreement. The goal is for students to leave public school prepared for adult life in the community, with the appropriate supports and services.

Improve access to adult services.

- 2.1: Require middle and high school level teachers to participate in in-service training on transition, person-centered planning, and advocacy as part of their required number of state days of training. Improve the quantity and quality of transition training in the Comprehensive System of Professional Development. Parents and parent groups should be invited to attend trainings.
- 2.2: Direct Texas Rehabilitation Commission to implement a presumed-capable policy for eligible transition age students and provide access in a timely manner, based on 1) the person having a disability, and 2) the belief that the services will benefit the person in terms of employment. TRC should:
 - (a) Begin serving students with disabilities prior to their senior year assessment;
 - (b) Increase opportunities for extended evaluations for employment services and extended supports by ensuring an adequate provider base, particularly in rural areas; and
 - (c) Increase opportunities for timely supported employment.
- 2.3: Direct the Texas Workforce Commission to increase the percent of services to students with disabilities and increase participation in transition planning (MOU level as well as individual level).
- 2.4: Provide access to the appropriate waiver according to the level of need and type of services required for individuals transitioning from:
 - (a) The Medically Dependent Children's Program (MDCP). Allocate a specific number of transition-age individuals to the consolidated waiver to support transition from MDCP to adult services.
 - (b) The Texas Health Steps Comprehensive Care Program (CCP). DHS Rider 7 b. (2) should be revised to allow CCP clients who are no longer eligible because of their age and are receiving private duty nursing to be enrolled in the most appropriate Medicaid waiver according to the individual's needs, and if necessary exceed the individual cost cap.

- 2.5: Continue and expand the Texas Workforce Commission Summer Jobs for Youth Program and expand eligibility to age 21 regardless of when the individual graduated.
- 2.6: Include long-term care information in Texas Education Agency parent manual.
- 2.7: Provide education and training (at the local level) on self-determination for students receiving transition planning through special education.

Rationale

Families often struggle to support their child with disabilities at home. When a child ages out of the education system, and/or turns 18, many families find that few services are available to provide care and assistance for their child. Children should not experience loss or reduction of services simply because of a birthday. One strategy for improving transition results is to strengthen family networks to increase their level of knowledge regarding transition and long-term services. This could be done through existing family networks and by developing transition support groups at the local level.

Parents and children with disabilities need comprehensive information on transition and need to be made aware of adult long-term service programs. The most appropriate avenue for distribution of transition information to parents and students is through the education system. Another way to promote effective transition planning is to improve the quality and quantity of transition training in teacher preparation/certification programs.

Although the Texas Rehabilitation Commission has no actual zero-reject policy, students should be presumed (by law) to be capable of employment. Families perceive that services are denied due to a lack of supported employment providers. Increasing the provider base, particularly in rural areas will improve timely access to supported employment services.

Coordination and Collaboration

INTRODUCTION

The system of long-term supports and services for children in Texas is spread across several human service agencies and consists of numerous programs and service options. The system is complex and often it is difficult for families to discern where to go for help. Due to the complexity and fragmentation, agency staff often struggle to keep abreast of the various program options and requirements in their own departments and rarely are able to offer information on programs in another agency. Consequently, there is no central resource available for families to help navigate the system to access services.

To improve families' ability to care for their children at home the Council believes that agencies should focus on designing a system of family supports that responds to families' needs in a timely manner to prevent crisis and expensive institutionalization. To accomplish this, better coordination and collaboration between agencies serving children is essential. All relevant health and human service agencies, including education, workforce, and juvenile justice, should be included in efforts to redesign and coordinate services for children and families. Eligibility for services across agencies should be based on the functional needs of the child rather than on specific diagnoses. Service arrays in all programs should be flexible and should address the skills training and unique needs of the child.

A collaborative review of all children's long-term care services by the agencies involved in providing those services would provide significant opportunities for redesigning the system to improve both information and referral as well as access to services. The Council supports all efforts to improve families' ability to access information, including the continued expansion of the 211 I&R initiative and the local access projects. Agencies should continue to identify opportunities to work together on behalf of specific children as well as on behalf of the entire system. Families should not be isolated because of the programmatic and funding silos that exist. Agencies should work together to look for creative solutions to the barriers that impede supporting families.

PROGRESS

Over the past two years, agency staff have met through numerous workgroups and advisory councils to discuss long-term care issues affecting children with disabilities and jointly strategize how to improve the system. When issues cross agencies, much more cross agency coordination is being attempted at both the state, regional, and local levels. Community Resource Coordination Groups (CRCGs) and Texas Integrated Funding Initiative (TIFI) sites are two examples of attempts in Texas to improve collaboration and coordination between agencies and local organizations.

COLLABORATION AND COORDINATION OF SERVICES RECOMMENDATIONS

Improve coordination and collaboration among state agencies by systematically identifying and reducing barriers to collaboration that exist within agency policies and procedures.

- 1.1: HHSC should lead an interagency task force to develop a strategic plan for children with disabilities and their families, including health and human service, education, workforce and juvenile justice agencies. The strategic plan should include an examination of:
 - (a) Barriers and implementation strategies to increase collaboration and coordination across agencies;
 - (b) Strategies to increase information sharing across agencies;
 - (c) Requirements within individual agencies for data entry and analysis that result in multiple data entry requirements; and
 - (d) Issue of “payor-of-last-resort” that reduces coordination and collaboration efforts among agencies and delays services to children.
- 1.2: Ensure children’s services are addressed in local access plans being developed through the implementation of the Real Choice grants and in the relocation projects promoting community integration.

Rationale

The mechanics of operation of the state agencies is becoming more difficult and complex, making collaboration and coordination among agencies more difficult to achieve. Frequently, it is the policies and procedures of the agencies that seem to prevent effective collaboration. Technology systems that do not interface prohibit coordination.

Improve information dissemination to individuals and families.

- 2.1: Designate a children’s expert in each region to assist serving children who use multiple HHS agencies. Additionally, develop regional expertise within HHS agencies to expand opportunities to implement best practices, provide coordination and technical assistance, improve cross-agency information, and ensure that families are able to access accurate and comprehensive information.
- 2.2: Require school districts to distribute information on long-term services and supports, including waiver waiting list information, to parents at ARD meetings. Ensure that appropriate information on long-term services and supports is also available for families of children with special health care needs who may not be receiving special education services.

Rationale

Knowledge is power, and for families it is the key to accessing services. Accurate information is difficult to obtain in the current system due to fragmentation, program duplication, disconnected technology, overloaded and uninformed case managers, and complex programs and procedures. Access to a comprehensive information and referral system will allow easier and faster access to services. TEA will consider adding information regarding long-term services to the parent handbook. This new information could be included in the next printing of the parent manual, which could occur as early as Summer 2003.

