



CHILDREN WITH SPECIAL HEALTH CARE NEEDS

A PLAN OF ACTION



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February 2007

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EXECUTIVE SUMMARY

In an era when federal and state initiatives are aggressively promoting home and community-based supportive living for aging adults and adults with disabilities, children with disabilities are conspicuously overlooked. The quality of their health care, accommodation, legal representation, and services in general is frequently substandard and inconsistent. A large percentage of those children are underinsured. Many experience delayed discharge from hospitals and institutions for lack of access to available home care services. Their families are often unaware of the programs for supports and services their children may be eligible for, and are often burdened with negotiating multiple-agency pathways to get assistance for their children.

Too many Connecticut families confront disturbing choices in order to access health care for their children with disabilities, including an over-reliance on institutional care. Connecticut children with disabilities need flexible options to supplement existing insurance coverage to access better care and conserve state resources.

Families would benefit from initiatives to recruit and retain a well-trained home and community-based workforce that offers creative alternatives to institutional care, and provide information and advocacy to protect their rights. Perhaps most importantly children with disabilities need to be recognized and valued as the children and citizens they are. The development of effective home and community-based services and supports would both meet the care needs of the children and significantly conserve state resources. Through raised awareness and education about who the children are and how they can contribute to their communities, the quality of services and subsequently the children's quality of life will improve drastically.

This report represents the summation of the Child Advocate’s Initiative on Children with Disabilities and Complex Medical Conditions to date. A broad and inclusive coalition of partners has mobilized to explore alternatives to optimize resources, improve access to care, and improve the quality of life for Connecticut children with disabilities and chronic medical conditions. Recommendations have been developed for a comprehensive strategy to improve the circumstances of children with disabilities in the following six priority areas: Access to health care coverage, home and community-based workforce development, integrated child care, legal resources, accountability, and public awareness.

RECOMMENDATIONS

Access to health care coverage and care

A combination of six programs and waivers are presented that will most efficiently and effectively support children in home and community-based settings. They include extending eligibility for SSI, expanding HUSKY Plus benefits, and seeking alternative Medicaid waiver and state plan options. Combining two or more of these options will ensure appropriate health care coverage and home supports for children with maximum subsidies from the federal government. There are states with multiple Medicaid waivers designed to serve different populations of adults and children with disabilities. To ease the administrative burden to the state, pursuing just two options for expanding access to Medicaid is recommended at this time:

- Fully fund all 200 slots on the Katie Beckett Medicaid Waiver.
- Amend the state Medicaid Plan to take advantage of the Medicaid buy-in option of the Family Opportunity Act.

Home and community-based workforce development

- Assess and quantify the unserved and underserved populations of children and their needs for services.
- Assess workforce needs, both professional and paraprofessional.

- Define barriers to development of a willing and able workforce.
- Develop initiatives to attract and retain a well-trained work force.
- Develop administrative supports for home and community-based agencies to enable recruitment and retention of qualified staff.
- Develop supportive educational and training initiatives.

Integrated child care services

- Assess capacity and needs for expanding capacity to serve children with disabilities in Connecticut child care centers.
- Identify funding streams for child care services that accommodate children with disabilities.
- Adjust regulatory language defining “home” for Medicaid-reimbursable home health nursing services.
- Extend benefits in home and community-based waivers or other state plan options for coverage of child care services where health supports are indicated.
- Develop resources for training and technical assistance for child care centers.
- Establish standards of best practice for child care.
- Consider state treasury bond funds for development of integrated child care centers on Connecticut college campuses for combined training and service provision.

Legal resources

- Establish a permanent legal resource following a “center of excellence” model designed to promote best practice through the development of professional standards and guidance, training, advocacy, and information for children, families, and all professionals interacting with them.
- Identify opportunities to broaden the base of legal advocates through recruitment and supportive initiatives.

Accountability

- To ensure accountability and promotion of quality services, transform the family support oversight and advocacy by the Connecticut Family Support Council, housed administratively in the Department of Mental Retardation, into an independent and comprehensive planning, implementation, oversight and accountability structure. The five state agencies that serve children with disabilities would form the Children with Special Health Care Needs Partnership "to improve health care access, quality, and family support for children with disabilities or complex medical conditions."
- The agencies would be mandated to report to an Oversight Council (formerly the Family Support Council).

Public awareness

- Conduct community focus groups to determine prevalent attitudes towards children with disabilities and opportunities for education and raising awareness.
- Conduct a review of public awareness initiatives regarding children with disabilities and assess for designs predictive of positive impacts.
- Develop a comprehensive public awareness campaign to improve attitudes and subsequently services and opportunities for children with disabilities.

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INTRODUCTION

Connecticut is home to a growing number of children with disabilities and chronic medical conditions who require complex long-term care. There were an estimated 118,517 children with special health care needs in Connecticut in 2001, accounting for 13.9% of all children in the state, exceeding the national rate of 12.8%. The quality of their health care, accommodation, legal representation, and services in general is frequently substandard and inconsistent. A large percentage of those children are underinsured (44.2%). Many experience delayed discharge from hospitals and institutions for lack of available home care services. Their families are often unaware of the limited number of state programs for supports and services and are burdened with negotiating multiple-agency pathways to get assistance for their children. The obstacles to services and supports are so enormous that the key program serving this population, (Title V/Children with Special Health Care Needs) may be reaching a mere 13 percent of the eligible population. Too many Connecticut families must confront difficult and confusing choices in order to access health care for their children with disabilities, including an over reliance on institutionalization. Consequently, Connecticut children with disabilities and complex medical conditions, particularly those from middle-income families, are at an increased risk of receiving poor health care. Further, the public's lack of understanding of, and expectations for, children with disabilities and complex medical conditions interferes with their ability to participate in their communities and achieve their full potential as individuals.

This report represents the summary of the Child Advocate's Initiative on Children with Disabilities and Complex Medical Conditions. The Child Advocate mobilized a broad and inclusive coalition of partners to explore alternatives to optimize resources, improve access to care, and improve quality of life for Connecticut children with disabilities and chronic medical conditions. The Coalition made recommendations for a comprehensive

strategy to improve the circumstances of children with disabilities in six priority areas, including access to health care coverage, home and community-based workforce development, integrated child care, legal resources, accountability, and public awareness.

Since the Office of the Child Advocate issued a report in 2001 outlining deficiencies of services to children with disabilities and chronic medical conditions, circumstances have not improved (Office of the Child Advocate, 2001). The 2001 report also identified problems of fractured state systems and the lack of a single point of entry for information or support services. Subsequent and ongoing investigations by the Office of the Child Advocate discovered what appears to be a substandard level of care for those children with disabilities or chronic medical conditions who were in the custody of the state. School attendance, recreation, and socialization were found to be consistently lacking among these children, while the health care provided to them did not routinely meet standards or pediatric professional guidelines.

The death of Leeana C. in April 2004 underscored the lack of professional oversight and quality of care that had become all too common with this population of children. Leeana C. was just turning three years old when she was placed in a large group home where the licensed practical nurses did not know how to manage her tracheotomy (Department of Children and Families, 2005). Her tracheotomy became obstructed with mucous and she suffocated. Observing the pattern of substandard care exemplified by the Leeana C. case, the Child Advocate determined that a major initiative is necessary to ensure the safety and well being of all children with disabilities and chronic medical conditions.

