

Children's Policy Council

***Recommendations for Improving Services
for
Children with Disabilities in Texas***

***Submitted to the Texas Legislature
&
Albert Hawkins, Executive Commissioner
Texas Health and Human Services Commission***

***As required by
House Bill 1478***

***by the
Children's Policy Council
October 16, 2006***

Children's Policy Council

October 16, 2006

To the Texas Legislature and Executive Commission Albert Hawkins, HHSC

The Children's Policy Council (Council) respectfully submits the following report, *Recommendations for Improving Services for Children with Disabilities in Texas*, as required by House Bill (H.B.) 1478, 77th Texas Legislature. This report is the culmination of months of evaluation, analysis, and development by parents of children with disabilities, health and human services agency staff, and community representatives. The report reflects the issues the Council has identified as requiring priority attention.

Texas children with disabilities deserve the opportunity to live in their communities with families, attend local schools, participate in recreational and leisure activities, and live the same quality of life as children without disabilities. Texas families work tirelessly every day to give their children with disabilities the same opportunities to thrive and meet their potential as children without disabilities. At times, these families need help. Family supports and services for children with disabilities are the essential elements that can keep families healthy and keep families together. Community supports and services are the lifeline that enable these children to grow up in a home, building skills that will help them thrive in their communities as adults.

The Council sincerely appreciates past efforts of the Texas Legislature and the Health and Human Services Enterprise to increase opportunities for children with disabilities to live meaningful lives. There is still, however, much work to be done. We believe that the recommendations in this report outline important steps that must be taken to improve access to needed community supports and services for these children and families. Additionally, the Council continues to support the funding requests outlined in the March 6, 2006 letter to Executive Commissioner Hawkins (Attachment A). The Council stands ready to assist with implementation of these recommendations in any way possible.

The Council respectfully requests your serious review and consideration of these needed changes as identified in the report recommendations.

Respectfully,

Colleen Horton
Chair

Children's Policy Council Members

Michelle Guppy, Family Member	Amy Litzinger, Youth Representative
Opal Irvin, Family Member	James Taylor, Family Member
Mary Klentzman, Family Member	Carmen Polhemus, Public Services Provider
Laurie Maddux, Family Member	Ron Roberts, Private Services Provider
Marianne Nevil, Family Member	Sherry Matthews, Business Community Representative
James Taylor, Family Member	David Evans, Funding Expert Representative
Suzan Cooper, State Agency Representative	

Ex-Officio Members: Department of Aging and Disability Services, Department of State Health Services, Texas Workforce Commission, Department of Family and Protective Services, Department of Assistive and Rehabilitative Services, Texas Education Agency, Texas Center for Disability Studies at the University of Texas, Texas Council for Developmental Disabilities

TABLE OF CONTENTS

Introduction.....1

Progress Made in Supporting Children and Families - The Good News.....2

The Challenges that Remain5

Recommendations.....7

Individual Recommendations8

Attachment A Funding Request Letter to Executive Commissioner Hawkins A-1

Attachment B House Bill 1478 ChargesB-1

INTRODUCTION

The Children's Policy Council

The Children's Policy Council (Council) works to assist the state in developing systems that support families in caring for their children with disabilities, allows children to grow up in families, and uses state resources effectively.

The Council, statutorily authorized by H.B. 1478, 77th Texas Legislature, 2001, is charged with assisting the Texas Health and Human Services Commission (HHSC) in developing, implementing, and monitoring long-term supports and services programs providing support to children with disabilities and their families. The Council continues to focus on its mission and work for systems change that will increase access to services for children with disabilities and their families and improve the quality of services provided.

The mission of the Children's Policy Council is 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.

Members of the Council urge policymakers to use the information in this report as a basis to work for change that will ensure that the needs of children with disabilities and their families receive priority attention. This report contains 18 recommendations that address the priorities of the Children's Policy Council.

Background

There are approximately 425,000 children and youth under age 21 with disabilities in Texas. These children come in different sizes, different colors, and from different cultures. They live in low-income, middle-class, and wealthy families. Some of these children have significant disabilities; some have milder disabilities that may not be visible to the untrained eye. Just as the children are different, so are their families. Some of these children are fortunate to have the love and attention of a nurturing family coupled with an active collection of extended family, friends, and neighbors. Some of these children have no family at all. Because the children and the families are all different, so are their family support needs. Some families of children with disabilities need minimal help and can easily take care of their child through their informal support network. Many others, however, require more extensive help in order to care for their child, keep their child at home in their community, and help their child thrive and meet his or her potential. This report will address the needs of children and families who need some level of formal family supports and services.

While families provide the majority of care for children with disabilities, we know that families often cannot do it alone. When looking for help, families often seek more formal services and typically turn to a variety of organizations and agencies. The primary state programs providing services and supports to these children include Medicaid, Medicaid waiver programs, and general revenue funded community care programs. The services offered by these programs become a lifeline for many families. When these services are not available, families can struggle to remain whole.

PROGRESS MADE IN SUPPORTING CHILDREN AND FAMILIES - THE GOOD NEWS

Texas has made progress in the past two years in improving services for families and children. One of the most relevant accomplishments has been the significant change in the culture of the decision-makers and the acknowledgement that children, including children with disabilities, do not thrive when forced to grow up in institutions.

Number of Children Residing in Institutions¹

Nursing Homes	DFPS	ICF/MR, State Schools & HCS	TOTAL
174	208	1,214	1,596

What are family supports and services?

Family supports include whatever the family needs to remain physically and emotionally healthy so that they can help their child thrive.

These may include: service coordination/case management, respite, attendant care/nursing services, parent-to-parent support, assistive technology, behavioral supports, parent training, durable medical equipment, minor home modifications, support family services, foster/companion care, specialized therapies, adaptive aids, medical supplies, pre-vocational training, and more.

Many Texas families are fortunate and have been able to access the community long-term supports and services their child needs. Other families, however, continue to wait for services to become available. For those families who cannot wait any longer, children are at significant risk of institutionalization.

¹ Source: HHSC. Data reflects the number of children residing in an institution as of February 28, 2006.

