

Feasibility Study of a Project of Supportive Housing for Families of Children with Complex Medical Conditions



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Executive Summary

This study assesses the feasibility for a project of supportive housing for children with complex medical conditions and their families including available on-site nursing care. The study grew out of concerns that a shortage of home nursing care and accessible affordable housing, forced children with complex medical conditions to remain in hospitals long after they could otherwise go home and, in some cases, families unable to obtain consistent nursing care in their homes were forced to yield custody of their children to DCF.

An advisory committee convened to explore whether there was interest among parents in the concept, collect families' input on project design and services needed in such housing, collect provider and other stakeholder input on the idea, search for similar national models, and evaluate the feasibility of the concept.

Parents surveyed were universally enthusiastic about the concept, very willing to move the entire family into such a project, and eager to give input. Parents report severe difficulty in accessing consistent nursing care in their homes and accessible, affordable housing appropriate to their families' needs. Critical services include care management and childcare that accepts children with complex medical conditions. Parents want some control over operations of the complex, however are not prepared to be responsible for day-to-day decisions. Parents stressed the need to hire staff with experience caring for children with complex medical conditions and a sincere commitment to work with parents and respect for the capacities of families. Nursing staff also emphasized the importance of working together with families to develop and implement successful care planning.

Recommendations of the report include creating a facility to serve eight families with a full-time care manager and an associated medical center with on-site nursing care available. Parents remain each child's primary care givers. Options included at the request of families include an associated childcare center that serves children of all abilities, an accessible playground and purchase of a wheelchair-accessible van. Design parameters important to parents and nursing staff, governance, service administration eligibility and eviction standards, avoidance of community resistance, special education funding, and implementation recommendations are also included.

Cost analysis of the feasibility of such a complex predicts significant state savings compared to DCF custody, hospitalization or even moderate community nursing care in individual homes, primarily through the use of shared nursing resources. Capital costs are moderate, ranging from \$2.5 to \$3 million for housing, with small additions to include the childcare, accessible playground, and transportation options. Potential funding sources are explored.

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Introduction

This study assesses the feasibility for a project of supportive housing for children with complex medical conditions to live with their families in a setting providing centralized access to medical services.

This feasibility study arose out of two sets of concerns. Providers and families have reported that some children with complex medical conditions were remaining in hospital settings long after they were medically appropriate for discharge to home because their families could not arrange consistent skilled nursing care at home, despite the fact that sufficient hours were approved by the state¹. The other concern, raised by Department of Children and Families (DCF) staff, was that some families were forced to relinquish custody of their children with complex medical conditions for similar reasons². There are other reports from families of avoidable hospitalizations of their children with complex medical conditions that were caused by the inability to find consistent nursing care.³ An advisory committee was formed to explore the potential for a housing complex including accessible, affordable housing for families with an associated medical center providing skilled nursing care available to all families living within the housing development. Members of the advisory committee are listed in Appendix A.

The need and the costs of care now

There is currently no comprehensive data on the numbers of children with complex medical conditions, their needs, their costs of care, or, in fact, agreement on a definition of children with special health care needs. However the purpose of this study is to assess the feasibility of a small pilot program, total numbers are not necessary. The goal is to determine if there are enough children and families in Connecticut who could benefit from such a housing arrangement and are willing to move in with the rest of their family, what services would be necessary to improve the lives of these families, and whether the project would be cost-effective for the state.

Of the 25 to 27 children staying at a Connecticut hospital on a recent visit, between 10 and 12 could be eligible for and could benefit from supportive housing.⁴ A typical case description will illustrate the costs of care for these children. A baby boy, born prematurely, was admitted to an acute care hospital at 5 months of age with a narrowing of his upper airway. He needed significant care

¹ Personal communications – Dr. John Pelegano, Hospital for Special Care, Public Health Committee Roundtable on Community-based Services for Children with Special Health Care Needs, Jan. 24, 2002

² Personal communications, DCF staff, *Report on Coordination of Services to Children with Special Health Care Needs*, OPM, et. al., April 2002

³ *Public Health Committee Roundtable on Community-based Services for Children with Special Healthcare Needs*, Jan. 24, 2002.

⁴ Personal communications – Dr. John Pelegano, Hospital for Special Care.

in the Pediatric Intensive Care Unit for 31 days, care which could not have been delivered at home. After a month, his condition was stabilized and he was eventually transferred out of the PICU to the hospital floor where he remained for another 53 days. His pediatrician estimated, conservatively, that the last 40 days of his hospital stay would not have been necessary if appropriate community services were available. He was eventually transferred to another hospital, where he remains over a year later⁵. At per diems rates of \$1,848 and \$899.37 at the two hospitals⁶, it is estimated that the costs of care for this child to date are \$476,838 above what would have been necessary if appropriate community services were available to his family. The annual costs of care for a child at the second hospital total \$328,270. It is important to note that these costs are federally reimbursable under Medicaid, so the net cost to the state of caring for a child is \$164,132.