Medicaid Waivers

INTRODUCTION

House Bill 1478 (77th Texas Legislature) added a charge to the activities of the Children's Policy Council to study and offer possible solutions to barriers affecting children with disabilities in Medicaid and Medicaid 1915(c) long-term care waivers. House Bill 2873 (76th Texas Legislature) required a workgroup to make recommendations on how to improve waiver services for families. Those recommendations were not implemented and the workgroup no longer exists. The original House Bill 2873 recommendations were the starting point of the Children's Policy Councils study. Recommendations were considered, modified, deleted if no longer appropriate, and expanded as appropriate to reflect current issues. Many state rules currently exist that limit access to certain services for certain populations of children. By simply amending outdated or ineffective waiver rules, access to needed community supports and services for children will be improved.

Medicaid is the major source of financing for long-term care for the elderly and for children and adults with disabilities, providing critical assistance for people with long-term care needs in the community. Medicaid's long-term care provisions are focused on low-income individuals and are limited in scope. Consequently, many people with long-term care needs, and their informal caregivers – spouses, family and friends - often bare substantial out-of-pocket costs and burdens. Nearly half a million individuals nationally in 49 states receive care through the home and community based option available as Medicaid 1915(c) waivers. A 1999 Supreme Court decision (*Olmstead v. L.C.*) promotes the use of home care as an alternative to institutionalization. Additional public resources are needed to fill gaps in the current system, improve access to home and community based care, and address concerns about the quality of long-term care.¹⁴

Texas currently has eight 1915 (c) waivers, six of which serve children. Some children are eligible for more than one waiver from more than one state agency. A general lack of knowledge and substantial misinformation among families and case managers in Texas can result in a child enrolling in one waiver when the services provided by a different waiver would better meet his or her needs. A method to move to the waiver most appropriate to one's needs will benefit the child and family and eliminate the practice of children being placed on multiple waiting lists, taking the first available opening, and migrating between waivers when the more appropriate program becomes available.

Many families who need medical care for their children find themselves in a Catch 22 situation. They don't make enough money to afford private health insurance, but they make too much money or have too many assets to qualify for Medicaid. Some Texans caught in this situation are able to access the Children's Health Insurance Program (CHIP).¹⁵ CHIP serves eligible healthy

¹⁴ Kaiser Commission on Medicaid and the Uninsured. *Medicaid's Role in Long-Term Care*. Washington, DC, March 2001.

¹⁵Mt. Joy, Greg. Texas Comptroller of Public Accounts. "Chipping Away at Medicaid." *Fiscal Notes*. Austin, Tx., August 2002, p. 12-13

children and children with special health care needs, but does not cover long-term home and community based care or family support services which are covered in Medicaid and Medicaid 1915 (c) home and community based services waivers. Therefore, access to Medicaid State Plan and Medicaid home and community-based waivers is vital to both low and middle-income Texas families.

PROGRESS

Although the Council is addressing this topic area for the first time, it is worth noting that a significant amount of effort and progress on expanding consumer/family directed services has occurred in the last 18 months. In July the Center for Medicaid/Medicare Services (CMS) approved the Community Living and Support Services Waiver (CLASS) amendment to allow program participants to hire, manage, and terminate their personal attendants and respite care providers. See recommendations below regarding the expansion of the consumer directed option.

MEDICAID WAIVERS RECOMMENDATIONS

Ensure children in waiver services have access to family-based alternatives.

- 1.1: Ensure that children with disabilities in the Child Protective Services system have the same access to waiver services as children outside the CPS system by allowing children above Level of Care 2 the ability to access waivers to obtain support services in the community.
- 1.2: Seek all necessary federal and state changes in rules, policies, and rate setting to allow for family-based alternatives such as shared parenting and alternative families in all waivers, including Community Living Assistance and Support Services and the Medically Dependent Children's Program.
- 1.3: Expand the eligibility of the Deaf Blind Multiple Disabilities waiver to include children and fund services for 47 children on the interest list. Amend the waiver as necessary to accommodate the support needs of children who are deaf blind with multiple disabilities.

Rationale

Some, but not all, waivers have the ability to pay for shared parenting and/or community-based alternatives. Making this option available in all waivers that serve children will allow more parents the option to choose a community-based alternative for their child rather than a shift-staff residential model. A child is more likely to meet his or her maximum potential in a nurturing, permanent relationship with a consistent adult/parent. A continued relationship with the birth family and decision-making by the birth family is possible under this option.

Children in CPS conservatorship should have access to the waiver services they would have been able to access if they had remained with their birth family. These waiver services can prevent more restrictive placements and provide funding for services after the child turns 18 years of age. Waiver amendments and rule changes will be necessary.

Provide consumers and families with comprehensive information on services available through Medicaid, CCP, CHIP, and Medicaid 1915 (c) waiver programs.

- 2.1: HHSC should facilitate the development of a user-friendly electronic Guide to Medicaid waiver programs, similar to “*A Guide to Medicaid Waiver Programs in Georgia*,” for consumers/families. A similar Texas-based guide would include: 1) a brief description of the Texas Medicaid program 2) a brief description of Texas Medicaid waivers 3) how to apply for Texas Medicaid Home and Community-Based waiver services 4) a description of services Medicaid covers and those not covered 5) consumer/family rights and responsibilities, and 6) helpful telephone numbers and web sites.

Rationale

Knowledge is powerful, particularly in a health and human services environment where access to long-term supports and services is fragmented across various agencies and programs. Comprehensive, easy to understand information will benefit families, agencies, and community-based organizations. In consideration of budget constraints, information should be maintained and updated electronically and hard copies made available as needed by printing the most recent information off the Internet at regional and local agencies, libraries, and community organizations.

Ensure that Medicaid long-term care waiver policies, services, and supports, including policies regarding individual’s budgets, are flexible, family driven, and based on family support principles.

- 3.1: Coordinate policies/procedures across Medicaid and all 1915C Medicaid waivers serving children with a focus on ensuring that no gaps exist between the Medicaid Comprehensive Care Program (CCP) and the waivers that serve children including Community Living Assistance and Support Services, Medically Dependent Children’s Program, Mental Retardation Local Authority and Home and Community-based Services, and the Consolidated Waiver Program.
- (a) Coordinate definitions for services/eligibility across waivers (such as "Medical Necessity") or explain the differences between the program definitions to families so they can best navigate and access appropriate services for their child.
 - (b) Use uniform assessments and streamline admission and annual planning and evaluation processes for waiver participants.
 - (c) Ensure access to all 1915 (c) Medicaid waivers based on the child’s income.
 - (d) Reconvene House Bill 2873 workgroup on a short-term basis to assist with clarification on how Medicaid, CCP, and waiver benefits are being coordinated from a family perspective and identify possible solutions including an explanation of medical definition differences.
 - (e) Allow for a bridge across waivers for children whose needs increase and could be served more appropriately in a different waiver.
 - (f) All waivers and CCP should adopt the Family Support Principals from the Children's Policy Council (See Appendix B).