By recognizing the benefit of keeping children with disabilities at home, the legislature and the health and human services agencies staff have focused on finding ways to improve systems and increase opportunities for families. The most recent initiatives include:

- Improved Permanency and Statewide Training Initiatives
As required by Senate Bill (S.B.) 40, Texas Legislature, 79th Session, 2005, permanency planning for children residing in Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) is no longer the responsibility of the facility where the child resides. The Mental Retardation Authorities (MRAs) now have responsibility for effective permanency planning. This change was implemented in order to remove the conflict of interest and, hopefully, improve the prospects for children currently confined to an institution to transition to family life. While permanency planning is an effective process, it is only as good as those performing the task. Recognizing this, the Department of Aging and Disability Services (DADS) partnered with EveryChild, Inc. (a family-based alternatives project) to conduct a series of statewide permanency planning trainings to improve the level of expertise. Ten trainings were presented across the state with over 1,000 individuals attending.
- Targeted Funding for Community Waivers for Children in Institutions
Texas was a leader in the country in operationalizing the “money-follows-the-person” funding mechanism allowing individuals in nursing facilities to use that funding to transition to community services. This opportunity, however, is not currently available for individuals in ICF/MRs. This leaves some families with no option but to keep their child institutionalized, as community services are not available. Rider 46 to H.B. 1, 79th Legislature, 2005, directed DADS to implement a system that would allow up to 50 children residing in ICF/MRs to transition to Home and Community-based Services (HCS), providing significantly improved options for these 50 children and their families.
- Targeted Funding for Youth with Disabilities Aging Out of Foster Care
Children with disabilities in the Texas foster care system typically have few options when they “age-out” of foster care services. Many of these individuals are forced into institutions when the foster care funding runs out. Recognizing that institutional care can be significantly more expensive than continuing community services, and recognizing the need to find alternative living arrangements for these young adults, Rider 54 to Article II of H.B. 1, 79th Legislature, 2005, directed \$1.8 million in HCS funding be targeted to children with disabilities aging out of the foster care system. This funding provided waiver slots for 63 individuals and was expended within the first year of the biennium, evidencing the significant need of this sub-population of children.
- Continuation of the Family-Based Alternatives Project
The Family-Based Alternatives Project began in 2002 and was intended to create a system that could provide alternatives to institutionalization for children whose birth family could no longer care for them without adequate support. As this had never been done in Texas, the task before us was enormous. Four years later, however, the project is making great inroads in the way providers serve children and families. The HHSC family-based alternatives contractor, EveryChild, Inc., continues to work with children confined to institutions, birth

families, and support families to ensure that every child has the opportunity to grow up in a family. Additionally, the expertise and experience of EveryChild staff is being shared with providers across the state so their efforts can be leveraged and the practice of developing support families will continue to expand. EveryChild staff continually provide training and technical assistance to a myriad of providers including child placement agencies, MRAs, HCS providers, home health providers, and more. All this is done with the objective of increasing the number of service and support providers willing to look for all opportunities to prevent institutionalization of children and to continue seeking family-based options for children currently institutionalized.

Children Moving from Institutions to Family and Community

For a six month period ending February 28, 2006²:

- o 60 children moved to less restrictive environments (other than family-based settings)
- o 123 children moved to family-based settings
- o 183 total children with developmental disabilities left an institution for a family, family-based setting, or other less restrictive setting.

➤ Rollout of a Significant Number of Medicaid Waiver Services (slots)

During the 79th Legislative Session, the Texas Legislature appropriated funding for approximately 9,360 additional Medicaid waiver “slots” (funding for community-based services). These slots are being offered to individuals and families on a quarterly basis throughout the biennium. Families currently being offered services have been on the waiting list for up to 13 years. The Council commends DADS for their efforts to ensure that individuals and families have access to these services as soon as possible.

➤ Expansion of Consumer Directed Services

Consumer directed services (CDS) benefit families in that they can select, hire, and train the attendants and respite providers that come into their home to help with the support of their child. Many families prefer this delivery model as it gives them more control and choice in who is working with their child. This model also helps to address the direct care worker shortage in that families can recruit neighbors, church members, and others who may not normally engage in this line of work. CDS has been available in the Community Living Assistance and Support Services (CLASS) and Primary Home Care (PHC) programs, and has recently been added to the Medically Dependent Children’s Program (MDCP). This delivery option is also being developed for inclusion in the HCS and Texas Home Living Waivers (TxHmL).

➤ Personal Care Services for Children

Another major systems change that is expected to be implemented in 2007 resulted from the Alberto N. lawsuit. The settlement agreement in this case requires the state of Texas to include personal care services for children with disabilities (physical, medical, behavioral and cognitive) in the Texas Health Steps Comprehensive Care Program (CCP). This systems improvement will help to balance the system of services for children creating an entitlement for community care services for eligible participants.

² Source: HHSC Permanency Planning Report, July 2006.

THE CHALLENGES THAT REMAIN

Significant unmet need continues to exist in Texas. Limited resources, vast rural areas, workforce shortages, program structure, economic factors, and much more all contribute to the inability of families to obtain the help they need for their children with disabilities. Some of these factors can be positively affected by increasing resources for community-based services; others can be improved by redesigning aspects of certain programs.

Following are the primary barriers that continue to exist that put children and families at risk. These barriers are addressed more fully in the Council recommendations.

➤ Long Waiting Lists for Community-Based Services

Individuals and families continue to wait many years to obtain community waiver services. Every waiver has long waiting lists, some of which can take more than ten years for a “slot” to become available. While institutional services are an entitlement and readily available, most families refuse to even consider the possibility of institutionalizing their child. Other families, however, are not always able to hang on. When community services are not available, families sometimes have no choice. Community services and family-based options are best-practices in supporting children with disabilities. Efforts must continue to reduce the waiting lists and make only needed services available.

Interest List

	CBA	CLASS	DBMD	MDCP	HCS
Current Interest List - June 30, 2006	45,318	15,091	13	10,111	30,398
Children under age 21 on Interest List – as of July 31, 2006	818	12,696	12	10,050	15,926
Children as a percentage of total Interest List	1.8%	84.1%	92.3%	99.4%	52.4%

➤ Multiple Waiver Programs and Lack of Flexibility of Waivers to Meet the Needs of the Child

Eligibility for Texas Medicaid waivers is currently based on labels and diagnoses. Additionally, the confusing, multiple waiver system in Texas causes much frustration for some families who have waited years for services. This is an ineffective way to distribute limited resources and often prevents children from receiving the services they actually need.