There are currently 459 children in DCF's custody identified with special health care needs including 23 in out-of-state placement and 104 in institutional custody in Connecticut, including several at acute care and other hospitals. From 1999 to 2002, the number of children with complex medical conditions in DCF's custody has doubled⁷. DCF reports a significant shortage of foster families licensed to care for children with complex medical conditions.⁸ The needs/diagnoses of the children with complex medical conditions in DCF's care vary widely including HIV/AIDS, Down's Syndrome, spina bifida, prematurity, prenatal alcohol and/or substance exposure, shaken baby syndrome, hydrocephalus, mental retardation, multiple sclerosis, neurological impairments, asthma, cardiomyopathy, cerebral palsy, hepatitis, and various developmental delays. Equipment and drug needs vary from none to extensive technology and pharmacy needs. Needs include ostomy care, home oxygen use, daily feed tubes, clean intermittent catheterization, insulin-dependent diabetes, continuous positive airway pressure without a trach, prematurity, wound or burn care, intensive pulmonary treatments, oral feeding difficulties, communication and adaptive equipment needs, gastroesophageal reflux with apnea spells and/or chronic lung disease, frequent overnight hospitalization, daily respiratory or cardiac monitoring, dialysis care, central line care, tracheostomy care and/or ventilator use, complex multiple drug regimens, terminal illness care, pre- and post-transplant care and total care for neuro-impaired children.⁹

Board and care costs for the children with special needs in DCF's care averaged \$16,911/year for the 198 children whose costs could be identified. The range in costs were from -\$42 (a recoupment of overpayment) to \$164,252/child. It is likely that these are underestimates as costs for children in institutional and/or

⁵ Dr. Robert Zavoski, CCMC

⁶ DSS

⁷ Report of the Collaborative Task Force, 2002.

⁸ DCF communications

⁹ database of children with special health care needs, DCF, and *Coordination of Services to Children with Special Health Care Needs*, OPM et. al., April 2002

grant-based care could not be determined and are reportedly the most complex and most expensive cases. It is unclear how much of DCF's Board and Care costs are federally reimbursable.¹⁰

It should be noted that programs caring for children with complex medical conditions have significant waiting lists. Connecticut's Katie Beckett Medicaid waiver program currently has 125 slots, all full, with over one hundred children on the waiting list.¹¹ Katie Beckett waivers allow children with severe disabilities who would otherwise require institutional care to be eligible for community and home-based care under Medicaid regardless of their parents' income. In addition to the basic Medicaid benefits package, waiver participants receive care management services including client assessment, care coordination and monitoring.¹²

While the costs of care to the state for these children is very high, it is important to recognize the costs to families. Families with special needs children often pay a significant amount out-of-pocket for their children's care; 9% to 12% of total family income is not uncommon. The costs are typically for services or equipment not covered by insurance or for costs above an insurance policy's lifetime benefit cap.¹³ A study of service utilization by children with special health care needs in commercial managed care found that parents paid 7% of the costs of care for their children – 17% of the costs of primary care and 7% of specialty care costs.¹⁴ According to a 1999 GAO report, ten percent of families with children receiving SSI for disability-related services spend more than the maximum allowable under SSI. This data "does not include services families needed but did not purchase because they could not afford them."¹⁵ In a national survey, nearly two thirds of parents of children with special health care needs reported that they had reduced their hours of employment or stopped working completely to care for their child. Half the families reported facing financial hardship in meeting their child's needs.¹⁶

National models

Despite an extensive search, no national examples or models of programs similar to this proposal were found. Dozens of sources were contacted (see Appendix B), email inquiries were posted on national listservs and bulletin boards,

¹⁰ personal communication – Karl Kemper, DCF

¹¹ Personal communication – Sharon Garrett, Marie Vitorelli DSS

¹² *Homecare for Seriously Ill Children*, OLR, 12/3/02.

¹³ P. Szilagyi, *Care of Children with Special Health Care Needs*, The Future of Children, Spring 2003.

¹⁴ H. Ireys, et. al., *Children with Special Health Care Needs in Commercial Managed Care: Patterns of Use and Cost*, Mathematica Policy Research for HRSA, Sept. 2002

¹⁵ SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services, GAO/HEHS-99-99, June 1999.

¹⁶ *What Do Families Say About Health Care for Children with Special Health Care Needs*, Family Voices, April 2000

and a literature review was conducted. Some models offered instructive features that are incorporated within this report.

Results

Parent input

The advisory committee began this study with direction to first poll parents of medically fragile children to determine if there is interest in the concept of the project (“If we build it, will they come?”). Once it was clear that there is overwhelming interest from parents in the concept, parents were asked for specifics to drive the program’s development and design. Parents were asked what they would like the project to look like, how it should be run, what services need to be included and what is important in hiring staff for the center. The interview guide, attached in Appendix C was administered to 35 parents of children with complex medical conditions – both in a large group and individual interviews, both English and Spanish speakers.

First, it is important to note parents’ reactions to being asked for their input, especially at the inception of the project. Reactions were strongly positive and ranged from excited, enthusiastic, articulate floods of information, to parents who were almost stunned to be asked their opinion. Clearly this was a new experience for most. Some parents at the group interview missed work to come listen and give input. The group asked for future updates on the status of the project, stayed long after the meeting to ask more questions, offered to review the draft of this report, and left their addresses to get copies of this final report. All were very generous with their time; several called and emailed days after the interview with more ideas and thoughts. The two parents who were not interested in moving in were also enthusiastic about the project and felt that it was an important option to offer other families.

Probably the most compelling theme across all conversations with parents was their feeling that they are not heard or understood – by providers, by agencies, by care managers, by government, by the people who are there to help them. A related theme was isolation – a deep feeling of being all alone. Feelings of “not being heard” came up over and over. One parent said, “No one listens. They nod their heads, but they don’t listen.” Living with families in similar circumstances in a setting that focused on their family’s needs was very appealing.