The Child Advocate's initiative began with two public meetings featuring national disability experts. The events were designed to raise awareness and engage a broad community in addressing the problem. Harriet McBryde Johnson, an accomplished attorney, author, and disability rights advocate who herself has a disability, invited the community to understand her own experience living with disabilities. She emphasized

that we need to appreciate all the possibilities and acknowledge the impossibilities of a child with a disability (McBryde Johnson, 2006). Robert Williams, a former Deputy Assistant Secretary with the U.S. Department of Health and Human Services, who also has a disability, stressed the impact of current economic trends that challenge all families, noting that since the recession started in 2001, nearly one fifth of all American workers have been laid off. Mr. Williams noted the competing needs of families of children with disabilities and the rest of the community. He challenged communities to take two approaches. First, given the competition for tax dollars, families would have to engage and convince the rest of the community that their children with disabilities are worth investing in, and the community at large would have to see value in the lives of the children. Second, Mr. Williams urged a focus on efficient use of our limited resources, the development and maintenance of an adequate and stable work force, and optimal use of every supportive subsidy available to the state (Williams, 2006).

Next, the Child Advocate convened multidisciplinary working groups to address four principal factors affecting the circumstances of children with disabilities and chronic medical conditions: access to health care, workforce development, legal resources and public awareness. Each group was asked to outline related alternatives for enhancing the health and wellbeing of children with disabilities and chronic medical conditions. The Child Advocate's working groups have shown remarkable commitment and productivity. In preparation for the 2007 Session of the General Assembly, their focus has been on immediate infrastructural opportunities, specifically regarding access to care. Alternatives to supplemental health insurance and issues of workforce development are being assessed. A coalition of legal experts and consumers has begun designing a permanent source of legal technical assistance, education, and advocacy. Developing public awareness campaigns to influence attitudes towards children with disabilities and their families will be a long-term complex effort.

In an era when federal and state initiatives are aggressively promoting home and community-based supportive living for aging adults and adults with disabilities, children are conspicuously overlooked. Connecticut children with disabilities need flexible options to supplement existing insurance coverage to access better care and conserve state resources. They could benefit from initiatives to recruit and retain a well-trained home and community-based workforce; creative alternatives to institutional care; and information and advocacy to protect their rights. Perhaps most importantly children with disabilities need to be recognized and valued as the children and citizens they are. The development of effective home and community-based services and supports would both meet the needs of the children and significantly conserve state resources. Through raised awareness and education about who the children are and how they can contribute to their communities, the quality of services, and subsequently the children's quality of life will improve drastically.

A Note About Terminology

This report addresses the circumstances of children with disabilities and complex medical conditions. Such children are also described as children with special health care needs, special needs children, or medically fragile children. For ease of narrative flow, a combination of descriptions is used throughout this report but the population referred to is the same. We have made every attempt to focus on children as children and not diagnoses or conditions, through the use of people-first language, avoiding "special needs children" or "medically fragile children" and encourage others to do the same.

ACCESS TO HEALTH CARE COVERAGE AND SERVICES

Advancements in technology and improved survival rates of children with congenital and acquired conditions have resulted in a large and growing number of children living with disabilities and chronic medical conditions (Mentro, 2003; Wegner et al., 2006). For the families of these children, their long-term and complex medical care needs present considerable financial burden. In 2005, four out of five American adults indicated they believed the government should help pay for health and long-term care services for people with disabilities and chronic health conditions when they are not able to pay themselves (Henry J Kaiser Foundation, 2005). Responses also suggested that three-quarters of Americans (76%) believed that all people who have disabilities are eligible for Medicaid. (Henry J Kaiser Foundation, 2005). In reality, many children with disabilities and chronic medical conditions are not eligible for Medicaid.

While the general public perceives a social obligation and is willing to assist people with disabilities, the misunderstanding about eligibility for Medicaid underscores how little is known about the circumstances of individuals with disabilities and how little public policy reflects public intent. In a study of the 2000 Medical Expenditure Panel Survey (MEPS) data, Newacheck and Kim (2005) noted that children with special health care needs incurred three times the expenditures and twice the out-of-pocket costs for health care than do typical children.

Generally, eligibility for the public insurance program is based upon the income of legally liable relatives. The eligibility criteria require parents with financial means and access to private or employer-sponsored commercial health insurance to utilize those resources. However, commercial insurance frequently has caps or limitations of coverage for health care services. The expense of uncovered complex medical care and long-term services can devastate a family's finances. This accounts for a large number of the underinsured children in Connecticut. According to the National Survey of Children with Special

Health Care Needs, 44.2% of Connecticut children with special health care needs were uninsured or underinsured in 2001. Newacheck and Kim (2005) concluded that while insurance is helpful, it is not a complete protection from potentially overwhelming out-of-pocket expenditures.

CURRENT OPTIONS FOR COVERAGE OF HEALTH CARE COSTS

There are several options for health care coverage for children in Connecticut, depending upon family income, employment, and a child's functional status: private or employer-sponsored commercial insurance, Medicaid, and the State Children's Health Insurance Program (SCHIP). However, each is limited in its ability to meet the needs of children with disabilities or chronic medical conditions:

- Private or employer-sponsored health insurance plans often have restrictions and caps on specialized services, including the number of home care visits or expenditures, typically 60 visits or \$5000 per year (Wegner, et al., 2006). There may also be restrictions of coverage based upon diagnosis versus medical necessity.
- Medicaid (HUSKY A) offers comprehensive coverage for all medically indicated services and equipment due to the application of early periodic screening, diagnosis, and treatment (EPSDT) mandates of federal law (Wegner, et al., 2006). Home care, including extended (shift) nursing care, is a covered service. However, there are restrictive income eligibility criteria. Connecticut families must have income below 185% of the federal poverty guideline to qualify for Medicaid (United Way of Connecticut, 2006).¹

¹ The federal poverty guideline varies with the number of people in the family. In 2005, for a family of 4, the HHS Poverty Guideline was \$19,350, making 185% approximately \$36,000.

- SCHIP (HUSKY B)² offers comprehensive coverage to all children who are otherwise uninsured with some premium-based cost to families with income over 235% of the federal poverty level. HUSKY B is administered through managed care organizations and caps certain services and expenditures. There is no coverage for extended nursing care at home. HUSKY Plus is a supplemental benefits package for children with special health care needs whose family income is under 300 % of the federal poverty level. It covers some additional specialized services but not extended home care (United Way of Connecticut, 2006).