- 3.2: Each waiver should provide flexible family support services to meet the unique needs of each family.
- (a) Families should be able to mix and match support services to meet the unique needs of the family. Waiver policy should embrace individualized solutions and move away from a "one size fits all" solution for children and families. For example, eliminate service type caps such as the 150 hour supported employment cap in the Home and Community Services (HCS) program at the Texas Department of Mental Health and Mental Retardation.
 - (b) Expand access to consumer-directed services options
 - (c) Expand consumer directed services to all 1915(c) waivers, regardless of the agency administering the waiver program
 - (d) Expand the type services available in the consumer directed services models.
 - (e) Allow flexibility in the authorization and scheduling of private duty nursing to allow families to use the services in a manner that best suits their needs.
 - (f) Extend to six months the authorization for private duty nursing in the Comprehensive Care Program.
- 3.3: Give families more flexibility in their budgets.
- (a) Allow families maximum flexibility in planning services, such as rolling over unused Individual Plan of Care (IPC) funds to the next year
 - (b) Increase flexibility on annual cap – allow over a 2 year budget cycle
 - (c) Hourly and daily respite should be available in all Medicaid long-term care waivers.
 - (d) Allow all waivers to pay the co-payment for children with private insurance as an incentive to keep private insurance and save Medicaid dollars.
- 3.4: With the exception of new demonstration or pilots, Texas Medicaid Waivers should include important family support principles such as:
- (a) Choice of providers.
 - (b) Statewide access.
 - (c) Income eligibility based on child's income.

Rationale

Program flexibility and consumer responsibility are compatible in waiver programs that serve children and adults. Within reasonable limits, increased flexibility empowers families to best meet the unique needs of the child with disabilities and the changing circumstances of the family. Eliminating artificial, unnecessary barriers improves the ability of the child with disabilities and their family to improve their quality of life and participate as valued members of their communities. Eligibility criteria for Medicaid waivers serving children with disabilities currently consider only the child's income. This enables families to access needed services and prevent costly institutionalization of children. Any decrease in the ability of children in families to access the services most appropriate to their needs will be detrimental to children. State policy should be aimed at increasing supports and services available.

Ensure that providers are sufficient and able to supply the level of services and staffing required by the plan of care.

- 4.1 Provider enrollment requirements and processes should be consistent across waivers and reporting requirements should be simplified. Providers should be able to serve children under different waivers.
 - (a) State should work with direct service agencies to improve wages and benefits for attendants.
 - (b) Improve quality of staff by recommending that background checks and CPR Certification be done prior to employment.
 - (c) Provider reimbursement rates should be consistent across waivers.
 - (d) Investigate allowing a 30-day transition period for providers when participants move from one waiver to another.
- 4.2 State should facilitate the recruitment of providers for all 1915(c) Medicaid waiver programs and offer technical assistance to new providers as needed.
- 4.3: Expand Community Living Assistance and Support Services Medicaid waiver services statewide by 2009 by expanding service areas to new counties each year.

Rationale

Texas is a large, diverse state and provider capacity must continually be developed to ensure that regardless of where in the state a child with a disability resides, services will be available to support the child and family. Quality of care is improved by continuity of direct care staff who know and are trusted by the child and family. Increased provider capacity, technical assistance, coordination of service, and adequate rates will improve access and quality of care.

Ensure denials of services are appropriate.

- 5.1: HHSC should designate an existing advisory committee of consumers, providers, and staff to:
 - (a) Review trends in denials and service-related complaints from families to ensure appropriate action and make recommendations to improve services.
 - (b) Review the appropriateness of certain utilization guidelines and the appropriate use of guidelines at the local level for services to children in waiver programs.
 - (c) Determine and implement strategies to educate service coordinators and Utilization Review staff on the appropriate use of informal guidelines when recommending service authorization levels for Medicaid waivers to prevent unintended restrictions and misuse of such guidelines.

Rationale

Denial of eligibility and reduction or termination of services can result in inadequate supports and services to permit an individual to participate fully in his or her community, to stay safe and healthy, and to live in the most integrated setting appropriate to the individual. Recent trends in denials, as noted by advocates, families, and data from the agencies, warrant further

investigation, identification of possible solutions, and implementation of new policies and procedures as appropriate.

Regulations

INTRODUCTION

Programs that support children with disabilities are regulated to ensure quality of care. The Department of Human Services (DHS) is responsible for the regulation of most long-term care providers. DHS long-term care regulatory staff visit providers and conduct surveys and certification reviews. Both institutional and community-based long-term services and supports programs are regulated via contract compliance measures and routine surveys and certification. Home and community-based providers are licensed as Home and Community Support Service Agencies. Facilities must be licensed and certified to provide services to meet state and federal standards. At intervals set by federal and state guidelines, DHS inspects over 6,100 regulated facilities/agencies to ensure state and federal minimum standards for care are met.¹⁶ When appropriate, DHS issues licenses and recommends federal certification. DHS also receives and investigates consumer complaints, recommends enforcement actions and promulgates rules. The Texas Department of Mental Health and Mental Retardation also has a role in working with DHS to ensure quality of care in their facilities and community care programs.

More than 1,500 children with disabilities under age 22 reside in some of type of shift-staff institution including nursing facilities, intermediate care facilities for the mentally retarded, DPRS licensed institutions for the mentally retarded, state schools, and group homes. New permanency planning requirements for children in facilities have begun to fall under greater scrutiny of surveyors who monitor compliance with the standards, emphasizing the need for regulatory staff to have a strong understanding of not only the statutory requirements, but also the goals and objectives of permanency planning. In addition, some child-serving facilities have closed over the past two years, causing a need for close monitoring of transition activities as children are relocated to other facilities or to less restrictive placements.

PROGRESS

Although the Council did not make prior recommendations in this area, individual Council members and Council support staff at HHSC have worked on the issues as they arose. Recent progress is noted below.

- A heightened awareness of the number of children in institutions and the supports and services they need.
- The Texas Council for Developmental Disabilities provided temporary funding for two positions at the Health and Human Services Commission to train and work with survey staff to ensure quality monitoring of permanency planning for children in Texas institutions as identified by Senate Bill 368 (77th Texas Legislature).
- Interested individuals continue to visit facilities that serve children to learn more about the population of children in the facilities, and the quality of their care.

¹⁶ Texas Department of Human Services. "Long-term Care Workgroup Report." Austin, Tx., May 2002.

REGULATIONS RECOMMENDATIONS

The Children's Policy Council proposes the following recommendations for entities and individuals regulating institutions where children are placed.