Waivers are so confusing. Entering each one is like walking into its own little universe. Each one serves a different population. There is a waiver for adults, there is a waiver for persons with deaf/blind designations. There is a waiver for those with mental retardation, a waiver for those with related conditions (whatever those are), and a waiver for kids with medical conditions. To make it worse, not all waivers have the same services, not all are available in all counties, not all pay the same amount. Getting on a Medicaid waiver is no cake walk. ~A frustrated Texas Mom

- Lack of Adequate Adult Services for Young Adults Aging Out of Children's Services
Children with significant disabilities sometimes need an intense level of services and support to remain in their family's home. If eligible for Medicaid, these children have access to all medically necessary services through the Texas Health Steps Comprehensive Care Program (CCP). This program has worked well for the children needing these services. However, when these children turn 21, the comprehensive services run out and some youth are threatened with institutionalization caused by their inability to access the needed level of services. Many families who have children aging out of the CCP or the MDCP are desperately trying to keep their child at home, but are unable to meet their needs through the services offered in the Community Based Alternatives (CBA) waiver – the only waiver immediately available to these children as they age out of MDCP or CCP.

This issue could be addressed through the recommendation of consolidating waiver programs and basing service provision on the functional needs of the individual. The current system does not allow these young adults with disabilities access to the most appropriate waiver or the appropriate services, sometimes resulting in their institutionalization.

- Limited Transition Services for Individuals Leaving the Public School System
Far too many children with disabilities leave the public school system and end up spending their days at home watching the TV, with little else to do. Transition services from school to work or post-secondary education are limited and often ineffective. Many parents have struggled through their child's educational years with little or no help from formal programs only to find that little assistance and few services are available once their child leaves school.

While we are hopeful that the additional transition specialists being made available through the Department of Assistive and Rehabilitative Services (DARS) will improve the situation, these young adults need more. We urgently need to improve comprehensive services to youth so that they can continue the community integration that they and their families worked so hard to maintain during the school years. Transition specialists must be skilled in developing employment opportunities, but must also be knowledgeable and skilled in guiding these individuals through the health and human services (HHS) system so that they can access the services they may need and are eligible to receive. Employment opportunities are not useful if the individual does not have the support to remain in the community.

- The Front Door to Institutions Remains Wide-Open
Even with the progress made, a substantial barrier remains to reducing the number of institutionalized children in Texas – the front door to institutions remains wide open. While children are leaving, new and often younger, children are entering facilities. Addressing the reasons why families place their children in institutions, and the process used to allow institutional placement of children is vital to slowing this trend. The data below shows a significant improvement in the reduction of children in large ICF/MRs with many moving to smaller residential residences. However, families facing the difficult decision as to how to care for their child with significant disabilities are forced to consider institutionalization because institutional services are an entitlement while community services continue to be available only after extended periods on waiver waiting lists.

Trends in Institutional Placements²

Institutional Type	Number as of August 31, 2002	Number as of February 28, 2006	Percent Change
Total all ICF/MRs and State Schools	962	706	-27%
<i>Large ICF/MR Facility</i>	264	110	-58%
HCS Supervised Living or Residential Support	<u>312</u>	<u>508</u>	<u>+62%</u>
	1,274	1,214	-5%

➤ Workforce Crisis – Shortage of Direct Care Workers

The shortage of direct care workers affects children and adults with all types of disabilities and is only expected to become worse if not addressed as a HHS priority. As everyone knows, the need for long-term services and supports, especially attendant and habilitation support, is growing. It is essential that we build a system that provides quality direct care and protects the individuals from abuse and neglect. As with everything else, we will get what we pay for, and, currently we aren't paying enough to expect quality care. The incredibly low wages coupled with the lack of any meaningful benefits makes it difficult, and sometimes impossible, to continue to hire dedicated workers. Our children and adults with disabilities needing direct care support are at risk if we do not make this a priority issue. The discrepancies between wages and benefits in the current system (state institutional workers versus community direct care providers), does little to promote the community programs that individuals and families want and need. Provider rates must be increased and we must work to ensure that the wages and benefits of direct care staff are sufficient to draw quality workers into the profession.

RECOMMENDATIONS

The Children's Policy Council has spent many months discussing and analyzing the current systems of supports for children with disabilities and their families. Through this analysis, the Council has identified 18 recommendations that we believe would have significant impact on children with disabilities in Texas. We are hopeful that the HHSC Enterprise and the Texas Legislature will take a serious look at the recommended changes and recognize that implementation of these changes will move us toward a more effective system of services for children with disabilities and their families.

The recommendations offered in this report are consistent with the national HHS goals and objectives and reflect the values and principles of the federal initiatives supported by Texas families and agencies including, but not limited to: Promoting Independence principles, the New Freedom Initiatives, the Real Choice Initiatives, Healthy People 2010, and the National Title V Child Health Children with Special Health Care Needs goals. These recommendations represent the best use of limited resources to accomplish the most effective outcomes that would maximize benefits to children with disabilities and their families.

² Source: HHSC Permanency Planning Report, July 2006.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #1

Texas should develop and implement plans to provide Medicaid buy-in options on a sliding-fee basis for children with disabilities in families with income up to 300% of the federal poverty level as allowed in the Family Opportunity Act provisions included in the Deficit Reduction Act (S.1932).

Background/Current Status

A large number of families of children with disabilities divorce, quit jobs, or intentionally lower their income to ensure their child qualifies for Medicaid. When parents of children with disabilities or special health care needs have to drop out of the workforce or keep themselves in a low-paying job just to remain eligible for Medicaid, in effect, the government is forcing parents to choose between near-poverty and their children's health care. As a result, families face a terrible choice in order to secure adequate health coverage for their children with special needs: 1) become or stay poor in order to retain Medicaid eligibility; or 2) give up custody of children with disabilities. These families are also unable to save money for the future because of strict limitations on resources. Many states have reported that increasing numbers of families are giving up custody in order to ensure that their children receive necessary health care services and support.

Medicaid is critical to the well-being of children with multiple medical needs because it covers a comprehensive array of health services that children with significant disabilities need. Many children with disabilities are uninsurable in the commercial insurance market or if coverage is available the premiums may be unaffordable for many families. In addition, private health plans often are much more limited in what they cover, so that even if coverage is available and affordable, it is often less than adequate for children with special health care needs.

To ensure adequate health coverage for children with special health care needs, and to prevent families from having to make decisions to lower income or give up custody to ensure such coverage, the state should fully participate in the Medicaid buy-in created in the Family Opportunity Act provisions of the Deficit Reduction Act. This provision allows states to create options for families with children who have special health care needs to buy into Medicaid while continuing to work. Parents would pay for Medicaid coverage on a sliding scale, allowing many families who have lowered their income, to return to work and begin **to contribute to the cost of their child's care.**

The Family Opportunity provision of the Deficit Reduction Act is **pro-work** because it lets parents work without losing their children's health coverage, **pro-family** because it encourages parents to work and build a better life for their children, and it's **pro-taxpayer** because it means more parents continue to earn money, pay taxes, and pay their own way for Medicaid coverage for their children. Texas should immediately and fully implement this provision.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #2

Expand “money-follows-the-person” (MFP) to include the Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) program, and aggressively pursue the MFP Demonstration Grants offered by the federal government as a result of the Deficit Reduction Act of 2005.