Access to Medicaid

Due to its level of coverage, Medicaid is the most desirable insurance from the point of view of benefits for children with disabilities. The federal government provides matching funds to Connecticut at a 50/50 ratio to state funds expended through Medicaid (Centers for Medicaid and Medicare Services (a), 2006). Medicaid reimbursement rates in Connecticut are problematic for many providers however, and will be discussed in the workforce section of this report. There are options to make Medicaid available to persons with higher incomes who would not typically be eligible through “waiver” agreements that expand eligibility criteria. There are also options to use Medicaid funds flexibly to cover home and community-based services (home and community-based waivers) for eligible persons who would otherwise be institutionalized in order to receive adequate care (Centers for Medicaid and Medicare Services, 2006). Waivers are not considered new or additional cost factors. A requirement of waiver agreements is that states must demonstrate that the cost of home and community-based care would be the same as or less (cost neutral) than an institutional placement (Lutzky et al., 2000).

² The State Children's Health Insurance Program (SCHIP), created by the Balanced Budget Act of 1997, enacted Title XXI of the Social Security Act and allocated about \$20 billion over five years to help states insure more children.

The family income limit of 185% of the poverty level to be eligible for Medicaid and the restrictions of Connecticut's Medicaid waivers significantly limit the number of children with disabilities who are eligible for Medicaid health coverage. An alternative potential access to Medicaid is through eligibility for Supplemental Security Income (SSI) that is available to children and adults with disabilities. Eligible children must meet disability and family income criteria. In most states, children who are eligible for SSI are automatically enrolled in Medicaid. The State of Connecticut is one of few states holding 209(b) status, meaning that the state uses a different definition of disability and different criteria for Medicaid eligibility than for SSI. However, the 209 (b) criteria require that the state allow families to "spend-down" their income on medical costs to the "medically needy income limit" in order to become income-eligible for Medicaid (The Lewin Group, 2001). The spend-down is the only current alternative for families to access Medicaid for their children without a waiver, but the medically needy income limit is drastically low and devastating to family stability. It is also re-evaluated periodically and eligibility is rescinded when family income rises again.

Connecticut has three waivers that can be applied to children including the Katie Beckett Waiver and two Home and Community Based Services Waivers administered by the Department of Mental Retardation (DMR HCBS Waiver).

The Katie Beckett Waiver, Deeming Waiver, or 2176 Model Waiver

This waiver is available to children based only upon the individual child's income and not that of the legally liable relatives. An eligible child must also have a disability or chronic medical condition that would otherwise require institutional care. Connecticut has funded only 180 of the federally allowed 200 authorized slots for children on the waiver. There is a waiting list of approximately 3-5 years. Although individual annual expenditures for each child on the waiver vary greatly, the average annual expenditure among all the Connecticut children in FY 2004 was only \$1,517 (Smith, 2006). The individual variation reflects the use of Medicaid as either primary or secondary insurance by enrollees. Some

families have barely utilized the Medicaid coverage, relying on their primary commercial insurance. Budgeting for the waiver is burdensome as the federal government only reimburses 50% of expenditures after the state demonstrates that the money has been spent (Smith, 2006). The state must allocate 100% of expected cost up front in order to have funds available to pay for services rendered. This ties up state resources significantly, even though a large portion of reserved funds will not be spent.

The DMR Home and Community Based Services Waivers (HCBS)

These waivers are available only to Medicaid-eligible clients of the DMR. Eligibility criteria include an intelligence quotient of below 70. Eligible children may enroll with a DMR HCBS Waiver to access flexible Medicaid funding for individualized home and community-based services. However, there is an extended waiting list for DMR services. Also, in order to apply for a waiver or any services through DMR, a child must first be assigned a DMR case manager. There is a waiting list for caseworkers and the department only serves children when funds are available (Department of Mental Retardation, 2005). The requirement of mental retardation and the large waiting lists considerably limit the range of this option.

NEW OPTIONS FOR ACCESS TO HEALTH CARE

Given that public opinion supports assisting children with disabilities accessing their care, and the need to maximize the effective, efficient use of state and federal funding, the state of Connecticut should consider several available options to improve access to comprehensive health care coverage for this population. The Child Advocate acknowledges efforts in Connecticut to develop options for universal coverage. However, even within a universal plan, it will still be critical to optimize the use of federal subsidies available to the population of children likely to utilize more health care services than their typical peers. A combination of six programs and waivers or waiver expansions are

presented that will most efficiently and effectively support children in home and community-based settings.³

- Fully fund the Katie Becket Waiver for children with severe disabilities and direct those with less intensive needs to alternative waivers or programs. All 200 slots authorized for the Katie Becket Waiver should be fully funded to include coverage for 20 more children. However, simultaneously with the development of new alternative waivers, the Katie Beckett waiver should be reserved for children with the most severe disabilities and complex care needs who are dependent upon technology. This would free up slots on the waiver that are taken by children who are not requiring the full benefit of the waiver but have no alternative supplemental options and provide for those children who will fully utilize the Medicaid coverage because of the severity of their needs (Johnson, et al., 2006).
- Combine SSI and Medicaid eligibility so all children who meet the disability criteria for SSI will automatically be eligible for Medicaid. The state should abandon 209(b) status and opt to enter into a “1634 agreement” with the Social Security Administration (SSA). Such an agreement combines SSI and Medicaid eligibility. Connecticut would adopt the same definition and eligibility criteria for Medicaid as for SSI. The SSA would then process all applications and determine eligibility for both SSI and Medicaid. All children eligible for SSI would automatically be eligible for Medicaid. (The Lewin Group, 2003). This option would make Medicaid available to more low-income children with disabilities, but it does not address the underinsured children from middle income families.

³ The reader is referred to *The Child Advocate’s Report on Improving Access to Care for Children with Special Health Care Needs: State Health Insurance Options* for complete details on three previously identified specific waiver and state plan options for Connecticut (Johnson, et al., 2006).

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- Expand HUSKY Plus supplemental benefits package and extend to families with incomes over 300% of the federal poverty level through a buy-in premium-based option. The HUSKY B and HUSKY Plus benefits packages could be updated to better reflect service needs of this population of children, including, for example extended home nursing care. Additionally, eligibility for the program could be extended to include families with middle to upper income who have insurance but are underinsured. They could buy-in to the program through a premium-based option. Either of these two options could be developed under a Section 1115 Research and Demonstration Project. Demonstration projects allow states to test policy initiatives promoting the original intent of SCHIP, which is: to improve health care for all American children (Centers for Medicare and Medicaid Services (b), 2006). An arrangement such as this has not been attempted by any other state. The most attractive benefit of using SCHIP funds is the slightly higher federal match assistance percentage (FMAP) at 65/35 ratio versus the Medicaid 50/50 match. In application for such a project, Connecticut would have to negotiate the expanded benefits and eligibility but it could be an option that increases access to those children with inadequate coverage despite family income. The buy-in premium would make the program somewhat self-funded although the state would still be exposed to financial risk. With the additional coverage, families would access help with care giving and would more likely be able to maintain their employment. As a result the state would benefit from uninterrupted income tax revenues in addition to savings on potential institutionalization costs. With access to health care coverage and therefore health care services for their children, families will be more likely to maintain their employment. Because this is a new and untested approach, approval from CMS is uncertain, as would be the timeline for implementation.