In response to the question of whether parents felt strongly that the project should be integrated – should include housing units for families without medically complex members -- one third didn’t care either way, but two thirds felt that the project should only include families with children with complex medical conditions. Concerns included a need to ensure that their child’s needs do not get lost, that the project focus on the challenges they face, and these families’ experiences. A common theme was that “other people don’t get it.”

All but two are interested in moving into the project based on the concept of accessible housing with associated nursing care on-site. Some were very interested; several parents asked where they could apply and how soon it would be available to move in. Many families are desperate – and as the interviews progressed, it became clear that the nursing shortage is only part of the problem; finding accessible affordable housing is at least as big a barrier to caring for their children, for many low-income families. Virtually every respondent also noted the need for childcare, especially childcare that will serve children with complex medical conditions. This was also noted in a report by OPM and other executive branch agencies on Coordination of Services to Children with Special Health Care Needs (April 2002); “Consistent child care support is a critical service in order for families to remain employed and productive in their communities in addition to caring for their children.” Most are still living with their children in the community, three have children in the hospital right now, one has lost custody to DCF and would like to get her child back.

Descriptive statistics on family circumstances¹⁷		
Housing	Own	1
	Rent	16
	Live with relatives	1
Housing costs	Avg. \$379.47/month, excluding the one who lives with relatives and pays nothing	
	High \$650/month	Low \$55/month
	4 offered that they are on Section 8	
Does your housing meet your family's needs?	Yes	3
	No	14
	The largest problems were lack of accessibility and needing more space, in that order	
Income	Avg. \$17,189/yr	
	High \$30,000/yr (two)	Low \$0 – looking for work
Health insurance	Medicaid	12
	Private insurance	2
	HUSKY B	2
	None	2
Child's medical needs	Severe	13
	Moderate	4
	Mild	0

¹⁷ Not all parents answered each question.

Interviews were also conducted with over 20 foster parents caring for children with complex medical conditions, both in individual and group interviews. None of the foster parents were interested in moving in, but their input was helpful in program and site design.

When asked if moving their other children to a new home and possibly a new school was a concern, several stated that they have moved many times to accommodate their child's needs and that this project might provide some stability for their family. Others noted that the reduction in stress on parents would benefit the whole family. A few commented that it would be better if they could stay in the same city or town, if possible. Some parents expressed a hope that the project might make life easier for their other children, who would not feel that they are the only family they know or the only child on their school bus with a brother or sister with special needs.

Degree of child's disability

The parents interviewed all have children with serious disabilities. All the parents interviewed had just a single child with disabilities. Most, but not all, had other children living in the home, up to 3 others. Medical conditions included cerebral palsy, AIDS, mental retardation, seizures, asthma, serious allergies and nutritional needs, apnea, and lots of respiratory infections.

Difficulty getting nursing care, quality of services, feelings of control/loss, registering complaints

Virtually all parents who are approved for nursing care have had trouble getting approved hours filled. Weekends are harder than weekdays. The only parents who hadn't experienced problems were a few with children in the hospital who have not yet had them home (since birth or since they became disabled), but most knew that this would become a problem. Children are often readmitted to the hospital because parents cannot get the help they need at home and become overwhelmed.

Own vs. Rent

All but one parent now rents where they live, but many were interested in eventually buying a home. Several at the support group suggested a rent-to-own option for the project. One felt that if parents own the units, they would be more invested in the success of the project.

Parents noted a crushing need for affordable housing. Sliding scale rents were suggested. The high cost of appropriate, accessible housing was a common theme.

Setting

Most parents wanted the project to “fit into the neighborhood” and emphasized that it should look like a home rather than an institution. No one wanted a large complex that looks like a housing project. Many argued that it should stay small – “not a big apartment building”. Several were very concerned about their privacy.

When asked about urban vs. suburban settings, most preferred it be close to a city, but not downtown. This preference was relatively soft – there was lots of discussion about the pros and cons of either. A safe neighborhood was stressed by several parents. A quiet neighborhood was preferred by the support group -- not on a busy street.

Accessible playgrounds/playscapes were mentioned often – with swings. Several parents preferred a private yard for their kids and a garden. One parent thought it would be nice to be in a place where you could take the kids for a walk, maybe to a park. Getting everyone in and out of the car is so difficult, that they don’t go out as much as she’d like.

Most preferred the model of separate, one-floor houses in an existing neighborhood to other models. A plan with a central medical unit physically connected to each apartment was the least attractive to parents. Several wanted a variety of sizes, different numbers of bedrooms available in the project. “Families don’t all come in one size.”

A good school system was important to virtually all parents. Many noted that having stores nearby and being close to their child’s hospital and doctors was important. “You never know when you’ll need milk.” One parent wanted it close to the hospital, but “not too close, we spend enough time there.” One (very definitive) parent said that the hospital should be within 20 minutes by car and an hour by bus. One noted the need to be close to a pharmacy – this has been an issue in several places she has lived. Several noted the need to be close to family, not only for social support but also as critical respite caregivers. Also mentioned were being close to church, parks, and an ice cream place. A few wanted it to be convenient to bus routes but others said that didn’t matter; most have cars.

Services available

Almost every parent noted the need for help in coordinating services – both in “arranging everything” and in identifying resources -- to help with the “huge juggling act” that takes over their lives. Several parents described care coordination as their full time job, more demanding even than providing their child with care. Support services needed include help in making appointments, arranging transportation, liaison to schools, and identifying resources. “I just

learned that you can have diapers delivered if your child is incontinent. I didn't know that. Someone who could keep track of those things would make a big difference."