Background/Current Status

Individuals with cognitive disabilities residing in intermediate care facilities for the mentally retarded are not able to access funding for community services through a “money-follows-the-person” mechanism. The lack of access to this funding mechanism causes individuals who want to move from ICF/MRs to community-based services to remain institutionalized. This violates the spirit and the intent of the Olmstead Supreme Court Decision.

Recognizing that the best way to ensure the safety and well-being of children is to have them grow up in nurturing families, Texas has taken steps to provide more opportunities for individuals and families to choose where they want to receive needed long term services and supports.

In 2003, the Texas Legislature approved a Rider that would allow state and federal Medicaid funding currently being spent to provide care to children and adults in nursing facilities, to be used to allow individuals to transition to community-based services. This was operationalized by transferring the funding in the nursing facility strategy to the community care strategy. During the 79th Legislative Session, the rider provisions were codified. To date, more than 11,000 individuals have used the money-follow-the-person strategy in order to leave nursing facilities and move back to their communities.

Texas has been a leader in the nation in the development and implementation of this initiative. Other states have used Texas as a model for developing their own MFP programs. Thus far, however, this opportunity has only been available to individuals residing in nursing facilities and not individuals residing in other long term care facilities such as ICF/MRs. Several pieces of legislation attempting to expand the MFP initiative were filed during the 79th Legislative Session, but none passed.

As a result of the MFP being limited to individuals in nursing facilities, children remain institutionalized in ICF/MRs because of the lack of funding for community-based services. Consequently, they are being denied the opportunity to grow up in families because of the type of disability they have and the type of institution they reside in.

While there are complexities involved in expanding MFP to other institutions, little has been tried and few incentives for conversion have been developed in Texas. It is time to seriously analyze and implement systems changes needed to provide individuals residing in all institutions the opportunity for choice including the ability to transition to communities.

In February 2006, the U.S. Congress passed the Deficit Reduction Act of 2005. One of the provisions of this Act provides funding for Money Follows the Person Demonstration Grants. These grants will provide states with an enhanced FMAP rate (Medicaid match) for one year, for each individual leaving an institution and moving to community-based services. DADS has stated that they will apply for this grant and will include stakeholders in the development of the proposal.

Action Steps Needed to Implement Recommendation

- Recognize that the choice of service settings should be controlled by the individual receiving the service (self-determination) and not by an industry (private and public providers).
- Submit a timely proposal for the MFP Demonstration Grant, ensuring that individuals with cognitive disabilities wanting to leave ICF/MRs are able to do so through this process.
- Develop and implement a plan for expanding the MFP initiative to individuals in ICF/MRs.
- Develop and make public a plan for allowing providers to voluntarily convert institutional services to community-based services (i.e., ICF/MR to HCS).

CHILDREN'S POLICY COUNCIL RECOMMENDATION #3

HHSC should direct the development of a coordinated, independent service coordination/case management system that would allow children receiving long term services and supports and their families to access effective, unduplicated service coordination/case management services.

Background/Current Status

Service coordination/case management services in children's long term care programs vary greatly in cost, quality, and effectiveness. In Texas, service coordination/case management is offered in numerous programs throughout the HHS enterprise, is delivered through a range of program structures and modalities, and is referred to by several different names (service coordination, case management, case coordination, targeted case management, care management, etc.). Service coordination/case management also varies in scope, method, intensity, accessibility, and duration. Additionally, children with extensive support needs receiving services from more than one program may have more than one service coordinator/case manager through more than one state agency. This can result in less than optimal services for children and families, as well as cause inefficient use of limited resources (staff time).

Service coordination/case management should be the responsibility of a person not associated with, or employed by, the agency delivering the services. If the service provision and service coordination/case management are not separated, a conflict of interest exists that prevents the case manager from being an advocate for the individual receiving services.

Developing an independent, coordinated service coordination/case management system would improve access to services for individuals and has the potential to reduce the fragmentation and duplication that currently exists, thereby reducing the high caseloads, improving quality, and saving the state valuable administrative resources.

Action Steps Needed to Implement Recommendations

HHSC is currently conducting a comprehensive study of service coordination/case management across HHS programs. The completion of that study should be used to spearhead the development of a strategic plan for consolidating, streamlining, and coordinating case management services, where appropriate. Any redesign of the service coordination/case management system should include an intense analysis of: comprehensiveness of service, specialization, caseloads, reimbursement rates, quality assurance, and access.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #4

CPC recommends the creation of a time-limited task force to work with private providers of long term care facilities providing institutional services to children with disabilities, to assist those interested in transitioning from facility-based to family-based services in formulating a viable business plan to make that transition.

Background/Current Status

Over the last few years there has been a significant trend away from large facility care for children as evidenced in permanency planning data. The most recent Permanency Planning Legislative Report (July 2006), reports a total of 1,596 children residing in institutions with 1,400 children being recommended for transition to the community.

Some large facility-based providers have expressed an interest in moving to a community-based model. They see a viable business potential in providing community-based services, but are reluctant to move forward due to the financial risks during the downsizing and transition. As a result, children and adults remain in ICF/MR facilities. State savings generated through the enhanced FMAP rate made available through Money-Follows-the Person Demonstration Grants could be used, in part, to move this initiative forward (see Recommendation #2).

Without a viable transition plan, there is a business disincentive that works against state permanency policy as outlined in S.B. 368 and the Governor's Executive Order #RP13 which seeks to assure family life for children. The state should promote discussion and implementation of transition plans from willing providers. Limited short-term incentives should be available to providers interested in moving toward a community-based services provision model.

Action Steps Needed to Implement Recommendation

DADS should initiate an open discussion with providers and other stakeholders, on a voluntary basis, to identify barriers to transition, seek potential solutions, and implement changes that would allow voluntary transitions. These analyses should be coordinated with any discussion resulting from Recommendation #2, Money Follows-the-Person.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #5

Consolidate appropriate waivers enabling families to obtain services based on functional needs.