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- Apply for a 1915(c) waiver to complement the Katie Becket waiver that would target underinsured children with less complex care needs. A separate type of 1915(c) waiver could target underinsured children whose special health care needs are less complex than those of children directed to the Katie Becket Waiver and whose families' incomes exceed Medicaid eligibility. States must demonstrate cost neutrality of each 1915c waiver, yet the advantages incurred by both the State and its citizens can be substantial. Kansas, New York and Vermont offer clear examples of the potential financial savings of home and community based waivers: "\$12,900 per child for home and community-based services in Kansas (2001), \$23,344 in Vermont (2001), and \$40,000 in New York (2001), as compared to per child institutional costs per year of \$25,600 in Kansas, \$52,988 in Vermont and \$77,429 in New York" (Geballe & Langer, 2005, p. 10). While the process of determining cost-neutrality can be time-consuming, it provides an estimate of state costs. States have the option to expand the array of services offered under a 1915c waiver and include such services as home health aides, transportation, medical equipment, environmental modifications, and medically supervised day care. States have a great deal of control in designing a waiver, both in terms of the services and the eligibility requirements. These requirements can vary greatly as exemplified by Illinois and Georgia where coverage extends to children who are dependent upon technology or considered "medically fragile", and to individuals less than 21 years who depend upon a ventilator or oxygen, respectively. Due to the mandatory process of involving public input in the development of a waiver application, there is public awareness concerning the waiver's availability, something often cited as lacking in Connecticut. Overall, 1915c waivers allow considerable state control, design flexibility, and public advocacy (Johnson, et al., 2006). This waiver could require primary coverage through private or employer-sponsored insurance with Medicaid intended as payer of last resort only. Sliding scale premiums could supplant overhead costs. The existing

Katie Beckett waiver has been passionately sought by families and advocates and has served children well but would be more effective if an alternative waiver were available to support those children with less intensive needs such as those able to use SCHIP funds as described above.

- Opt for a state plan option under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) to extend Medicaid eligibility to children who meet the SSI definition of disability regardless of their legally liable relative's income. Abandoning the 209(b) status as described above would expand eligibility for Medicaid to all SSI-eligible children and would open the pathway to a TEFRA option for an alternative access to Medicaid if not through a different 1915 (c) waiver. This program is available to children with special health care needs who are not eligible for SSI benefits due to their parents' income or resources; only the child's finances are used to determine eligibility. TEFRA provides the full range of services covered by Medicaid to children who would otherwise require an institutional level of care (intermediate care facility-MR, nursing facility, or hospital care), but live at home. Twenty States currently use the TEFRA option to provide comprehensive Medicaid coverage to underinsured children with special health care needs. While TEFRA covers a similar population as the Katie Beckett waiver, it is a state plan option not a waiver and thus has no extraneous limits (Oklahoma Health Care Authority, 2006). TEFRA covers a relatively small number of children, averaging only 1,230 children per state with a wide range from 10 to 4,300 children. Since many children have other insurance options, TEFRA is the payer of last resort; a study in Minnesota found the cost per child for Medicaid was only \$8,100 (Bazelon Center for Mental Health Law, 2002). TEFRA creates an entitlement for all children who qualify ensuring that no child is excluded based on limited State resources, medical diagnosis or another arbitrary reason. To take

advantage of the TEFRA option, Connecticut would have to discontinue the 209(b) state option (Johnson, et al., (2006).

- Include children in the current proposal for the Money Follows the Person Demonstration Project and develop community-based supports for those currently institutionalized. Public Law 109-171, the Deficit Reduction Act of 2005, contains two significantly promising options for assisting children with disabilities to access appropriate care. The first is the Money Follows the Person (MFP) Demonstration Project. The purpose of the MFP projects is to continue to support the deinstitutionalization of people through home and community-based services. This is another potentially flexible use of Medicaid funds to support individuals living in the least restrictive settings of their choice. Covered benefits include live-in care givers, homemakers, case management, and professional home care services. Eligible individuals must have lived in a Medicaid-funded inpatient settings for no less than six months and continue to require the same level of care. Inpatient facilities are defined as hospitals, nursing facilities, intermediate care facilities for people with mental retardation (ICF/MR) and institutions for mental disease. Services provided in the project must be self-directed by either the individual or the individual's authorized representative. The state of Connecticut, through the Department of Social Services applied for this project in November 2006 for a target population of 700 people of all ages phased in over five years (Department of Social Services, 2006). Qualified residences where beneficiaries may be served include homes, apartments or group homes that accommodate no more than four unrelated individuals. Children with disabilities who are residing in hospitals, nursing homes, ICF/MR, and residential treatment facilities could benefit from this option in moving back to their own homes or communities. Although the federal law is clear that children are covered by this option, as acknowledged in the Connecticut DSS proposal, the design of the Connecticut

program appears to target an elderly population. Proposed staff for the program would be housed in an agency for the aging and recruitment would focus on nursing homes. Membership on the steering committee does not reflect any expertise or advocacy in the pediatric population. The MFP demonstration could serve children well through flexible funding of services such as day care or personal care attendants where highly skilled staff is not required but vigilant care is. However, it would only apply to the children who are already living in institutions and may not be useful as a deterrent to such placements. An attractive feature of the MFP demonstration project is an enhanced federal match assistance percentage (FMAP). Paragraph (5) of Sec. 6071 (e) indicates that the FMAP will be increased by up to 25% of cost for Connecticut, or a 75:25 federal-state ratio of Medicaid expenditures. This would be a higher rate than even the SCHIP 65:35 match.

- Amend the State Medicaid plan to adopt the Family Opportunity Act allowing families to purchase Medicaid coverage. A second promising option under Public Law 109-171, the Deficit Reduction Act of 2005 is the Family Opportunity Act, also known as the Dylan Lee James Act. It includes a state option to allow families of children with disabilities to purchase Medicaid coverage for such children.⁴ There are no income limits on this option, although the federal government will only match Medicaid expenditures for families whose income is below 300% of the poverty level. A child would need to meet SSI-defined criteria for disability. Parents are required to participate in employer-sponsored health insurance when available and where the employer pays at least 50% of the premium. A uniform sliding scale Medicaid premium would be established by the state based upon family income with parameters: no more than 5% of family income where income is less than

⁴ Chapter 6, Section 6062(a).

200% of poverty level and no more than 7.5% of family income where family income is greater than 200% of the poverty level. States may opt to reduce Medicaid premiums to reflect premiums paid on employer-sponsored insurance. The state may also pay the employer-sponsored insurance premium and/or waive the Medicaid premium where “undue hardship” is noted. The buy-in option affords a flexible use of Medicaid coverage as a supplement to underinsured families and gives children access to comprehensive health care in a home setting. The Medicaid FMAP of 50%, however, is not as attractive as the SCHIP 65% federal match. Extending the option to families in income brackets greater than 300% of the poverty level, even with self-funding premium fees, would place the state at financial risk. This provision does not require a waiver but would require legislative action to amend the state plan or create the covered group. The buy-in to Medicaid option established through the Family Opportunity Act can be available to families with a broader range of income. Even though there is no federal match for children whose family income is over 300% of the poverty level, it does represent an avenue to cost savings if institutionalization and complete dependence on Medicaid and state custody are avoided. Administratively the buy-in option does not require a

- waiver and therefore may have less initial administrative burden to the state.