Ensure adequate knowledge and training on permanency planning for those responsible for overseeing quality of services in facilities in order to make sure that a child's overall developmental needs, including the need for nurturing, attachment, quality of life and well-being are addressed in addition to the medical, health and safety needs.

- 1.1: Provide training to operators, surveyors and trustees to increase their knowledge of permanency planning and to assure that surveyors identify inadequate practices and institute appropriate corrective actions regarding a child's permanency plan.
- 1.2: Develop regulatory expertise across all health and human services regions, with a person in each region who knows the requirements and responsibilities for children with developmental disabilities who are institutionalized, with a priority on regions where specialized pediatric units/facilities exist.

Rationale

Children in institutions are dependent on that facility for their total care. But few facilities adequately address a child's total care, beyond basic health and safety requirements. Regulatory activities are the key vehicle for the enforcement of permanency planning requirements. Few operators or trustees know pediatric issues. Some children are grouped in pediatric wings or facilities, but many are scattered across the state in facilities that serve primarily the geriatric population. Surveyors need to understand that the state has embraced the philosophy that children belong in families. Additionally, TDHS has only one pediatric nurse, TDPRS has very few staff with a primary focus on children with disabilities and TDMHMR has one position focusing on children with mental retardation at their central office.

Improve the capacity of surveyor's to oversee and respond to quality of service issues for children in institutions.

- 2.1: Streamline the process TDHS uses to prove that a facility is not providing quality services to children after opportunities for the facility to improve services have been provided.
- 2.2: Develop incentives for facility operators who conduct quality, effective permanency planning for children in their care.
- 2.3: TDMHMR should amend their process of developing directed plans of correction to recognize permanency planning requirements for children. TDMHMR and TDHS should work together to ensure that survey documents adequately identify children and permanency planning requirements. TDHS should ensure that a facility, which has child residents, must include an appropriate sample of children in their survey process.

Rationale

Providers with a history of poor service provision can stretch the appeals process for years, requiring a significant investment of staff time and resources for TDHS. Poor quality providers with enough capital to establish sophisticated legal, accounting, and business incorporation strategies further complicate the ability to eliminate poor quality in Texas. On the other hand, some facilities may develop exemplary practices for permanency planning for children, thus depopulating children in their own facilities. Surveyors who discover best practices in the area of permanency planning should have tools to recognize and reward those facilities and operators.

MHMR may require a directed plan of correction when there are trends in a facility or provider company. Since it is not apparent by the survey document that the survey relates to children, a change in the form may be needed. The survey form may be a federally mandated document and would require the state to work with the federal entities to improve the document.

Ensure a child's environment is as developmentally appropriate and safe as possible while in an institutional setting.

- 3.1: Create a regulation that children under age 18 with disabilities cannot reside in the same room with adults.

Rationale

Currently, children in residential facilities can live with adults in the same room. Although the stay of a child in an institution is considered temporary, during that stay children should be with other children and/or in a child-focused environment. Additionally, there is no prohibition against mixing children and adults in a waiver funded group home. Providing an opportunity for all children to grow up in families is an important goal; however, while capacity to offer families more community-based choices is under development, children residing with other children (as opposed to adults) benefit from age-appropriate environments and activities.

Funding

INTRODUCTION

Texas is facing austere budget times and, just like all the other states, is struggling to meet increasing requests for services and supports with fewer new federal, state and local resources than in recent years. According to a report from The Kaiser Commission on Medicaid and the Uninsured, dated July 30, 2002, state tax revenues are falling more sharply than they have at any time in more than ten years. More than half of all states reported that they are considering or implementing waivers this fiscal year. Initially promoted as a mechanism for states to expand coverage within existing resources, state and federal financial constraints mean that these waivers could be used to reduce benefits, limit enrollment, or impose higher cost-sharing for some beneficiaries, beyond what is permitted under federal Medicaid rules.¹⁷

It is more urgent than ever that funds be used to promote those programs that move toward a system of supports for children and their families. It is critical for children to access appropriate health and long-term supports and services as early as possible in their development. It is well established that early intervention efforts pay off both in increased function for children as they grow into adults and in terms of the savings of resources by lessening severity and impact of disability. It makes good “cents” for Texas to look at its children as a barometer of its overall well-being. With more than 1,500 children in shift staff institutions and at least 17,000 children known to be waiting for community services, it becomes essential to assure that the state is funding timely services to Texas children within the critical developmental window. Research on informal care-giving has highlighted the intense emotional and physical burdens on some caregivers - particularly those who are the primary supports for people with longer-term or terminal illnesses and when major cognitive impairment is involved. Policy efforts and community support activities need to recognize that supporting caregivers will require a wide range of approaches that recognize the geographic dispersion of families and the desire of many elderly and disabled persons to live independent lives.¹⁸

Paid professional and paraprofessional care is one of the main sources of formal support for caregivers. Yet, in a recent national study, given the range and level of care provided by the informal caregivers, remarkably few reported being assisted by paid professionals in the year prior to the survey. One in four said that services were not available or were unknown to them. One in three who had an unmet need indicated that finances were the obstacle. About one in five users of paid assistance expressed concerns about the quality of available help, and there is clearly a need for expanding the provision of information and support to families in these circumstances.¹⁹

¹⁷ Kaiser Commission on Medicaid and the Uninsured. *State Budgets Under Stress: How are States Planning to Reduce the Growth in Medicaid Costs*. Washington, DC, July 30, 2002.

¹⁸ Donelan, K., Hill, C., Hoffamn, C., Scoles, K., Feldman, P., Levine, C., and Gould, D. “Challenged to Care: Informal Caregivers in a Changing Health System.” *Health Affairs*, (July/August 2002), p. 222

¹⁹ Donelan, K., Hill, C., Hoffamn, C., Scoles, K., Feldman, P., Levine, C., and Gould, D. “Challenged to Care: Informal Caregivers in a Changing Health System.” *Health Affairs*, (July/August 2002), p. 222-231.

The Children's Health Insurance Program (CHIP) data indicates that 20% of children met at least one of the screening criteria for special needs – mostly medication dependence. Children with complex special health care needs in the program are five times more likely than healthy children to go to the doctor at least once, and four times more likely to make appointments for routine care than healthy children.²⁰ The program serves as a benefit to the children with disabilities and special health care needs.

The Council supports promoting development of service systems for underserved individuals and access to health, long-term services, and supports regardless of which disability a child has as his or her medical diagnosis.

PROGRESS

- Community care programs were expanded to serve a limited number of additional individuals by appropriations in the 77th Legislative Session.
- A method to allow “funding following the person” was authorized by the 77th Legislature and has been implemented for individuals in nursing facilities choosing to transition to community based services (DHS Rider 37).
- A method to allow for a current participant in DHS Medicaid 1915(c) waiver programs to exceed the individual cost caps of the programs was authorized and implemented (DHS Rider 7b).
- Transition, relocation, housing, permanency planning and family based alternative initiatives have been funded.
- The CLASS Medicaid waiver program is expanding to 118 counties by 2003.