Background/Current Status

The current system of multiple waivers is fragmented, confusing, and frustrating to families. It is difficult for families to know what programs their child may be eligible for and what waiting lists they should place their child's name on. There is no central resource with information on all the waivers that can assist families. Many families wait for years for their child's name to rise to the top of a waiting list only to discover that their child had been on the wrong waiver waiting list. These families are then forced to go to the bottom of the "appropriate" waiting list. This can lead to an additional five to ten year wait for services depending on the program.

The existing waiver programs are inequitable. A diagnosis or "condition" often determines the type of program an individual is eligible for instead of an actual assessment of the individual's functional support needs. Due to the fact that the waivers were developed over time, designed by different departments, and advocated for by different disability groups, the current waiver programs differ significantly in: services available; maximum level of services allowed; service reimbursement rates; rules and regulations, and monitoring. This creates a system that is administratively costly and confusing for state staff as well as the individuals and their families.

Because the current waiver programs are diagnosis based, many individuals who desperately need supports and services to remain in their communities, but who do not fall into particular categorical diagnostic groups, are left with no services at all or, at the very least, are not able to access the types of services they need. While some waivers provide services to similar populations, the waivers are not equitable in the services they offer.

Consolidating appropriate waivers would help to alleviate some of the mass confusion associated with the current system that causes families frustration and heartache when they cannot obtain the services their child needs. This is especially true for individuals with traumatic brain injury and autism.

The state of Texas currently has the following 1915(c) waivers: Community Based Alternatives (CBA), Home and Community-based Services (HCS), Community Living Assistance Supports and Services (CLASS), Medically Dependent Children's Waiver (MDCP), Deaf/Blind/Multiple Disabilities waiver (DBMD), Texas Home Living (TxHmL), Consolidated Waiver Program (CWP), and Star+Plus waivers for community services. Each waiver serves different populations that have some similar and some differing support needs. Not all waivers are available to all ages, or in all Texas counties, creating problems during transition periods.

Action Steps Needed to Implement Recommendations

HHSC should direct DADS to convene a time-limited task force of agency staff, consumers, advocates, and providers to analyze current waivers, identify issues and barriers that need to be addressed, and design a more streamlined, consolidated waiver system.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #6

Recognizing that the consolidation of waivers (see #5 above) will take time, the CPC recommends the development of proper guidelines and oversight, to allow children to obtain the most appropriate and necessary waiver services.

Background/Current Status *(Note: The background and current status are essentially the same as for Recommendation #5. This recommendation is considered a stop-gap measure to be used until the consolidation of waivers based on functional needs is developed and implemented.)*

When a child is offered Medicaid waiver services, he/she should have access to the appropriate needed services. If those services are not available in the particular waiver offered, but are available through another waiver program, access to the appropriate waiver should be granted. Children should not suffer the consequences of an illogical system of waivers.

The current system of multiple waivers is fragmented, confusing, and frustrating to families. It is difficult for families to know what programs their child may be eligible for and what waiting lists they should place their child's name on. There is no central resource with information on all the waivers that can assist families. Many families wait for years for their child's name to rise to the top of a waiting list only to discover that their child had been on the wrong waiver waiting list. These families are then forced to go to the bottom of the "appropriate" waiting list. This can lead to an additional five to ten year wait for services depending on the program.

The existing waiver programs are inequitable. A diagnosis or "condition" often determines the type of program an individual is eligible for instead of an actual assessment of the individual's functional support needs. Due to the fact that the waivers were developed over time, designed by different departments and advocated for by different disability groups, the current waiver programs differ significantly in: services available; maximum level of services allowed; service reimbursement rates; rules and regulations, and; monitoring.

The state of Texas currently has multiple 1915(c) waivers. Each waiver serves different populations that have some similar and some differing support needs. Not all waivers are available in all Texas counties, adding to the confusion. Not all waivers are available to all ages, creating problems during transition periods.

This creates a system that is administratively costly and confusing for state staff as well as the individuals and their families. Because current waiver programs are diagnosis based, many individuals who desperately need supports and services to remain in their communities, but who do not fall into particular categorical diagnostic groups, are left with no services at all or, at the very least, are not able to access the types of services they need.

Action Steps Needed to Implement this Recommendation

DADS should be directed to develop guidelines that allow children with disabilities who are offered Medicaid waiver services, access to the waiver services appropriate to their functional needs.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #7

Agencies should develop policies and procedures to allow allocation of existing general revenues as flexible community supports to be used to postpone or prevent institutional placement for at risk children.

Background/Current Status

There are limited options for families of a child with significant disabilities when there is a family emergency. The decision for placement is often made under stress and desperation and is not always in the best interest of the child and/or the family. Agency staff assists families with the major decision of placement without considering minor interventions that could postpone or prevent placement. Often what is needed can be found within the community at a significantly lower cost than institutional placement.

Family assistance funds are available through some agencies but are usually restricted by guidelines that limit the family's options. For example, respite funds are an invaluable resource, but by definition their use is limited. Children's Mental Health has a creative contract requirement for flexible community supports and an equitable and accountable process for disbursement. Even though there is limited funding, parents direct the available funds to what they identify as their need. Family choices do not come from a menu, but are family driven as personal strategies to keep their child at home. The ability for each state agency to use available funds would offer this option to multiple families and the choices would not be limited by diagnosis of the child.

Action Steps Needed to Implement Recommendation

With direction from the legislature, HHSC, DADS, DARS, the Department of State Health Services (DSHS), and the Department of Family and Protective Services (DFPS) should develop a process for application and disbursement of funds that are accessible, accountable, and assures no duplication of funding. An independent third party should evaluate the process to assure that the use of the funds meet the stated objective of prevention or postponing institutional placement.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #8

CPC recommends funding strategies be re-instated to support training and conferences targeting children's services and supports.

Background/Current Status

Agency staff and providers report that access to conferences and training opportunities have diminished tremendously over the past few years. Quality of care for children and youth services is at risk. Workforce retention is compromised.

The concern over the impact on quality of care is exacerbated for children and families who require the coordination of services and supports across agencies. State child-serving agencies and local affiliates need to be aware of complementary programs in order to prevent duplication of services, increase appropriate access of necessary services, and coordinate a more efficient integrated service delivery approach that utilizes best practices.

Statewide conferences can offer the opportunity to bring together urban, rural, border, and frontier regions of the state to network and learn local, regional, state, and national promising practices. Experts in specific areas (i.e., age related, disability focused, child welfare, etc.) may be brought together to present information related to collaborative approaches to serving populations of children and youth and their families that require coordination among multiple agencies.