TABLE 1. Coverage Options			
OPTION	TARGET	INCOME LEVEL	FMAP
1634 Agreement (Abandon 209b)	SSI-eligible	Below 185 % POV	50
SCHIP Husky Plus Wrap-around	Underinsured	All incomes	65
Money Follows the Person	Medicaid-funded Institutionalized	Below 185% POV	75
Katie Becket Waiver	Severe disabilities	All incomes	50
FOA Medicaid Buy-in	Underinsured	Below 300 % POV Above 300% POV	50 None
TEFRA Option	Underinsured	All incomes	50
1915 (c) Waiver	Underinsured	All incomes	50

RECOMMENDATIONS

There are states with multiple Medicaid waivers designed to serve different populations of adults and children with disabilities. The State of Connecticut has limited its waivers for children to just the three: the Katie Becket Waiver and the two DMR Home and Community Based Service Waivers described above, two of which restrict eligibility by intellectual disability. While adding several waivers is clearly an option, and would maximize the number of children served, the administrative burden of developing and overseeing six to eight waivers in one year could be unreasonably taxing. Funding the full 200 slots in the Katie Becket Waiver would extend services to 20 more children without administrative burden and should be pursued. The other two best options for the time being are the Medicaid buy-in through the Family Opportunity Act and the SCHIP demonstration project. The higher federal match of an SCHIP program is most attractive but the uncertainty of approval and the unknown timeline present disadvantages for a population of children in immediate need. The Family Opportunity Act option was approved and promoted by the federal government. It also only requires an amendment to the state plan so has minimal administrative burden for establishment. Therefore, in addition to fully funding the Katie Becket Waiver, it is strongly recommended that Connecticut amend the state plan to take advantage of the Medicaid buy-in option in the Family Opportunity Act. In the context of a dialogue regarding universal health care all of the above-described options should continue to be considered for incorporation in a state plan. Optimizing any and all federal match on the cost of health care coverage will be critical for high users of health services, including children with disabilities and complex medical conditions.

HOME AND COMMUNITY-BASED SERVICES

The Kaiser surveys that revealed the public's sense of obligation and willingness towards assisting those with disabilities sets a tone for action. This sense of social justice is by no means separate from the demand for efficiency in social welfare programs during unstable economic times. It is clear that children with disabilities are at risk for poor quality care and inappropriate long-term placement separate from their families. The recent trend to institutionalize children is contrary to all that has come to be understood about the value and cost effectiveness of home and community-based care. It is also remarkably in conflict with current policy to return to, and maintain, adults and elderly persons in the community. Perhaps this divergence can be explained by a general lack of knowledge about the experience of children with disabilities.

Support for children with disabilities accomplishes more than access to quality care and nurturance of optimal growth and development. Support for children with the right mix of services can result in parents maintaining stable family environments, employment and continued contribution to a community's tax base. Support for children with disabilities is the equivalent to the effect of the Ticket to Work and Work Incentives Improvement Act (P.L. 106-170) that has enabled adults with disabilities to return to work without losing health insurance and care services (U.S. Senate Committee on Finance, 2003). Parents caring for children with disabilities could similarly benefit. Connecticut state policy reflects the commitment of home and community-based care expressed by the federal government but the absence of that same commitment to children is notable.⁵

⁵ The State of Connecticut has made a strong commitment to deinstitutionalize elderly and adult citizens with disabilities through legislative initiatives and development of home and community-based supports, services, and funding streams. Access to skilled and unskilled caregivers, adult day care, transportation and other innovative community-based services has been facilitated through flexible use of Medicaid funds (Department of Social Services, 2006). Similar efforts on behalf of Connecticut children have been significantly lacking. Among the several state agencies serving children with disabilities there is no comprehensive strategic plan or commitment to ensure access to home and community-based living with in-home services and supports.

Children delayed in neonatal and pediatric intensive care units are at high risk for the complications of nosocomial infections and developmental delays. Maclean (2003) conducted an extensive review of the literature and found that institutionalization has significant negative effects on child development in all realms. The author noted studies conducted as early as 1945 that identified progressive deterioration of physical, emotional, intellectual, and social development among institutionalized children. Children delayed in hospital units also monopolize those services and resources from other acutely ill children and create a back-up of service access. Connecticut has only one sub-acute pediatric unit in a rehabilitation hospital. The 30-bed unit has become a permanent placement for 10-15 children. With the exception of a very small number of families receiving funding through the Department of Mental Retardation (DMR) to self-direct (independently contract for caregivers and services) necessary care for their children with mental retardation, there are no avenues of direct family financial support. The only options are to access Medicaid through a family asset spend-down or a small number of Medicaid waiver options and hope that home care staffing will be available. Families face dismal options of persistent impoverishment, institutionalization, or loss of custody just so a child can maintain eligibility for Medicaid (US Senate, Committee on Finance, 2003). The final alternative is through neglect petitions and transfer of custody of a child to the State Department of Children and Families (DCF).

In DCF care, the future may be even more dismal for children with disabilities. The agency has neglected development of community based foster care and appropriately sized group homes to accommodate these children. Instead they have relied upon a few overcrowded foster homes and group homes that have up to 12 children with competing complex medical needs. The exact number of children with disabilities in placement is not clear. DCF maintains a “*Medically Complex Children in Placement*” database. As of December 2006, 403 children were included in the database, with 95 recorded as being

placed in institutional settings (Department of Children and Families, 2006). The number of children recorded in the database may not accurately reflect the number of children with disabilities or complex medical conditions in DCF care. All children's DCF files should contain a medical profile. On those profiles there is a field for categorizing a child as "medically complex." The only children who are included in the Medically Complex database are those for whom the field for medically complex on the medical profile is checked off. Unless a DCF resource nurse or medical professional is involved in a child's case and has influenced the documentation, the data collection relies upon non-medical DCF caseworkers to assess children's medical conditions and accurately categorize their needs. Furthermore, the categorization of "medically complex" is not equivalent to the Social Security Administration's definition of disability. Therefore it is not all-inclusive and may not capture the children with disabilities who have been placed in institutions, including the approximately 400 such children placed out-of-state at the time of this writing.

WORKFORCE DEVELOPMENT

Home and community-based health care services can initially be divided into professional services and para-professional services. Each group has distinct educational and training needs as well as regulatory or licensing obligations. Typical home and community-based professionals include nurses, physical therapists, occupational therapists, speech therapists, respiratory therapists, psychologists, social workers, and behaviorists. Para-professionals may include home health aids, homemakers, child care workers, personal care attendants, therapeutic mentors, and respite workers.