Some parents asked for training to help them better care for their children and access to a professional for questions who is close by. One asked for help keeping track of her son's medications.

Respite was also raised as a very large need for parents. The ability to take a few hours or even a day or two to recharge was noted by many parents. Nighttime coverage was often noted as a serious problem. One parent said, "I can't remember the last time I slept through a whole night. Not for years." But some parents said that other times were more critical – such as feeding times.

During discussion, the need for help with stressed out families became clear. Support should be broadly defined and not limited to assistance for the special needs child and their medical services. Assistance should include services that support parent employment and improve school adjustment for siblings, to ease stress on the whole family including the medically complex child. Both formal support groups and more natural ways to communicate and share experiences were emphasized. Families describe support groups as being critical to their "mental health" despite the fact that it is very difficult to get to them. Several parents mentioned the need for grief counseling. Families often say that they learn far more about resources and approaches to help their children from other parents than from any other source.

No parent volunteered a need for recreational opportunities, but almost all liked the idea when it was offered, many with suggestions. Several asked for activities in which all family members could participate. A visiting massage therapist was enthusiastically endorsed. Many offered the idea of an adoptive grandparent program – several knew of successful programs and others felt that this would be an important way of building positive relationships with the community.

Childcare

Offering childcare services as part of the project drew very strong positive responses. The employment of every parent surveyed has been affected by an inability to find appropriate childcare and/or nursing care in the home. Many cannot work outside the home, but several desperately want to. Several stated that if they had reliable childcare for all their children, they could continue their education and improve their families' financial health.

Childcare staff with experience in caring for children with complex medical conditions and their families was critical. Parents were generally positive about the idea of including community children in the center as long as their children had guaranteed spaces. One was interested in "helping out" at the childcare

center and suggested that it be a way for parents to support the project. The need for after school and vacation options for older children was mentioned often. Homework help and access to computers was also mentioned.

Staff issues

Some expressed concerns about the quality of care their children had received in various settings. Many stated that they were their child's best caregivers, but didn't always feel that professionals recognized that. A willingness to work with parents and respect that they know their child better than anyone, to tolerate differences, and understand the realities of their lives was strongly noted by many parents. Several parents discussed learning to "pick your fights and what to let slide". By and large, parents understood that they needed to learn this lesson as well as caregivers.

Parents seemed genuinely puzzled by the question of whether they have any control over who cares for their child. Most never even considered that they might have a say; most were just happy to have anyone come. One noted that when she complained to the agency about a caregiver, they were very responsive and understanding about her concerns, however it took two weeks to find another caregiver. It is important to note that in a survey of parents of special needs children in HUSKY, among those who felt a need to file a formal complaint about their child's care, only 45% actually filed a complaint.¹⁸

When asked what they saw as important for project staff – the majority cited experience working with children with complex medical conditions and a willingness to listen to families. No particular degrees or other qualifications were mentioned.

Many noted disappointment with care managers assigned to help them. One mother said, "I need a care manager just to coordinate all my care managers." Many felt that the workers' first loyalty was to the agency, institution or program that employs them rather than to the families they serve. Several noted that care managers rarely cross program lines and only offer help in accessing the services provided by the entity for whom they work.

Governance

Parents were told that similar projects in other states fall on a continuum between parents having total control over the project including choosing the site, purchasing the property, planning and directing renovations, hiring and managing staff and an agency controlling the entire project from beginning to end and parents have to appeal to the agency for input. Most parents preferred something closer to an agency than self-control. They strongly wanted input into decisions

¹⁸ *Children with Special Health Care Needs Enrolled in HUSKY Part A: Survey to Assess Access to Care and Satisfaction*, Children's Health Council, December 2000.

but did not want significant responsibility. One parent summed it up with “I don’t have time or energy for anything extra.” Others noted that there will inevitably be disagreements between families on critical issues and having an independent third party in charge could help diffuse those conflicts.

Most liked the idea of a regular advisory group of parents having a significant role in running the project. The support group came to consensus that the parent advisory group should be elected by the parents. The group has to have a substantive role in running the project, or as one parent put it “it would be just like fighting with the insurance company.” There should be regular, two-way communication with parents about operations, new proposals, upkeep, etc. Parents wanted a good system for addressing grievances – both about care for their children and in operating the project (e.g. parking, smoking, loud parties, barking dogs, trash).

Other issues

Clear understandings among parents of their roles, their rights and their responsibilities in the project were seen as critical. The large group debated what kinds of behaviors would get you kicked out of the project, can you do that if they own the unit?, what to do if the medically complex child no longer lives there or no longer needs that level of care, exit planning, what if people don’t pay the rent, how to decide who gets in, and several other weighty issues. Maintenance was a big issue for many parents. Living in a “nice” place with rules that are enforced was important.

Several parents also stressed good community relations – many had heard of problems at group homes. Building good relationships with emergency services was a priority.

Input from providers and other stakeholders

Nurses and social support staff caring for children with complex medical conditions and their families

Interviews were conducted with over a dozen nurses and social support staff (see Appendix A). Nurses included those in Connecticut and from other states, working in hospital, group home and nursing settings. A copy of the Memorandum of Understanding between a community nursing agency and clients that is the product of years of experience is attached in Appendix D.