Regional conferences can offer unique training and networking opportunities at a local level to foster greater community collaboration that will result in a more efficient, effective, integrated system of services for children. Through regional trainings, communities may be more able to bring together teams of public and private sector child-serving organizations along with families and the faith-based community to attend a more accessible event to learn and assimilate best practices regarding serving children, youth, and families.

Training conferences can offer the opportunity to bring together urban, rural, border, and frontier regions of the state to network and learn local, regional, state, and national promising practices. Experts in specific areas (i.e., age related, disability focused, child welfare, etc.) may be brought together to present information related to collaborative approaches to serving populations of children and youth and their families that require coordination among multiple agencies.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #9

DADS should provide ongoing, broad-based permanency planning training for providers, staff, and stakeholders across service delivery systems.

Background/Current Status

Permanency planning for children is a process of communication and planning with families and children to help identify options and develop services and supports essential to the eventual and planned outcome of reuniting children with their own family or a support family. Currently, there are 1,596 children residing in institutional settings (per Permanency Planning Legislative Report, July 2006), with 1,400 children recommended for transition to the community.

Permanency planning is a vital piece of current state initiatives aimed at reducing the number of institutionalized Texas children. While permanency planning is not new to Texas, it has changed significantly over the past several years. Additionally, the responsibility for conducting permanency planning has changed to a totally new entity, causing a significant need to build a base of skill and expertise. The skills and expertise staff acquire through permanency planning training not only benefit children currently confined to institutions, but allow staff to more effectively support families of children at risk of institutionalization.

DADS has successfully provided permanency planning training to state and local provider agencies in the past. A greater awareness in the community and within systems of what constitutes effective permanency planning is an essential on-going need. The use of effective permanency planning for at-risk children can prevent admissions to more costly in-patient settings, correct misunderstandings, and educate staff in institutions, facilities, and the community, on the benefits of meaningful permanency planning.

Action Steps Needed to Implement Recommendation

DADS should provide ongoing, regional, on-site, broad-based permanency planning training for staff, contractual providers, cross-agency stakeholders, and families that includes permanency planning for children in institutional placements and for children at-risk of out of home placement.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #10

Under the direction of HHSC, DADS should conduct a comprehensive comparative market analysis of both public and private direct care providers, analyzing the wages, benefits, skill and experience of facility-based direct care workers and community-based direct care workers to determine if rates and benefits are sufficient to ensure a quality community direct care workforce.

Background/Current Status

The state must make efforts to build and maintain a quality direct care workforce for children and adults with disabilities, as well as aging Texans. Families of children with disabilities who are receiving community services through Medicaid waivers and other community care programs have difficulty finding and retaining quality attendant services due to low wages and lack of benefits. The current rate is simply not sufficient to recruit and retain responsible and reliable workers.

The wages and benefits available for direct care workers varies and is typically different when looking at institutional versus community based services. There are also significant differences in wages paid to community-based workers depending on the program providing the service. This is true even though the service may be exactly the same. The current system also does not allow (except in limited cases) opportunities to pay higher wages to those who are providing services to individuals with more intense needs requiring a higher level of skill.

To ensure the longevity of a quality direct care workforce, pay scales should be sufficient to provide a living wage, wages across programs should be equal for the provision of same or similar services, wages, and benefits should be comparable regardless of institutional versus community employment, and enhanced rates should be available for direct care workers requiring a higher level of skill based on the functional needs of the individual.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #11

The Texas Legislature should appropriate funding to allow full implementation of the Child Abuse Prevention and Treatment Act (CAPTA) requirements as set forth by federal mandates.

Background/Current Status

The federal Child Abuse Prevention and Treatment Act promotes partnerships between child protective services and community-based organizations to ensure assistance is provided in the most effective manner for children caught in abusive situations. One provision in CAPTA requires states to develop policies and procedures for the referral of any child under the age of three years who is involved in a substantiated case of abuse or neglect to early childhood intervention (ECI) services.

A similar requirement was added to the federal Individuals with Disabilities Education Act (IDEA), which establishes state ECI programs. In December 2004, Public Law 108-446 reauthorized IDEA. It included a similar requirement that state policies and procedures require referral to ECI of children under the age of three who are involved in a substantiated case of child abuse or neglect, are identified as affected by illegal substance abuse, or identified as affected by withdrawal symptoms resulting from prenatal drug exposure.

Neither CAPTA nor IDEA reauthorization included additional funds for states to implement the requirements. Additional funding will be needed to assess these young children for developmental delays and social-emotional disturbances and provide ECI services to those who need them.

DARS/ECI has requested funding at the baseline level to allow screening, referral, and enrollment in ECI as required.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #12

HHSC should build on the intent of H.B. 2292 (77th Legislature), by directing the development of an inter-agency collaborative effort to ensure that DARS transition specialists receive training on long term supports and services from the Texas Workforce Commission (TWC), DADS, DSHS, HHSC and DFPS so that essential information will be available to youth approaching adult services.

Background/Current Status

IDEA defines transition as a coordinated set of activities designed to help a student move from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), adult services, independent living, and community participation. Many agencies may provide services that will be needed by a young person as they move toward adulthood. Navigating this maze of service agencies is challenging for students and their families and may result in students leaving the public school system without the assistance they need as young adults.

The Council applauds DARS for creating 100 Transition Vocational Rehabilitation Counselors (TVRCs) from existing positions and through attrition within DARS. The creation of these positions represents an innovative approach to address a huge gap in the service delivery system. The success of these positions, however, will depend on the DARS transition specialists' knowledge of a broad spectrum of community resources and the ability to work very closely with selected schools, public and private agencies, and other community entities. The success of youth with disabilities after leaving high school will not only depend on employment or post secondary education opportunities, but will depend on access to an array of community-based services that will allow the individual to remain in his/her community. In order to adequately address the need to assist students in the transition process and to ensure that students with disabilities have adequate information about community supports available as they move toward adulthood, it is critical that the DARS transition specialists receive training on available community supports and long-term supports and services from TWC, DADS, DSHS, and HHSC.

Interagency collaborative training should include information and resources on long-term services and supports, employment, education, funding/insurance coverage, recreation, independent living, transportation, emergency preparedness, and health care.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #13

HHSC should conduct a longitudinal study in collaboration with other relevant agencies to determine current trends in outcomes for youth exiting high school, analyzing variables such as employment, community integration, health, and quality of life.

Background/Current Status

While pockets of state and national data exist, little is known about youth outcomes in Texas with respect to employment, community integration, and quality of life specifically, which if studied, could yield public policy priorities for youth with disabilities.