Even with optimal health care coverage, the shortage of appropriately trained and willing home and community-based providers is a persistent obstacle to children with disabilities living at home. In the case of children who are dependent upon technology, the presence of competent and reliable staff is most critically appreciated. A shortage of pediatric home health care providers further complicates access to care for children with disabilities

and chronic medical conditions who require assistance to live at home. In recent years, the shortages of nursing and ancillary staff and limitations on reimbursement have caused a number of home care agencies to drop pediatric services nationwide (Wegner et al., 2006). Haight, Gauthier & McCourt (2006) surveyed Connecticut home care providers and identified only 14 of 70 respondents who provided extended shift care for pediatric clients. In an earlier study, 31 percent of Connecticut families surveyed reported that they had not received needed and authorized home care services for their children (Matrix Public Health Consultants, 2003). Even with insurance coverage, if there is no access to home health care services then parent/caregivers are fully responsible for sometimes round-the-clock care of their children. In cases of children with complex and intensive needs, their care may interfere with parents being able to work. The 2001 National Survey reported that more than 28 percent of Connecticut families of children with special health care needs experienced a family member leaving employment in order to provide care to the child (Mentro, 2003). Subsequent financial strain can be catastrophic to a family.

Insufficient insurance coverage and a shortage of appropriately trained and adequately reimbursed home care staffing are major factors in determining whether a child with disabilities can even live at home (Balinsky, 1999; Mentro, 2003; Wegner et al., 2006). Despite demonstrated cost effectiveness and recognition of the more appropriate developmental setting being found at home with family (Wegner et al., 2006), an increasing number of children experience delayed discharges from acute and sub-acute hospitals or are placed in institutions for long-term care.

RECOMMENDATIONS

The Child Advocate's working group on home and community-based work force development determined work force development should be addressed on several levels. First there must be an assessment of the necessary infrastructure: types of services available; capacity of service agencies to recruit and retain staff; factors affecting

recruiting and retention such as reimbursements and overhead; workforce training; and education resources. Next, the actual workforce needs must be understood in terms of roles, functions, necessary training and preparation, and salary and benefits.

The home and community-based work force shortage is a consequence of several factors, including low wages, lack of benefits, difficult work, and lack of training. As cited previously, limitations on rates of reimbursement have caused many agencies to drop pediatric services. The administrative burden required to operate as a Medicaid certified agency is also perceived by many providers as overwhelming and costly. Strategies to develop a competent, adequate workforce will have to include initiatives for training, reimbursement, and administrative supports. Definitive information about the children and their needs, data that continues to elude state agencies serving children with disabilities, will have to be collected and analyzed in order to best develop a workforce to serve them.

The Child Advocate's working group on work force development has outlined several priority steps.

- Single, consolidated annual data collection and reporting across the relevant state agencies. This effort might be coordinated through or with the Medicaid Managed Care Council. Current data is not reported in a regular, comprehensive way that allows Connecticut to have a clear picture of the population, family needs and trends, and progress in achieving family/self-directed care (including home-based care).
- Assessment of work force needs in all levels of care: professional and paraprofessional.
- Development of initiatives to attract qualified personnel to all levels of care including educational loan forgiveness programs, subsidized benefits packages, training and educational programs, and improved reimbursement rates and salaries.

- Examine opportunities for integrating concepts of home and community-based care into current training and educational programs.
 - Identify settings and supports for practical or clinical rotations.
 - Develop post-graduate specialty curricula.
 - Develop a colloquium of care inter-agency training and in-services resource among home care agencies, schools, hospitals and other providers.
 - Include family and informal caregivers in training opportunities.
- Develop opportunities for shared resources among provider agencies.
 - Shared case management between home care agencies (requires regulation change).
 - Share para-professionals between school, home, and respite.
 - Seek respite providers among all of a child's providers.
- Ensure a process of determining care for each child that begins with a family's determination of its own needs. There should be checks in the system to ensure that this is happening and that self-direction continues throughout the process.
- Improved benefits and wages for workers.
- Results-based accountability throughout the system to ensure that actual, measurable progress toward meeting the needs of children with disabilities is made.
- Seek best practice models to develop new or improve current home-based provider agencies in regards to quality of care, consistency of able staffing, adequate salaries and benefits, engagement of families, and high level of client and staff satisfaction. The "Family Lives" Massachusetts model has been suggested as a prototype.

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- Pursue specific home care regulatory changes through multi-department re-drafting of regulations that haven't changed since 1982.

INTEGRATED CHILD CARE SERVICES

The 2000 U.S. Census indicated that 63% of children under the age of five were spending up to 37 hours in some form of child care (non-maternal care) predominantly because women were returning to work (Smith, 2002). The need for child care among families exists for all children regardless of ability. But Booth-LaForce and Kelly (2004) noted in a comparison of typically developing children that children with disabilities were more likely to utilize informal relative child care than the center-based care their typical peers were using. The authors expressed concern that relative care could be less beneficial for lack of socialization and integration with typical peers, particularly in terms of preparing for transition to school.

The Americans with Disabilities Act of 1990 mandated that child care facilities accommodate children with disabilities so long as the accommodation does not present “undue burden” (significant difficulty or expense) (Gil deLaMadrid, 1996). Yet a large number of child care providers in Connecticut and throughout the country do not provide such accommodation. Most cite the lack of training to meet special care needs of children with disabilities (Booth-Laforce & Kelly, 2004; Gil de LaMadrid, 1996; Fewell, 1993). The State of Connecticut has endeavored to assist with ADA compliance through the availability of state bond funds for structural renovation including the building of ramps and widening of doors. But structural accommodation does not address the challenge of staff training needs and cost of increased staffing ratios. Children with disabilities often require more intensive staffing ratios yet child care providers are not able to adjust rates to offset the cost of extra staff.

The Child Advocate's working group has obtained a grant to conduct a brief feasibility study for expanding child care capacity to serve children with disabilities in Connecticut. The study will examine the availability of child care providers willing to integrate funding sources, staffing needs, expertise and training needs, and other factors affecting access such as transportation and structural adjustments. The working group will also review best practices and identify standards and guidelines to be integrated into initiatives for integrating child care services. Fewell (1993) reviewed successful programs in the United States and proposed guidelines for integrated child care. The author identified several factors that influenced successful integrated programs:

- Leadership
- Family involvement in developing programs
- Track record of high quality child care
- Positive attitudes among staff towards integration
- Funded technical assistance for center-identified needs
- Consultative entity that took responsibility for conducting assessments, developing child-specific programming, and evaluating quality of care. This service addressed the "undue burden" of program development and evaluation (Fewell, 1993).

As with health care services, funding is a key ingredient in successful access to child care services. The Medicaid waivers and state plan options like the SCHIP HUSKY Plus program may provide this funding. The state has several Medicaid waivers that cover the expense of *adult* day care programs yet, remarkably, there is no coverage of child care. The federal waivers allow states to be flexible in meeting the unique needs of their populations (Ducket & Guy, 2000) and could be broadened in Connecticut to do so.

Even without the benefit of a waiver, standard home care services, including nursing and personal care could be directed to a child care setting. There is discrepancy in the interpretation of "home" in home care and Medicaid reimbursement for services rendered

in a child care setting. The state of Connecticut did clarify the definition for Medicaid reimbursement so children can take their benefit to child care (Public Act 06-188,§50). However, the language limited that interpretation only to those children covered by HUSKY A, the Medicaid managed care insurance program and neglected those children on straight Medicaid through a waiver.

Proposed legislation in the current 2007 session would expand the applicability of the definition. The US Court of Appeals made it clear in *Skubol v. Fuoroli*, 113 F .3d 330 (1997) ruling that it is unreasonable to define home health nursing services as only those provided in a recipient's home. The court ruled that a child entitled to a number of hours of service coverage should receive the hours of service wherever they may be provided.