FUNDING RECOMMENDATIONS

Recognize the urgent developmental needs of children when funding long-term care services. Fund community services first, both for individuals in need of services and for funding children's services within the state budget, regardless of agency or program (*see Promoting Independence section*).

- 1.1: Prioritize children who are in institutions. Children under age 18 residing in institutions as defined by Senate Bill 368 should be prioritized for funding that supports children moving into families in the community.
 - (a) This may be accomplished by providing waiver slots for all requesting transition to families, or by allocating 50% of appropriated slots.
 - (b) Expand the Rider 37 concept to allow funding to follow the child to the community for children residing in any LTC facilities, as defined by Senate Bill 368.

²⁰ Shenkman, E., Col, J., Schaffer, V., Du, Y., and Vargas, D. *Quality of Care in the Children's Health Insurance Program in Texas*. Institute for Child Health Policy, July, 2002.

- 1.2: Children with disabilities age 12 and under should not be admitted to any institution (as defined by Senate Bill 368). Funding for diversion from institutions will be necessary, especially when a child is at imminent risk of institutional placement.
- 1.3: Fund agency permanency planning efforts.
- (a) Fully fund DHS appropriations request to continue permanency planning efforts in nursing homes;
 - (b) Continue funding HHSC's appropriations request to continue funding permanency planning training and monitoring;
 - (c) Fully fund MHMR's appropriations request to ensure permanency planning for 300 children in ICF/MRs and state schools.
- 1.4: Increase the timely availability of community-based services with flexible choices for families and children statewide by increasing the number of waiver slots available for children in institutions and those waiting in the community:
- (a) Serve additional children and their families whenever efficiencies are gained (*see Family Support section of this report*);
 - (b) Increase funding to expand the CLASS program statewide by 2009 (*see Medicaid Waivers and Family Support sections*);
 - (c) DHS board should replenish \$250,000 per year in the original DHS In-Home and Family Support funding for FY 2002-2003 (*see Family Support section*);
 - (d) Increase funding for the Deaf Blind Multiple Disabilities waiver to serve 47 children on the interest list (*see Medicaid Waivers section*);
 - (e) Increase TEA non-educational funding from \$987,300 in annual funds to the previous \$2,000,000 annual amount for community-based support services for certain children with disabilities at risk of institutional placement for educational purposes (*see Family Support section*);
 - (f) Extend Medicaid State Plan eligibility for children whose eligibility is based on disability criteria to 12 months continuous eligibility;
 - (g) Blend community/facility funds at the local level. Pay for community services first, and if more restrictive setting is needed on a temporary basis, pay for it with blended community/facility dollars (*see Promoting Independence section*);
 - (h) Fund an adequate number of community-based waivers to accommodate children in small ICF/MRs and PRS licensed institutions that are not currently part of Texas' Promoting Independence Plan.

Strategically expand best practices and pilots, which have successfully demonstrated effective and efficient options, statewide by 2004-2005.

- 2.1: Expand systems of care for children's services in the state by expanding the number and scope of blended funding models for children's services. Develop and fund a demonstration model to integrate community services per region based on systems of care/wrap around services. (*See Case Management and Family Support section*)
- 2.2: Don't let pilots languish. Maintain and begin to expand family-based alternatives to institutional placement for children. Add two new sites for the Family-Based Alternatives

- project. Develop a plan to roll this out state wide, possibly over a 6-year period. *(see Promoting Independence section).*
- 2.3: Fund case manager cross training and a case manager summit in each region to address interagency programming and resources, permanency planning, and cultural sensitivity. *(see Case Management section)*
- 2.4: Fund or designate a child case manager in each region with expertise across agencies and programs with a focus on community integration and the responsibility to develop and maintain a cross agency community integration network within the region. *(see Case Management section)*
- 2.5: Fund a parent of a child with a disability as a parent liaison at each long-term care agency at the state level and designate a regional parent liaison from existing or new staff by 2004. *(see Family Support section)*
- 2.6: Develop and fund versions of single case manager models including independent case management functions and family direction in decision-making. *(see Case Management and Family Support sections).*
- 2.7: Maintain and expand funding for family support initiative sites. *(see Family Support section)*
- 2.8: Expand parent as case managers to pilots statewide. *(see Case Management section)*
- 2.9: Expand DHS Rider 7(b) to include children transitioning from CCP to CBA, even if they are not in MDCP due to waiting lists or because they have not been provided the appropriate assistance in getting on the waiting lists. *(see Medicaid Waivers section)*
- 2.10: Fund the continuation of the Traumatic Brain Injury Council. *(see Family Support section)*
- 2.11: Explore options to expand flexibility for PRS to develop services for children at LOC 5&6 in family-based services models and continue/expand current pilots where this option is allowed for some children. *(see Promoting Independence and Medicaid Waivers)*
- 2.12: CPC subcommittee, HHSC state Medicaid Office, and revenue maximization consultant should review, advise, and monitor options for matching state-funded family support services with Medicaid while preserving the flexibility that is currently available. *(see Family Support section)*
- 2.13: Leverage and maximize federal funds for service expansion, but do not penalize non-Medicaid eligible children and families by making them ineligible for new or existing Medicaid 1915(c) waivers or cutting valued state funded family support programs;

Reduce funding barriers. (See the Promoting Independence, Family Support and Medicaid Waivers section)

- 3.1: Ensure access to health and related long-term supports and services for uninsured, underinsured, and indigent children.
- (a) Fully fund CHIP up to 200% of the Federal Poverty Level (FPL) without reducing benefits – limit cost sharing;
- (b) Fully fund the CSHCN program at TDH so there is no waiting list for medical or family support services.

Rationale

The funding recommendations above support moving further toward a system of support for children with disabilities and their families by improving: 1) training for case managers and direct care providers, 2) access to health care and ongoing supports and services which provide assistance for the child and the family caregivers, 3) provision of accurate and comprehensive information, and 4) public awareness and sensitivity. Establishing a method to fund emergency services, including 24-hour supports when necessary, will ensure that children can maintain their place in the community and family when an emergency arises.

Medicaid funds many long-term care and family support services, however access to CHIP, CSHCN, and state funded family and medical supports is also critical. The state must honor the CHIP benefit to all children. Fully funding CHIP will prevent additional measures to limit program costs.

There are many things that can make a family ineligible for Medicaid, such income and other assets. Access to Medicaid through Medicaid 1915(c) waivers by only considering the child's income and assets is highly valued by families of children with disabilities and must be a key element of waiver programs now and in the future. Medicaid waivers are less expensive than institutional services in the aggregate.