Workforce and Youth

We know trends from national research, which indicate a substantial reduction in education attainment and a wide gap in employment, earnings, dependency on public programs and poverty for youth with disabilities. We know that meaningful careers consistent with abilities and interests, effective participation and career preparation, and work-based learning experiences are positive experiences for youth with disabilities. It is well known that obtaining health care insurance with service coverage enables individuals with disabilities to live independently and enter or rejoin the workforce. We have some state data on youth exiting the education system, but little longitudinal data that could help shed light on the bigger picture in terms of what specifically is happening with youth once they are out of the education system.

Community Integration and Quality of Life

The ease with, and extent to which, transitioning youth with disabilities are integrated in their communities are important aspects that influence a quality of life. Some factors include independent living skill development and financial, community, and family support. We know that empowering youth will maximize economic self-sufficiency, independent living, and inclusion and integration into society. Decision-making at the individual and systems levels, ensuring informed choice, providing for self-determination, ensuring full participation, and recognizing self-advocacy are quality of life indicators.

Yet a comprehensive study of youth with disabilities that would give us insight as to the specific trends in outcomes in Texas has yet to be undertaken. It is unclear whether youth with disabilities are successfully transitioning to adult life outside the public school system, are being fully integrated in their communities, are achieving gainful employment, and are living productive lives.

Improving outcomes for youth with disabilities is an essential function of state policy. Independent living and economic self-sufficiency for transitioning youth with disabilities are legitimate outcomes of public policy. Therefore, it is imperative to study current trends in outcomes of transitional youth with disabilities to promote support in their ultimate quest for independence, productivity and self-worth.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #14

Increase supported employment opportunities for youth with disabilities exiting from high school by: 1) increasing training to ensure providers and consumers understand and access currently available supported employment services; 2) increasing cross agency collaboration to maximize existing supported employment resources; and 3) researching best practices from other states to identify ways in which Texas can augment existing supported employment opportunities.

Background/Current Status

Young people with disabilities leaving the school system frequently find there is no coordinated adult system of services and supports to help them find work, housing, and recreational and leisure activities. Many have difficulty finding jobs because they have not gained the academic, technical, and social skills necessary to find and/or maintain employment. Although transition requirements of the IDEA are designed to help students successfully leave school to live and work within the community, too many young adults end up sitting at home with very little involvement in their communities and without jobs. Young adults with disabilities want to work in the community, but they need ongoing support to access and maintain employment. This support is called "supported employment."

Within the past decade, there has been a significant increase in the number of people participating in supported employment. These are individuals who historically were confined to their homes, adult activity centers, sheltered workshops, nursing homes, and institutions. Competitive employment was not likely to be in their futures as long as they participated in segregated employment. The use of trained employment specialists, informed coworkers, mentors, and technological supports, together with enlightened legislation such as the Americans with Disabilities Act (ADA), have greatly enhanced the employment possibilities for people with significant disabilities. Unfortunately, hundreds of thousands of people with disabilities still remain left behind in segregated centers. Many more are on waiting lists for employment services despite the fact that people with significant cognitive, physical, and behavioral challenges have demonstrated their competence in the workplace.

Despite encouraging signs of change, the bulk of day program resources in Texas still serve to maintain people with significant disabilities in segregated work centers. Even though many individuals and their families want integrated employment opportunities, the vast majority have been unable to access the supports they need to make it happen.

DADS has committed staff and monetary resources to participate in the State Employment Leadership Initiative (SELN) that has been offered by the National Association of Directors of Developmental Disabilities Services and the Institute for Community Inclusion. The SELN project is designed to assist DADS in evaluating current supported employment practices, provide ongoing technical assistance and consultation, and link DADS to other states that have solved barriers to expanding and improving employment supports. Ultimately, the goal of this project is to improve employment-based outcomes for adolescents and adults with developmental disabilities.

Action Steps Needed to Implement Recommendation

DADS should continue participation in the SELN project and ensure that consumers and advocates are integral in evaluating current services and solving barriers to expanding and improving employment supports across all DADS programs.

DADS should ensure that competitive employment and the full array of necessary supports are available in the following programs or funding streams:

- ICF/MR program,
- Home and Community Based Services program,
- Texas Home Living program,
- Community Living Assistance and Support Services program,
- Consolidated Waiver Program, and
- Local mental retardation services.

DADS should collaborate with DARS on clarifying roles and responsibilities and in identifying areas for improved communication and collaboration.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #15

Continue and expand Riders 46 and 54 (S.B. 1, Article II, 79th Legislature, Regular Session) initiatives to ensure funding is available for children residing in institutions to have opportunities to transition to families.

Background/Current Status

Due to the developmental urgency of children, it is imperative that the state makes every effort to prevent institutionalization or minimize the length of institutional placements. Research has shown that institutionalization of children negatively impacts all areas of their development. Furthermore, the longer children are institutionalized, the more significant is the negative impact.

To increase opportunities for institutionalized children to return to their birth families or to transition to a support family, the Texas Legislature included two riders in the appropriations bill during the 79th Legislative Session. Rider 46 allows for up to 50 children residing in an IICF/MR to transition to community-based services during the 2006-2007 biennium. Rider 54 directed that \$1.8 million in HCS waiver funding be targeted to children aging out of DFPS foster care, to provide an opportunity for them to remain in families past the age of 18 years.

The funds dedicated to Rider 54 have been exhausted during the first year of the biennium, evidence that the need exceeds the supply. When children with significant disabilities age out of foster care, there is little opportunity for anything but long-term institutionalization unless they have access to a community-based waiver that would provide funding for on-going community care.

In compliance with Rider 46, DADS submitted an amendment to the HCS waiver, creating new waiver slots targeted specifically for children living in an ICF/MR. While the initial intent of this rider was to provide an opportunity to pilot the money-follows-the-person initiative in the ICF/MR program, DADS has decided to use available funding for these children in lieu of creating rules that would allow for decertification of any ICF/MR beds. All 50 slots are scheduled to be used in the current biennium.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #16

The DFPS level of care system and the adoption subsidies for children with developmental disabilities should be revised to ensure that all children with developmental and medical disabilities have access to a family and the necessary supports and services.

Background/Current Status

The current DFPS level of care system does not provide appropriate or sufficient guidance to ensure that children with disabilities in foster care receive the level of care needed to provide appropriate supports and services. While the level of care system was re-designed several years ago, it still does not provide specific direction to enable Youth for Tomorrow staff to consistently assign appropriate levels of care for children with disabilities. The consequences of an inadequate level of care system fall to the children who are not able to receive the services and supports they need.