WORKFORCE DEVELOPMENT

Workforce development for child care staff is incorporated in general workforce development initiatives for home and community-based services. An additional consideration is the integration of workforce education and practice. To that end, making state treasury bond funds available for the development of integrated child care centers on state and community college campuses could be an opportunity for practical experience in service provision as a class requirement. The home and community-based workforce shortage will not be readily resolved. While solutions to the lack of in-home supports are being sought, alternatives must also be considered. The option of child care services with capacity to serve children with disabilities has been largely overlooked.

The Child Advocate's working group on workforce development recognized that one alternative to effective use of available and appropriately trained community-based providers is to ensure flexibility of settings where care is provided to children with disabilities. Child care settings represent opportunities for efficiencies of scale in shared resources. More importantly, they provide a developmentally appropriate integrated setting where children benefit from socialization and peer activities. To that end, the work

group proposed initiatives to expand the number of child care facilities with capacity to serve children with disabilities.

RECOMMENDATIONS

- Assess capacity, and needs for expanding capacity, to serve children with disabilities in Connecticut child care centers.
- Identify funding streams for child care services that accommodate children with disabilities.
- Adjust regulatory language defining “home” for Medicaid-reimbursable home health nursing services.
- Extend benefits in home and community-based waivers or other state plan options for coverage of child care services where health supports are indicated.
- Develop resources for training and technical assistance for child care centers.
- Establish standards of best practice for child care.
- Consider state treasury bond funds for development of integrated child care centers on community college campuses for combined training and service provision.

RIGHTS OF THE CHILD: LEGAL RESOURCES

The legal rights of children encompass more than just mandates for education, eligibility for subsidized insurance or even right to life. While these issues are key, the plethora of activities and mix of professionals who come in and out of a child's life all have legal interests and liabilities. First and foremost, the legal rights of children and their families should be made clear and resources to best inform them should be readily available. The interpretation of those rights should also be available in the form of technical assistance to inform and educate children, families, providers, and other persons in the children's circle of support. Information about avenues for justice and protection, including the availability of advocacy and supports, is necessary. Just as important is information about the legal obligations and liabilities of professionals who are engaged in caring for, or representing, children's interests. It must be available and widely disseminated in order to ensure well-informed decision-making and best practice in pursuit of a child's best interest and desires. Information about the legal obligations of state systems and the federal mandates that affect availability of options to states in order to provide services and supports for children should be available and scrutinized. Providers also have related interests in being fully informed of legal liabilities. Wang and Barnard (2003) identified concerns about liability as an obstacle to nurses choosing to care for children with complex medical needs at home.

There are a number of federal mandates that affect and protect the lives of children with disabilities, some of which were previously discussed. In regard to promoting home and community-based services, the Olmstead decision linked the intent of legislation and advocacy expressing the rights of people with disabilities to be a part of their communities. In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the ruling affirmed the right of individuals with disabilities to live in their communities. Judge Ginsberg determined that placement in an institutional setting for long-term care of a disability was a form of

isolation and such, “unjustified isolation...is properly regarded as discrimination based on disability” in violation of provisions of the Americans with Disabilities Act (*Olmstead*, 527 U.S. at 597). The circumstances of institutionalized children are frequently overlooked in the dialogue about institutionalization, but its effects on their health and development can be profound. This is why specific protections exist, including the Individuals with Disabilities Education Act, 20 U.S.C. 1400, *et seq.*, which mandates a free and appropriate public education in the least restrictive setting. The residential placement of children in institutions for care and treatment frequently prohibits access to least restrictive educational settings. In *Connecticut Association for Retarded Citizens, Inc (CARC) v. Gareth Thorne et al* (Civ. A. No. H-78-653), CARC challenged the care, living conditions, and the residential placement of the individuals with mental retardation who were residing at the Mansfield Training School. The resulting consent decree set the policy and practice of the Department of Mental Retardation (DMR) to support individuals in community settings. Perhaps because the DMR does not have a mandate to serve children, there was no similar application to protect children from institutionalization.

The inconsistencies between federal and state mandates underscore the necessity for legal resources for Connecticut children with disabilities and the professionals in their lives. The Child Advocate’s working group on the legal rights of the child proposed two initial strategies to establish permanently available legal resources to children and the professionals who serve them. First, the group proposed a gathering of stakeholders to assess specific needs and map out a long-term strategy for developing a statewide resource. Participants should include but not be limited to youth, families, advocates, state agencies including the Judicial Branch, law schools, legal services, health care providers, and educators.

The ultimate goal will be to establish a permanent entity of legal resources, technical assistance, and advocacy with the purpose of assisting children and their families, training

professionals, and promoting expertise regarding children with disabilities and their special rights. A “center of excellence” model would serve as a primary source of professional development, guidelines, and standards of practice.

RECOMMENDATIONS

- Establish a permanent legal resource following a “center of excellence” model designed to promote best practice through the development of professional standards and guidance; training; advocacy; and information for children, families, and all professionals interacting with them.
- Identify opportunities to broaden the base of legal advocates through recruitment and supportive initiatives.

OVERSIGHT AND ACCOUNTABILITY

At least five Connecticut state agencies administer services to children and their families. Among those five agencies state coordination is almost non-existent. There is no established chain of communication or inter-agency response system. No state program is adequately reaching the population they are intended to serve. Only about 13 percent of eligible children are served by the Department of Public Health's Title V Children with Special Health Care Needs Program – a care coordinating, service supplemental program funded by the Federal Maternal Child Health Block Grant. A 2001 estimate of 118,517 Connecticut children with special health care needs identified by the National Survey far exceeds the 15,440 children the Department of Public Health reported serving in 2004 (Maternal Child Health Bureau, 2006). The lack of a single point of entry and the confusion associated with poorly described sources of information result in an inaccessible system. Establishing a system with clear goals, coordination, and accountability would be a giant step toward improving the future for children with disabilities and their families. In the absence of a centralized system, a single source of oversight will foster a transition to a more functional and effective system.

In effort to understand options for services, oversight, and accountability among state agencies serving children with disabilities, the Office of Legislative Research was engaged to report on structures within other states. One such report, "Governance Structure Models for Children with Special Health Care Needs Programs" (2006-R-0682, Nov. 2, 2006), identified a variety of state models, including the Kentucky Commission for Children with Special Health Care Needs. That commission operates clinics for children with disabilities throughout Kentucky.

Rather than create or move programs out of existing state agencies, the Child Advocate's Working Group determined that the most feasible and immediate option for improving

services for Connecticut children was to improve oversight and accountability of existing Connecticut programs. The group has proposed the transformation of existing family support oversight and advocacy by the Connecticut Family Support Council, housed administratively in the Department of Mental Retardation, into a comprehensive planning, implementation, oversight and accountability structure. The proposal models the statutory mandate of the existing Behavioral Health Partnership and its oversight council. In this language, the five state departments would form the Children with Special Health Care Needs Partnership "to improve health care access, quality, and family support for children with disabilities or complex medical conditions." The departments would report to an Oversight Council (formerly the Family Support Council) made up of family members, state legislators and other officials, a pediatrician, a mental health provider, and leaders from the health insurance, nursing, and business sectors. The Oversight Council would be co-chaired by a family member and a state legislator. It would be housed in the legislative branch, as are the oversight councils for Behavioral Health and Medicaid Managed Care.