A nurse who used to run a community nursing agency shared a very moving letter of thanks they received from a parent’s employer (Appendix E). Finally getting consistent care for his son had allowed the parent to become a more productive and satisfied worker than he had been before his son’s illness.

The importance of accommodating the needs of staff was emphasized, not only because of the current nursing workforce shortage, but because they must feel supported and respected to provide the best care to children and their families. Great emphasis was placed on respect and feeling part of a team all working to provide the child with the best care. Salary needs were not primary.

Important issues for nursing staff include, in no particular order:

- Mutual respect with parents
- Having a staff lounge where they can relax, with a bathroom
- Clean, pleasant, bright work environment
- Flexible hours and scheduling
- Good benefits – health, paid time off, retirement
- Safe location
- Good two-way communication with parents – easy to talk, keep updated on child’s status
- Plenty of time available to help parents learn how to care for their child, to answer and ask questions
- Written, comprehensive understanding with parents about the nurses’ role – including
 - Nurses are not babysitters for other kids
 - Nurses are not housekeepers
 - Nurses want to work with parents, but will not compromise the child’s health in any way -- “our license is on the line”
 - Collaborate to develop treatment plans
 - Then everyone sticks to them
 - Explain how scheduling is done, how time is allotted, when the schedule is set
 - Schedule a month ahead so families can plan
- Clear protocols of care
- Clear definitions of what staff perform which functions – RNs vs. LPNs vs. CNAs
- Separate staff who develop care plans and monitor care from those who carry out the treatment plans and provide direct care services
- Clear procedures for emergencies
- Extensive back up planning
- Hire nurses who are comfortable working with parents, flexible
- Respect family confidentiality and privacy
- Nurses are not responsible for providing transportation
- Both nurses and families have the right to refuse to work together under certain conditions
- Continuity of relationships
- Opportunities to expand skills and move up the career ladder
- Continually reassess the program and each case, modify practices to address needs and improve care

- Listen to nurses in design and implementation, reward creativity
- Create a team environment

Most staff were not positive about offering respite services for community families not living in the project. One group home visited offered short-term respite services over several years for one child at a time. Despite the huge demand from families they were forced to end the service because it was unworkable both for staff and for the children who live in the home permanently. Having one slot in the home change residents often was very disruptive for staff and for residents. Each time a new respite client arrived, there was a steep learning curve for staff to understand that child's needs that required a great deal of time away from the other residents. As one staff person described it, "This is a home. Inviting in rotating guests constantly is very wearing on everyone – the staff and the kids." While respite for families still living in the community is a very large need, providing it in a residential community may not be appropriate. Providing respite for children who live in the project could easily be accommodated.

Childcare staff

Access to childcare provides important supports for families with children with complex medical conditions, allowing needed respite, allowing for employment by both parents and providing socially diverse experiences for children.¹⁹ In addition to benefiting children with special needs – the benefits to typical children are significant including both learning about and becoming comfortable in an environment with children of all abilities. Observing adult teachers caring for special needs children helps others recognize the strengths of all children.²⁰

In 2001, INFOLINE received 336 requests for childcare centers serving children with special health care needs. Among parents who could be contacted for follow up, problems included programs that did not accommodate their children's needs, waiting lists, high costs and hours that did not meet the family's needs.²¹ A survey of Birth to Three participants in Connecticut found that nearly a third had difficulty finding childcare for their children with special health care needs.²²

A recent survey of childcare centers in the Hartford area found that while most childcare centers express the intention to enroll children with special needs, there are significant barriers including concerns about adequate staff training, the need for individualized attention and maintaining staffing ratios for all children, as well as subjective concerns. Keys to good child care placements for children with special health care needs included a good working relationship between parents

¹⁹ Public Health Committee Roundtable, Community Based Care for Special Needs Children with High Technology Needs, April 16, 2002

²⁰ *Children with Special Health Care Needs in Child Care Centers*, Alexis Fedorjaczenko, Spring 2003

²¹ Special Needs Feedback, Child Care Infoline, Jan. 1, 2001 through Dec. 31, 2001

²² *Children with Special Health Care Needs in Child Care Centers*, Alexis Fedorjaczenko, Spring 2003

and staff, adequate staffing to meet every child's needs, adequate staff salaries to ensure continuity of care, and extensive staff training including workshops/in-service trainings, education from doctors and parents specific to each child's needs, and special education training. Having staff with specific training in meeting the needs of children with special needs was important.²³

Specific accommodations for special needs children in childcare settings must focus on good communication with parents and curriculum development for children of differing abilities. Simple modifications such as purchasing puzzles with knobs on the pieces, squeeze only scissors, large size Legos, space at each table for an adult to assist the child during feeding times, increased space between tables and walls, Velcro to attach toys and equipment to walls rather than hooks, designs allowing all parts of each room to be seen by an adult at all times, Velcro foot straps on bikes, and appropriate labeling of storage areas so all children can participate in all activities and clean up after²⁴.

Staff at childcare centers serving both "typical" and special needs children, one in Connecticut and one in Maryland, were interviewed. There was great warmth and a clear commitment to the work in all interviews. Staff radiated an obvious enthusiasm and dedication to serving all children, and recognition of the challenges facing families with children with complex medical conditions. Both centers were created to fill a pressing need for childcare that can accommodate children with complex medical conditions and both struggle financially to continue that mission. In one case, the principle founder continues to devote considerable sums of personal funding to ensure the center can make payroll on a regular basis. Both centers have long waiting lists.