The level of care system in the DFPS system continues to be driven by a culture that assumes that intense support needs should be considered temporary and that a reduction in that level is to be the expected goal. For children with significant developmental and/or medical disabilities, long term intense supports and services may be necessary to maintain the child's health and well-being.

Additionally, adoption subsidies offered to families willing to adopt children with developmental disabilities do not provide the needed incentives relative to the cost of future care for these children. The health and human services enterprise should review the adoption subsidy rates to design a system that makes it economically feasible for families to adopt children with significant, on-going, and sometimes life-long support needs. Adoption of children at the specialized and intense level of care should be supported through enhanced subsidies, on-going Medicaid services, access to waiver services, and on-going service coordination.

Action Steps Needed to Implement this Recommendation

The DFPS Commissioner should appoint a task force consisting of agency staff, Youth for Tomorrow staff, EveryChild, Inc. staff, adoptive parents of children with significant disabilities, adoption agency staff, and others with a significant interest in ensuring that children with disabilities have the opportunity to be full members of a family. The task force should be charged with evaluating the current system as it relates to children with developmental and medical disabilities and make recommendations for change that will ensure access to the appropriate level of services and create a system that makes adoption a reality for more children with developmental disabilities.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #17

Increase access to adequate family counseling for families raising children with disabilities to ensure healthy families and healthy marriages.

Background/Current Status

Families of children with disabilities may experience extraordinary financial, physical, and emotional stress. Family stress contributes to additional challenges in assuring the best physical, emotional, and overall developmental outcomes for children, especially children with disabilities. The divorce rate for families with children with disabilities is disproportionately higher than the divorce rate for all families. Family stress presents a significant challenge to a family's capacity to continue to care for their child with a disability in their own home. As a result, some children come into state-funded institutional care. In addition, internal family conflicts and pressures often result in siblings requiring services from other agencies or carrying negative family dynamics into their lives as adults.

Currently, children with disabilities must have a mental health diagnosis for families to receive counseling. In most cases, a mental health diagnosis is not appropriate for a child who is medically fragile or who has a significant developmental disability. Private insurance allows diagnoses for parents and/or siblings to receive help, but for those without insurance coverage, there is little to no clinical resource. Family education services are available through some programs, but clinical mental health intervention is not available through Medicaid for family counseling.

CHILDREN'S POLICY COUNCIL RECOMMENDATION #18

Set consistent (higher) standards of providers of Specialized Wheeled Mobility, Seated Positioning, and Related equipment in order to increase agency and provider quality and accountability.

Background/Current Status

This type of equipment was once considered only a simple subset of Durable Medical Equipment (DME). With continued enhancements in technology, a broader range of available specialized products, and expanded applications in the treatment of conditions like scoliosis, diminished respiratory function, and skin breakdown exposure, it has become increasingly essential to ensure that this type of equipment is provided with the involvement of experienced, knowledgeable, and professional providers.

Without the involvement of appropriately qualified and experienced professionals, there is increased exposure to waste resulting from:

- a) Premature replacement of inappropriately specified equipment, and
- b) Ineffective treatment outcomes due to inappropriate applications of equipment.

Additionally, there is the potential, in some cases, of exposing the patient to increased medical risk as a result of inappropriately specified or provided equipment.

Generally within the current Medicaid program, Specialized Wheeled Mobility, Seated Positioning and Related equipment is a covered benefit under Home Health. Under current policy, there are no minimum provider qualifications or restrictions in the provision of this equipment to the Medicaid program other than being registered as a DME provider, which increases the potential for intentional fraud and unethical business practices. The Children with Special Health Care Needs Services Program has established a policy under which a provider of custom equipment must be approved as a specialized provider in order to provide such products within the program, but current policy within this program should be considered a starting point rather than a model.

Other states and state Medicaid programs have established program policies that restrict or otherwise limit provision of certain types of equipment.

Action Steps Needed to Implement Recommendation

HHSC should:

- (a) Develop or identify from existing sources, appropriate credentialing criteria for Specialized Wheeled Mobility, Seated Positioning, and Related equipment providers,
- (b) Identify and implement a cost effective and functional system for ongoing approval and monitoring of qualified providers, and
- (c) Develop reimbursement policies to ensure the availability and involvement of qualified providers when Specialized Wheeled Mobility, Seated Positioning, and Related equipment is identified by the physician as appropriate for the care and well being of the individual.

March 6, 2006

Albert Hawkins
Executive Commissioner
Health and Human Services Commission
4900 N. Lamar
Austin, Texas

Dear Commissioner Hawkins,

The Children's Policy Council has spent considerable time over the past few months developing recommendations to be considered during legislative appropriations request development. These recommendations were sent to HHSC and the HHS agencies last week. In addition to the agency specific program recommendations, we are writing to request that you continue to support expanded funding for existing programs serving children with disabilities and the families caring for them.

We greatly appreciate your efforts during the 79th session to obtain additional funding for waivers that resulted in over 9,000 new waiver slots. We also appreciate the efforts of DADS, DSHS, and DARS to protect funding for programs such as In-Home and Family Support programs, the Children with Special Health Care Needs Program, Children's mental health programs, and ECI. Recognizing that significant unmet needs still exist, we request that you request increased funding for waivers and other programs providing services to children with disabilities to ensure that families are able to keep their children at home.

Texas has made considerable progress over the past several years in addressing the large number of children in various institutions through permanency planning requirements, the family-based alternatives project, as well as targeted funding for children residing in ICFsMR. However, as a result of the long waiting lists for services and the inability of many families to access crucial services, children are still *entering* institutions. We hope that you will strongly support initiatives that increase opportunities for children to receive needed services and allow families to remain intact.

If you would like to discuss this request, please contact me at 232-0754 or by email at colleen.horton@mail.utexas.edu. We greatly appreciate your serious consideration of expanding funding for children's programs and your ongoing advocacy on their behalf.

Respectfully,

Colleen Horton,
Chair

Copies to:

Dr. Charles Bell, Deputy Executive Commissioner
Bobby Halfmann, Director, HHS Systems Budget and Policy
Tracy Henderson, Chief Financial Officer
Addie Horn, Commissioner, DADS
Gordon Taylor, Chief Financial Officer, DADS
Carey Cockerell, Commissioner, DFPS
Eduardo Sanchez, Commissioner, DSHS
Terry Murphy, Commissioner, DARS

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 State Health Services, 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)).