Future Issues

1. Through CPC community services subcommittee identify and support opportunities for coordination of community-based family-to-family networks in Texas.
2. Study issues relating to public awareness and ongoing HHS agencies public education campaigns.
3. CPC should work with appropriate stakeholders to research and evaluate certain placement issues, including the potential for using a Rider 37-like mechanism for children with disabilities not covered by Senate Bill 368 (Permanency Planning legislation), but who reside in residential settings for extended periods of time. This may include an evaluation of: a) children with disabilities who may be inappropriately placed in the juvenile justice system, b) children placed in facilities in other states, and c) children in residential treatment facilities.
4. Child Protective Services, in conjunction with the CPC should evaluate adoption policies and procedures for children with disabilities and identify and make recommendations to remove barriers that prevent or frequently impede ease of adoption of children with disabilities.
 - (a) The CPC can look at how children's individual needs are met in the initial adoption placement and in the post adoption situation and make recommendations to CPS, and
 - (b) The CPC can address training and services for adopting families.
5. Further study on issues around child-care and how families of children with disabilities can gain better access.
6. Study advocacy resource centers as a best practice, including the use of volunteers in these centers. The study should identify characteristics of a possible future demonstration pilot.
7. The Children's Policy Council, in partnership with the state Medicaid office and the Center for Public Policy Priorities, should study
 - (a) Options for coverage of long-term care services and options in the Texas Medicaid State Plan;
 - (b) TEFRA option to expand Medicaid eligibility, and;
 - (c) Medicaid buy-in options for children with significant disabilities.
8. Examine other state's experiences and research options to allow family members (such as siblings who are age 18 or over or other family members outside the residence) to be paid for providing respite and personal attendant services in the In-Home and Family Support program.
9. Monitor the current permanency planning efforts by receiving quarterly progress reports from the DHS permanency planning contractor and the family-based alternatives contractor.
10. Ensure ongoing evaluation of the effectiveness of the permanency planning data currently being collected with respect to children residing in institutional settings.

11. Local and state agencies should identify and implement strategies to overcome child specific, community, and statewide barriers identified in the permanency planning data being collected by HHSC.
12. HHHS should investigate the feasibility of developing an integrated collaborative strengths-based and comprehensive assessment that could be used to share information between agencies, for children using multi-agency services. The Council recommends building upon the Texas Integrated Functional Assessment (TIFA) to the extent possible. The Council will work with the future development of TIFA to ensure an evaluative component that is consistent with the family support principles adopted by the Children's Policy Council. Children who need complex integrated services will benefit greatly from an integrated assessment model.

Conclusion

The initial report from the Children's Policy Council was submitted in September 2000. While much work has been done to identify issues affecting children with disabilities and their families, families continue to struggle with a fragmented system that for many provides little opportunity for support. Texas continues to institutionalize more children than any other state and continues to maintain some of the largest community services waiting lists in the country. Many families are in crisis.

Texas has learned much over the past several years with respect to children with disabilities and the services and supports needed to help them remain in families and meet their potential. We have also learned from families the types of supports needed to promote the emotional health of the family unit to enable families to stay intact and care for their child. The Health and Human Services Commission in cooperation with several state agencies have begun new initiatives aimed at improving the systems of care and providing better options for children and families.

The recommendations in this report have two primary purposes: 1) to reduce the number of Texas children residing in congregate care institutions, and 2) build a better system of family supports that will enable families to care for their children at home. Through previous legislation, the state declared that:

It is the policy of the state to strive to ensure that the basic needs for safety, security and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs. The state and local communities must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible. (House Bill 885, 75th Texas Legislature)

Texas must continue to work to improve the quality and availability of long-term services and supports for our children with disabilities. Many recommendations in this report can be implemented in the near future with little or no new funding, or by restructuring current funding for children with disabilities. These include:

<u>Section</u>	<u>Recommendation</u>
Promoting Families	1.1, 1.2, 2.2, 3.3, 4.3, 1.4, 1.5, 3.5
General Family Support	1.1, 1.2, 1.5, 2.3
Case Management	1.1, 1.2, 2.2, 4.2, 5.1, 5.2
Transition	1.1, 2.2, 2.6
Coordination and Collaboration	1.1, 1.2, 2.2
Medicaid Waivers	2.2, 2.3, 4.1, 4.3, 4.4, 6.1
Regulations	1.2, 2.1, 3.1

Work should begin as soon as possible to implement many of these recommendations.

Appendix A: House Bill 1478 Charges

The Children's Policy Council is charged with studying and making recommendations in the following areas:

1. Access of a child or a child's family to effective case management services, including case management services with a single case manager, parent case managers, or independent case managers;
2. The transition needs of children who reach an age at which they are no longer eligible for services at the Texas Department of Health, the Texas Education Agency, and other applicable state agencies;
3. The blending of funds, including case management funding, for children needing long-term care and health services;
4. Collaboration and coordination of children's services between the Texas Department of Human Services, the Texas Department of Health, the Texas Department of Mental Health and Mental Retardation, and any other agency determined to be applicable by the work group;
5. Budgeting and the use of funds appropriated for children's long-term care services and children's health services;
6. Services and supports for families providing care for children with disabilities;
7. Effective permanency planning for children who reside in institutions or who are at risk of placement in an institution;
8. Barriers to enforcement of regulations regarding institutions that serve children with disabilities; and
9. The provision of services under the medical assistance program to children younger than 23 years of age with disabilities or special health care needs under a waiver granted under Section 1915(c) of the federal Social Security Act (42 U.S.C. Section 1396n(c)).

Appendix B: Family Support Principles

PRINCIPLES OF FAMILY SUPPORT IN TEXAS

- Families are supported in using family-directed, family-centered planning to ensure full participation, choice, and control in decisions related to their families' wants and needs.
- All children are valued and each child deserves the opportunity to meet his or her potential, which can best be accomplished when children grow up in families.
- Families are provided complete and unbiased information.
- Families decide who will provide their chosen services and supports.
- Services and supports are flexible and change with the evolving experiences of families.
- No one is excluded due to difficult or challenging circumstances.
- Services and supports focus on the entire family; the child who has a disability, parents, siblings, and others involved.
- Services and supports are reliable and easily available, but not imposed on families.
- Services and supports are available before families experience extraordinary stress.
- Families are supported to have an active presence in all aspects of their community.
- Family-to-family support and networking are encouraged and facilitated.
- Families are recognized as critical to meaningful decision-making, planning, development, implementation, and evaluation of a statewide system of services and supports, and their participation is supported.
- Services and supports are implemented based on policies and programs that meet the needs of families as they identify them.
- Family diversity is honored, recognizing family strengths and respecting differences.