Every interview participant felt that the most important qualification for staff was a solid commitment and desire to care for children with complex medical conditions. Surprisingly, neither center suffers from large staff turnover rates, which is very unusual in childcare. Most attributed that to the fact that they screen for dedicated, experienced staff. Each has an RN on site as well as access to other professionals as needed, benefiting both the medically complex and typical children. The importance of on-going training for staff, both formal in-service trainings and individualized training on specific issues as they arise, was emphasized. All offered that good communication with parents, both as children are enrolled and on a daily basis, is critical to their ability to care for every child well. In one center, parents are asked to stay with their child at the center for the first day or two after enrollment. Both centers strongly focus on parent involvement and "parent-driven" planning for each child.

Keeping staff satisfied and supported was an important goal at both centers. Having a separate staff-only room, where they can take a break when necessary, is important, as it was to the nursing staff interviewed. Suggestions included a

²³ *ibid*

²⁴ *Inclusion in the Preschool Setting*, Deanna Jordan, Earlychildhood.com

place to lie down, a radio or TV, and a place to store snacks and drinks. Recognition such as Employee of the Month and Staff Appreciation Days were important. One center strongly advised against one-on-one staffing for any child – they felt that it was disruptive and not the best way to serve all children.

Transportation is a very large issue. Accessible transportation is very expensive for centers, but critical to ensuring that children can attend consistently.

Staff emphasized the importance of good design – it is important for any designer to work with staff and parents from the beginning. It is far less costly and disruptive to design the center well from the start than to fix problems as they arise. Important factors include lots of space for wheelchairs, equipment and staff and careful placement of sinks, bathrooms, sleep rooms, and changing areas relative to traffic flow. There must be no steps or platforms as in other childcare centers; everything must be on one level. Activity areas can be identified by different color flooring. All tables and activity areas must be wheelchair accessible. It is critical that the playground is accessible and they strongly advocated for rubberized flooring over wood chips. It is critical to keep the playrooms free of objects that could harm children or serve as a barrier to access such as rocks or toys/equipment left in the wrong place.

Coop Initiatives

Cathy Ludlum, a resident and founder of a Coop Initiatives project in Manchester, was interviewed by phone and in her home. Coop Initiatives is a model of congregate housing that integrates units for people with and without disabilities. The concept is that the entire community will come together to provide for the needs of all the residents. Coop Initiatives does not include medical centers or services. Coop Initiatives works on a shared ownership model – neither a typical rental nor ownership arrangement.

She described how the unit is governed – how problems like loud music, visitors, pets, etc. are handled. Residents have significant responsibilities in running the co-op including maintenance, recruiting new residents, and overseeing finances. Time requirements for meetings are often seen as a burden by residents. Over the 11 years since the project opened, they have had to evict several people. People get a lot of help before the Board resorts to an eviction. The Board of Directors are all residents. She emphasized the importance of building a cohesive community based on trust very early in the process – before construction. She described the initial vision that everyone would come together into a friendly, shared community with lots of shared social activities and informal interaction between neighbors. Unfortunately it has not worked out that way. Cathy said, “It sounds very romantic, having control and input, but it turns into ‘Oh God, not another meeting!’” “The community is not dead, but it is tired and beleaguered.” She noted that residents have to be willing to give up some privacy, “everyone knows everyone’s business.” This model isn’t for everyone.

She emphasized the need for clear rules with clear consequences for breaking them, e.g. leaving bicycles on sidewalks, use of the community room, pets, and visitors, parking. The rules were written together by all the residents and are modified as necessary. Prospective residents go through a lengthy training program, are screened for fairly narrow income limits and get background credit and police checks. Income eligibility constraints, necessary because of the way the project was originally financed, have made it very difficult to find appropriate families to replace people moving out. Turnover in residents is very high.

The shared ownership model has been problematic. Residents do not have control over their own units in the way homeowners do and that has caused considerable tension over the years. It was hoped that a feature of home ownership would lead to a more stable community, with residents feeling more of a commitment to the co-op. Cathy said that this “backfired.” Many were unable to handle the responsibilities of co-op living and did not understand the restrictions.

Cathy’s strongest recommendation was that there be a purposeful plan to build a cohesive community, rather than assuming that it will happen naturally. The greatest strength of the co-op is that residents run it. If residents aren’t getting along, aren’t working together – a lot of time is wasted on solving that. While the plan was to have lots of formal and informal social interactions (and that is cited by parents of special needs children as one of the best features of the proposal), it doesn’t happen in Cathy’s project because it isn’t anyone’s specific job to arrange those interactions and because residents are overwhelmed with the responsibilities of running the co-op.

The co-op has had to face the question of whether a family has to move out if their disabled family member no longer lives there. The answer, decided by the residents, was no. Twice the families moved to another, non-accessible open unit. She noted the need for grief counseling available to every resident when someone dies.

Community resistance

Group home and childcare administrators and staff noted strong community concerns in establishing housing and other programs for children with complex medical conditions. One foster parent who cares for children with special health care needs was sued by her new neighborhood – she counter sued and was awarded a judgment protecting the children’s civil rights. Several noted that the tension can last many years into the future.

The best advice to avoid community problems were to be as open as possible about the project with the community early in development and making clear every intention to work with the community when possible, but that the project will be built. On-going efforts to engage the community were emphasized including

addressing complaints quickly, holding regular open houses, participating in community programs such as foster grandparents, and engaging the neighbors in common recreational activities. Many respondents felt that the inclusion of an integrated childcare center that is available to community residents would make the project far more attractive to communities.