RECOMMENDATIONS

- To ensure accountability and promotion of quality services, transform the family support oversight and advocacy by the Connecticut Family Support Council, housed administratively in the Department of Mental Retardation, into an independent comprehensive planning, implementation, oversight, and accountability structure. The five state agencies that serve children with disabilities would form the Children with Special Health Care Needs Partnership "to improve health care access, quality, and family support for children with disabilities or complex medical conditions."
- The agencies would be mandated to report to an Oversight Council (formerly the Family Support Council).

PUBLIC AWARENESS

A common characteristic of most cultures in the 21st Century is the value for ability. Humans walk, talk, eat, lift, get dressed, run, and play. When circumstances are otherwise, whether by accident of birth or life, there is a tendency to make every effort to rehabilitate, to “make whole” again, to make “normal.” Historically, those who could not gain or re-gain full physical functioning were cast off or hidden in back rooms or institutions. The attitudes that shunned those persons persist today (Gething, 1992). There is a tension regarding the value of life when a person has complex medical needs or severe disabilities with the intense care and support that is required. Reflecting concerns regarding strained health care systems, officials of the Church of England incited renewed debate recently when they “argued that the high financial cost of keeping desperately ill babies alive should be a factor in life or death decisions.” (Sears, 2006). Similar dialogue is occurring in Connecticut. A November 2006 Hartford Courant article quoted a Connecticut physician suggesting “[p]eople worry that we are saving a baby's life only to condemn them to a life of handicap.” (Waldman, 2006).

This kind of dialogue neglects the perspectives and personal experiences of people with disabilities. Despite the laws established to protect and accommodate them, people with disabilities, including children, commonly experience social isolation, discrimination, inadequate health care, and marginalization (Lillesto, 1997; Smeltzer et al, 2005). The Child Advocate’s Public Awareness Working Group focused on the action steps necessary to increase public awareness about the value and abilities of children with disabilities. The importance of engaging whole communities in a renewed conversation was stressed. One method may be to use focus groups to explore community attitudes and knowledge about children with disabilities or complex medical conditions and subsequently develop a plan to promote public awareness and education. In addition to engaging and raising awareness among the general public, all actions for change will target the continuum of

people who are involved with children from the moment of birth and throughout all stages of a child's life. Those are the people in the best position to influence how families perceive their children and how communities welcome them.

The initial phase of this work includes a review of similar efforts, either community-driven or publicly mandated, around the globe. This will include an assessment of details of initiatives that predict success in achieving raised awareness and changes in attitude toward people with disabilities. Resources for conducting focus groups and consulting with marketing experts are being sought and partnerships in the initiative established. The long-term goal will be to develop a comprehensive public awareness campaign designed to improve attitudes towards children with disabilities with subsequent improved quality of care and life experience. The first action step will be the identification of audiences and the development of specific efforts for specific audiences. The public education message will include a detailed illustration of what it means to live with a disability, emphasizing each individual's potential and their ability within disability. This should include a plan to document the stories of people with disabilities and make them available to the public, building on the success of the recent CPTV series *Able Lives* a program that explores the lives of Connecticut citizens living with disabilities. The Group also recommended the need for a central information resource that could provide information access to a wide audience and that all information should be fully accessible to those with limited reading and language skills.

RECOMMENDATIONS

- Conduct community focus groups to determine prevalent attitudes towards children with disabilities and opportunities for education and raising awareness.
- Conduct a review of public awareness initiatives regarding children with disabilities and assess for designs predictive of positive impacts.
- Develop a comprehensive public awareness campaign to improve attitudes and subsequently services and opportunities for children with disabilities

A FINAL WORD AND ACKNOWLEDGMENT

The work of the Summit on Children with Disabilities was a beginning in devising strategies to adjust public infrastructure to better support and integrate children with disabilities and complex medical conditions. Identifying and implementing changes in service delivery, funding, and program development may be the easiest leg of the journey. The real challenge is making a change in how we as a community--as advocates, doctors, politicians, teachers, parents, neighbors and the guy standing in line at the grocery store--value every child and see the gifts and contribution of every child as a member of our community. The Office of the Child Advocate and the wide range of committed partners in this initiative will continue to engage communities across Connecticut to promote the value of all children regardless of ability.

The Child Advocate would like to acknowledge the commitment of so many partners to the initiative on behalf of Connecticut children with disabilities and complex medical conditions. Remarkable partnerships have developed in this initiative and we apologize for any partners that we missed from the list below.

Advanced Wheels	Center for Children’s Advocacy: Medical Legal Partnership
AFCAMP	Communitas
AJ Papanikou Center for Excellence in Developmental Disabilities Education, Research & Service	Connecticut Association for Home Care
All About You Home Care	Connecticut Behavioral Health Partnership
Autism Spectrum Resource Center	Connecticut Birth to Three
Ben Haven	Connecticut Children’s Medical Center Violence Prevention Program
Boys and Girls Club	Connecticut Commission on Children
Carolyn Cartwright	Connecticut Family Support Council and Family Support Network
Carrie Berman	

Connecticut Health and Educational Facilities Authority	Klingberg Family Center
Connecticut Lifespan Respite Coalition	Sarah Liebskind
Connecticut Public Television	Manchester Community College
Connecticut Women's Education, and Legal Fund	Members of Connecticut General Assembly
Council on Developmental Disabilities	Medicaid Managed Care Council
Department of Public Health	National Center for Boundless Playgrounds
Department of Children and Families	New Canaan Special Education
Department of Mental Retardation	Nora Groce
Department of Social Services	Office of the Healthcare Advocate
Department of Education	Office of Policy and Management
Sarah Dunion	Office for Workforce Competitiveness
FAVOR	Office for Protection and Advocacy for Persons with Disabilities
Goodwin College	Quinnipiac Law School
Groton Parks & Recreation	Robert Perske
Hartford Public Schools	Saint Joseph College
Hospital for Special Care	St. Vincent's Special Needs Services
Harriet McBryde-Johnson, Esq.	United Electrical Workers
Jewish Association for Community Living	Universal Health Care Foundation
Kids as Self Advocates	Robert & Helen Williams
Klebanoff & Alfano, P.C.	Yale School of Nursing

A special thanks also to those who committed their expertise, time, and energy to assisting the writer, Assistant Child Advocate Moira O'Neill, with editing this report:

Thomas Brooks, Commission on Children

Terry Cote, Department of Mental Retardation

Carolyn Des Rochers, Office of the Child Advocate

Christina Ghio, Office of the Child Advocate

Elysa Gordon, Office of the Child Advocate

Julia Rusert, A.J. Pappanikou Center of Excellence for Developmental Disabilities

Victoria Veltry, Office of the Health Care Advocate

Faith Vos Winkel, Office of the Child Advocate

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