PRINCIPLES OF SUPPORT FOR CHILDREN AND YOUTH WITH DISABILITIES

In addition to the Principles for Family Support in Texas, the following principles apply to children and youth with disabilities.

- Children and youth experience support, care, and love from families, neighbors, and others in their community.
- Children and youth are valued by their community and have opportunities to contribute to others.
- Children and youth feel safe and secure in their community.
- Children and youth are supported to stand up for their beliefs and act on their convictions.
- Children and youth are encouraged to develop a strong sense of their power as individuals.
- Children and youth are supported and encouraged to achieve self-determination.

Appendix C: Funding Principles

Periodically, the Children's Policy Council will hear and receive reports on legislative budget requests, proposed funding reductions, new grant applications, pilots, and initiatives. The Council will use the following principles upon which to understand and comment on funding issues. These funding principles align with the family support principles and values expressed in the Council's September 2000 report.

The following PRINCIPLES will be used as guidelines to review and comment on funding as it affects children with disabilities and/or special health care needs and families requiring health and long-term services and supports. Funds should:

- Increase the timely availability of community-based services with flexible choices for families and children statewide.
- Serve additional children and their families whenever efficiencies are gained.
- Expand the number and scope of blended funding models, such as Systems of Care and other wrap-around services for children's services in the state.
- Increase evidence based best practices for specific family, school, and community-based supports such as family support, permanency planning, and non-traditional/community-based services with outcomes based on family satisfaction and measurable outcomes.
- Strategically expand best practices and pilots, which have successfully demonstrated effective and efficient options statewide.
- Ensure access to health and related long-term supports and services for uninsured, under-insured, and indigent children and for children whose family income exceeds Medicaid and SSI income limits.
- Build capacity for community services for children based on the urgent need for children to grow up in families.
- Fund community services first for children in need of emergency services. Prioritize community-based services for children in the state budget, regardless of agency or program.
- Reduce reliance on facility-based, out-of-home options and funding methods, which shift costs for facility-based services into future funding cycles, reducing the already limited resources available for community-based services.
- Leverage and maximize federal funds for service expansion to include both Medicaid and non-Medicaid eligible children.
- Increase choice and flexibility at local and family level to address needs identified by the community and family by allowing funding to follow the child from more restrictive placements to support the child in the family, school and community.
- Promote prevention for out-of-home placement and secondary disabilities and promote early intervention
- Promote development of service systems for underserved individuals and access to health, long-term services, and supports regardless of disability.

Appendix D: Best Practices

CASE MANAGEMENT

- Funding access to case management based on the functional need for the service and not on income or diagnosis.
- Empowering families to be the collaborator and integrator of services.
- For children involved with several systems at once, developing case plans with reinforcing, rather than conflicting goals.
- Allowing case management strategies that vary under differing circumstances, since not all families require the same degree or type of case management or collaborative support.
- Involving the private sector in access and assistance.
- Combining service coordination and advocacy as functions of case management.
- Linking children and families to information, services and supports by trained, knowledgeable, resourceful case managers.
- Protecting against conflict of interest by separating the functions of case management and the provision of direct services.
- Streamlining access to services, with a single point of access and entry into services.
- Allowing for maximum consumer/family choice, which balances quality of life and personal safety.
- Supporting continuity and development of long-term trusting relationships between case managers and families.
- Establishing reasonable case load sizes and minimizing or eliminating other tasks, which compete for the case manager's time and attention.

COORDINATION AND COLLABORATION

- Identifying children, and the services needed by children with disabilities and their families, as a priority in the State.
- Developing common philosophies, visions, goals, objectives, and priorities that promote the coordination and collaboration of systems of services across agencies and programs, ages and diagnoses.
- One needs assessment per family, uniform joint eligibility and application procedures, coordinated policies for identification, assessment, referral and common quality assurance measures that ensure a family's needs are met.
- Ensuring that staff are knowledgeable about services they provide, as well as the array of service options available from other agencies and community organizations through new employee orientation and ongoing in-service training.

- Cooperating with community service organizations, the media, and private sector businesses to create a comprehensive package of services.
- Working actively with families and agencies on policy development and decision-making.
- Using a joint cross agency central database, exchanging information regularly, sharing information with families, and protecting confidentiality.

WAIVERS

- Consumer/Family Directed Services
- Flexible Family Supports
- Income eligibility based on the child's income and assets
- Comprehensive service array
- Ability to supplement other more limited third party resources
- Provision of an alternative to institutional care
- Cost caps based on aggregate, not individual limitations
- Funding following the person to their preferred service location
- Ability to pay for community-based alternatives (foster/companion care, surrogate family services) for individuals who are not able to live in their own/family home

REGULATIONS

- Partnering with facility staff, operators and survey staff to ensure appropriate quality of care and successful transition of children to a nurturing parental relationship in a family – based setting as soon as possible.
- Collaborating across agencies and communicating.
- Providing information to trustees and families regarding community-based options and allowing adequate time, in the case of a facility closure, to facilitate exploration and decision making by families.
- Providing notice to all responsible parties of all funding/program options as soon as possible after a closure is known to the responsible state agencies.

FUNDING

- Timely access to services.
- Adequate funds to insure quality services and appropriate scope, duration and frequency of services.
- Seamless access to services and, when necessary, the transfer of funds between programs and services (funding following the eligible consumer).
- Ability to exceed the individual cost cap as long as federal requirements for cost neutrality are met.
- Access to funding streams based on eligibility determination tools that reflect functional needs as opposed to diagnosis.
- Medicaid expansion through buy-in.
- Support for caregivers.

Appendix E: Barriers

Many of the barriers that existed two years ago when the previous report was developed continue to contribute to the inability of children to access services that would allow them to grow up in families. Additional barriers have also been identified.

- Existence of funding structures that promote institutionalization over family care.
- Families need preventive as well as intervention and crisis supports with flexibility in the programs and services to deliver what they need when they need it. Trusting families to know what they need and/or the ability to assist the family in identifying what those needs and services are is lacking.
- Lack of Family-Based Alternatives which is defined as a family setting in which the family provider(s) are specially trained to provide support and in-home care for children with disabilities or children who are medically fragile.
- Complexity and fragmentation within the HHS system makes it harder for families and case managers to be knowledgeable and effective in finding and coordinating supports and services.
- Case management can be somewhat intrusive, particularly when, due to rapid staff turnover, families have one case manager after another in rapid succession, a term the Council coined as serial case managers.
- Multiple case managers per child/family and no one identified as the lead causes duplication of effort and can cause more complexity and less privacy for the family. There is no master plan of care across programs and agencies.
- Funding to implement Senate Bill 36 (77th Texas Legislature) for cross agency training of case managers was not appropriated.
- Case management is often an entry-level job with low pay and job performance standards contrary to effective case management.
- Potential conflicts exist between the desired outcomes and needs of the child and family, limitations of the programs offering supports and services, and job performance criteria for case managers.
- Cost shifting between programs and agencies makes coordination more difficult for case managers and families.
- Case management is still combined with service provision in many programs, giving some program providers a vested interest in the plan of care.
- Lack of assistance to apply for Social Security Income benefits and information on how to appeal denials.
- Medicaid benefits available to adults are significantly less comprehensive than those available to children. This often leaves families struggling to obtain the services needed to keep the individual in the home.