Concerns of local officials regarding special education costs for children living with their parents in the project were raised.

Recommendations

Facility

It is recommended that a small, eight to ten unit project of supportive housing be developed, with dedicated space for a “medical center”. While several site plans could fit this model, it is critically important that the project first be a home, part of the existing neighborhood, and a medical facility second.

The site should be close to a city but not downtown. The site should be close (but not too close) to important medical resources such as hospitals and doctors’ offices. Families need to be close to stores and other commercial areas. Access to public transportation is important to a small number of families. A good local school system is critical as are safety and privacy.

Homes must be accessible with plenty of space to accommodate large equipment. A nearby accessible playground was important. There should be some common space where families can meet, hold social activities, share information, hold support group meetings, and meet with providers to discuss their children.

There must be easy access to the medical center regardless of weather conditions; this was important to both parents and nurses. The medical center must have a private, comfortable staff-only area.

Specific design issues voiced by parents, in no particular order:

- Everything on one floor – this was noted by many parents
- Private, secure entry to the home
- Unbreakable windows
- Laundry facilities in each home
- Low windows you can see out of from a wheelchair
- Accessible light switches
- Include a playroom – a place to keep all his equipment with the other children’s toys and “stuff” “It would be nice to have the living room be a living room and not look like a gym.”

- Possibly a common activity room with equipment that is too expensive for one family to buy alone
- Lots of space – some of the equipment is very large
- Separate small sink just for medical use
- Lots of storage space for medical supplies
- Good sized refrigerator
- No carpeting – hard to move strollers and wheelchairs and hard to keep clean
- Attached garage or covered carport – it takes time to get kids in and out of the car, hard in rain or snow
- Sturdy ceilings that could accommodate a swing and a lift system
- Emergency call buttons
- Big bathrooms with handles on doors
- Elevators if not on one level
- Ramps
- Ample, convenient handicapped parking spaces
- Dedicated parking spaces for each unit, with visitor spaces clearly marked
- Central air conditioning, humidifiers and dehumidifiers
- Fire alarms high, out of kids' reach
- Child lock on outside doors
- Nice fences around private yards, white picket fences were suggested
- Intercoms

The medical center should also look as much like a home as possible. Parents did not favor living in a complex with a medical facility. Keeping as much equipment portable and specific to individual children was important to families and nurses, and facilitates billing to Medicaid. The center must have dedicated space for private communications with parents and children as well as a well-organized charting and administration area.

The childcare center should be designed in close consultation with parents, teachers and experts in early and special education. The center should be built to standards for and secure accreditation from the National Association for the Education of Young Children (NAEYC) including curriculum, teacher – child interactions, relationships with parents, staff qualifications and professional development, administration, adequate staffing, physical environment, health & safety, nutrition & food service and evaluation.²⁵ The space must include no barriers to every child engaging in each activity, such as distinguishing different areas of activity (blocks, water, etc.) with different colors of flooring rather than platforms. It was emphasized that many accommodations for special needs children cost no more than typical childcare centers, but are simply design choices. However remediation of poor choices later can be costly.²⁶

²⁵ NAEYC Accreditation Criteria, National Association for the Education of Young Children.

²⁶ Connecticut Children's Investment Partnership

Governance

Most parents preferred that the facility be run by an outside agency/company but that a group of parents, a Parent Advisory Committee, have oversight responsibilities. Parents of children with complex medical conditions need to have control over the systems of care that they and their children rely on, but conducting day-to-day oversight is not realistic given significant time constraints. The rules governing resident responsibilities and rights must be developed by the Parent Advisory Committee and staff but enforced by an independent agent. A clear, easy to use and responsive grievance procedure must be designed by parents and staff, clearly communicated to all residents and staff, and complaints must be resolved quickly. The privacy of anyone filing a grievance must be strictly protected. Feedback on the resolution of grievances must be provided regularly to all residents and staff.

The Parent Advisory Committee should conduct a formal evaluation of the project at least yearly. The evaluation should include a confidential survey of both residents and staff, an evaluation of challenges encountered in the last year and their resolution, standards of care and operations, and a group of goals for next year. The Committee must have access to independent support services and resources in conducting the evaluation.

Eligibility and eviction standards

As demand for this housing is likely to be high, it is important to give priority to families and children who will most benefit, including those at risk of losing custody to DCF because of inability to access skilled nursing care and children in a hospital ready for discharge but awaiting appropriate community placement. Any potential resident with a history of violence, criminal activity or difficulty living in congregate housing situations should be excluded. Beyond these parameters, the Parent Advisory Committee should create standards for eligibility that will be executed by an independent agent.

Eviction should be a last resort. Rules of residents' responsibilities and rights should be clear and all potential residents should provide informed consent agreeing that violation of the rules will lead to eviction. There must be intermediate notifications of problems and resources offered to resolve any issues. A process for evictions must be developed by parents and staff, agreed to by all, and then enforced by an independent agent.

Service administration

There are at least four different functions involved in this project – development and building, property management, service provision and childcare operation. It is important that selection of agents to perform these functions be experienced and sensitive to meeting the needs of people with disabilities, their families and

medical facilities. To ensure the best quality and selection from the broadest range of available options for each function, independent procurement for each function would be optimal.