- Children age-out of the Children's Health Insurance Program and the Children with Special Health Care Needs Program at age 18 and 21 respectively. Other health care benefits are not always available or are less comprehensive.
- Children in Child Protective Services conservatorship age out of foster care funding at age 20. This often forces these individuals to move to adult congregate care facilities.
- A significant lack of quality information for parents and individuals regarding adult services, Medicaid waiver programs, waiting lists, etc.
- Health and human services agencies currently compete for the same decreasing dollars, leading to “turfism” between agencies, and making open communication and collaboration more difficult.
- There is a lack of coordination and ownership of children with complex, expensive needs.
- Collaboration typically focuses on the most difficult situations; combined with other barriers, it often is unsuccessful, leading to the conclusion that “collaboration does not work.”
- There is no funding available for collaborative work; funding is categorical and is tied to “traditional services.”
- Agencies have high turnover rates, are understaffed, and often function in a crisis mode.
- There is a lack of understanding and collaboration with non-traditional community organizations, natural supports, and volunteers, thus these resources are underutilized.
- Most Texans, including private citizens, elected officials, and even providers have a limited understanding of the scope of problems affecting current and future long-term care consumers, including:
 - Lack of case managers who are knowledgeable about all community-based programs throughout the Texas health and human services agencies.
 - Lack of understanding or knowledge of research in pockets of society and the system about the developmental consequences of long-term institutional placement of children.
 - Insufficient training for those responsible for permanency planning for children in institutions.
 - Lack of adequate training for providers of services.
- Families have difficulty developing the expertise in learning about services and supports within and across agencies and how to comply with various rules and regulations.
- Regional variations in knowledge and interpretation of new permanency planning requirements among facility operators, trustees and surveyors.
- Low pay and lack of benefits for direct care personnel results in staffing shortages and compromised quality.
- Lack of incentives to recruit and retain direct care workers, exacerbating shortage of quality direct care workers.
- Medical and clinical models still overshadow best practices of child focused, family centered, community-based systems of care.

- Childcare for children with disabilities remains difficult; there are no state requirements for inclusion of children with disabilities; childcare administrators cite liability issues as real concerns.
- Transition remains disjointed: Early Childhood Intervention (ECI) support child and family but only to age three. The lack of continuity across programs and service systems causes ineffective transition planning from birth through adulthood. The handoff from infant to toddler to adolescent to youth to adult services and supports is not seamless, resulting in interruption of valuable time and needed services and supports.
- Provider issues such as lack of providers, especially in rural areas, to serve children with complex medical needs, training in specialty areas such as autism and traumatic brain injury, and staff turnover
- Access to services for children whose parents' income exceeds Medicaid income limits
- Lengthy waiting lists and lack of sufficient services for children while they are waiting
- Institution closures are usually within a very short time frame
- Some children residing in facilities are clustered together in child serving group homes or nursing facilities while others are scattered across the state.
- Critical service gaps exist (prescription drugs, dental care, services to specialized populations such as persons with traumatic brain injury)
- Waiting list data does not accurately represent need due to variations in waiting/interest list, lack of a definition of knowledge about what people are waiting for (what they need), and overlap between the lists

Appendix F: References

Bruner, Charles . *Thinking Collaboratively: Ten Questions and Answers to Help Policy makers Improve Children's Services*. Washington, DC: Education and Human Services Consortium, 1991

Busch, N., Ruffing, T., Rudenick, J., Sullivan, H., and Meimeyer,. "Exploring a Single Case Manager for Children with Disabilities, Final Report for the Texas Health and Human Services Commission." October 2001.

Children's Long-Term Care Policy Council. "Moving to a System of Supports for Families." A Report to Don Gilbert, Commissioner, Texas Health and Human Services Commission. Austin, Tx., September 1, 2000.

Donelan, K., Hill, C., Hoffamn, C., Scoles, K., Feldman, P., Levine, C., and Gould, D. "Challenged to Care: Informal Caregivers in a Changing Health System." *Health Affairs*, (July/August 2002) pp. 222-231.

Georgia Department of Community Health. *Home and Community Services: A Guide to Medicaid Waiver Programs in Georgia*. Atlanta, Ga., n.d. (Brochure).

Governor's Committee on People with Disabilities. *Moving From Institutions to the Community: A Blueprint for the New Texas*. Austin, Tx., 1992.

House Bill 1478 (77th Texas Legislature).

Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. 1: Lessons Learned from Other States*. Austin, Tx., 2001.

Lyndon B. Johnson School of Public Affairs, University of Texas. *Planning a Successful Family Support System for Texas, Vol. II: Current Services and Future Policy*. Austin, Tx., 2001.

Mt. Joy, Greg. Texas Comptroller of Public Accounts. "Chipping Away at Medicaid." *Fiscal Notes*. Austin, Tx., August 2002, p. 12-13.

Kaiser Commission on Medicaid and the Uninsured. *State Budgets Under Stress: How are States Planning to Reduce the Growth in Medicaid Costs*. Washington, DC, July 30, 2002.

Kaiser Commission on Medicaid and the Uninsured. *Medicaid's Role in Long-Term Care*. Washington, DC, March 2001.

Rosenau, Nancy, "Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities." *Policy Research Brief*, Research and Training Center on Community Living, University of Minnesota, Vol. 11, No. 2, September 2000.

Seton Health Care Network. "Out of the Emergency Room: Communicating Healthcare Options to Low Income Texans." Austin, Tx., July 2002 page 37

Senate Bill 367 (77th Texas Legislature).

Senate Bill 368 (77th Texas Legislature).

Senate Bill 36 (77th Texas Legislature).

Senate Bill 1234 (77th Texas Legislature).

Senate Bill 43 (77th Texas Legislature).

Senate Bill 374 (76th Texas Legislature).

Shenkman, E., Col, J., Schaffer, V., Du, Y., and Vargas, D. *Quality of Care in the Children's Health Insurance Program in Texas*. Institute for Child Health Policy, July, 2002.

Texas Department of Health and The Central Texas Network for Children with Special Needs. "Power Parent Training: Parent Handbook, Playing the Qualifying Game for Children with Special Needs." Austin, Tx., March, 2002.

Texas Department of Human Services. "Long-term Care Workgroup Report." Austin, Tx., May 2002.