As there may be several agents performing different functions all serving the same group of families at the same site, good communications are critical. For example, a complaint of someone parking in the wrong space or leaving a bicycle on the sidewalk may not be a priority for general property managers, but in serving families with medically complex, disabled residents these are critical to the well being of residents. Strong lines of communication and accountability for responsiveness are critical.

Care management

Access to care management is critical to the success of this project. It is important that there be one person accountable to parents first. Prime qualifications for the care manager are flexibility, creativity and resourcefulness and an understanding that they serve families first, not the agency that employs them. Listening to families and following their direction is their first priority.

The care manager should be selected by the Parent Advisory Committee, subject to regular evaluations by the Committee, and approval by the Committee must be the basis for continuing their employment. The Committee will have dedicated, independent resources/support to conduct these supervisory activities. Appropriate leadership training, facilitation and other supports must be available to Committee members and potential members.

The care manager must work with families to develop an individualized plan of care and services for each child and family, developed by everyone who cares for and is responsible for the child. The care plan must be approved by parents, with defined roles and responsibilities. The care plan must be re-evaluated on a regular basis, more often if necessary. The importance of active participation of parents and children in developing and revising the care plan cannot be overstated.

The care manager's job must not be limited to help coordinating services for the medically complex child, but to assist the entire family with support services and counseling as needed. It takes strong families to meet the challenges of raising a medically complex child. The care manager's role should include support services for healthy siblings and parents, including support for employment. The care manager also needs to be sensitive to residents who may need services they have not requested, for example mental health, substance abuse treatment or other counseling services.

The care manager must also have the principle role of managing the project including serving as parents' liaison to property management, health plans,

nursing staff, state agencies, childcare staff, schools, providers, and other key resources. The care manager is expected to be able to productively connect families with all the resources available in their community, not just those offered by the agency or institution that employs them. The care manager must have knowledge of and access to an array of community medical, educational, transportation, and social service resources as well as familiarity with the complexities of programs serving children with complex medical conditions and their families, including Title V, HUSKY and HUSKY Plus, Medicaid, special education resources, and SSI. The care manager needs to have strong conflict resolution skills and experience.

The care manager must also be responsible for developing a cohesive internal community including support groups, resource sharing, recreational and social activities, as well as ensuring good relationships with the wider neighborhood and municipality. The care manager should be responsible for identifying training needs and arranging appropriate educational opportunities for staff, families and community members.

Nursing and childcare staff

It is critical that nursing and childcare staff be well paid, supported and have all the resources they need to provide care to children. Staff should be chosen based on a commitment to caring for children with complex medical conditions and preference should be given to those with such experience. Staff should also be chosen based on a commitment to working cooperatively with parents. The Parent Advisory Committee should decide what role they will have in hiring decisions.

Staff must be involved directly in developing rules and policies and have full access to the grievance process without concern for their employment. Clear routes of communication with parents, children, property management, the care manager, and other staff must be developed and monitored.

Sufficient time must be allotted to allow for communication with parents, charting and other necessary documentation.

Accessible playground

Parents often mentioned a lack of public play spaces for their children with complex medical conditions. Physical play is critical to healthy development of all children. The ADA has minimal requirements for playgrounds, but a truly accessible playground that meets the needs of children of all abilities goes beyond those minimal standards. Those include the ability of children in wheelchairs and walkers to access the large majority of structures without leaving the security of their wheelchair or walker. Playgrounds must address the needs of children with sensory and developmental disabilities and the play

behaviors of all children. Playgrounds should present children with fun, safe opportunities to engage and overcome challenges appropriate to all levels of ability²⁷. Playgrounds should include shock absorbing surfaces at least 6 feet in all directions around play equipment (surfacing mats of safety-tested rubber were favored by childcare center staff), no ability to attach ropes, chains or other lines to play equipment, no protruding hardware, no spaces that could trap children or their equipment, guardrails on ramps and platforms, no sharp points or edges, no tripping hazards, good supervision of children, and attentive maintenance.²⁸

Costs

Operating Costs for the proposal

Service

Wide variations in the potential needs of residents at any given time make all cost estimates uncertain. These estimates are meant as an illustration, not as a guide for implementation.

This budget assumes one FTE care manager at an annual salary of \$58,240, four FTEs Registered Nurses at \$35/hour and four FTE aides at \$15/hour. This provides for 24 hours/day, 7 days/week care capacity. A factor of 1.2 fold is included to reflect vacation and sick time. Fringe benefits are assumed to be 22% and administrative overhead is 20%. This center is to serve 8 children in total, although it is not expected that all eight will be using the center at the same time. Parents are to remain the child's primary caregiver. All school-aged children will attend school on a regular schedule. Rental subsidies are included to keep rents at the levels currently paid by surveyed parents (approximately 26% of income or \$400/month). The amount included below, \$30,000 reflects an estimate that half the subsidies would be secured through other funding mechanisms (see Funding Sources section). A project-based Section 8 designation would make these subsidies unnecessary. Hourly wages were estimated by working nurses and hospitals to include weekend and evening allowances.

²⁷ Boundless Playgrounds, Inc.

²⁸ Home Playground Safety, Provider Watch

Annual Service Costs		
RN – 4 FTEs	160 hours/wk @ \$35/hour X 1.2	\$349,440
Aides -- 4 FTEs	160 hours/wk @ \$15/hour X 1.2	\$149,760
Care Manager – 1 FTE		\$58,240
	Payroll subtotal	\$557,440
Fringe benefits	Plus 22%	\$680,077
Administrative support	Plus 20%	\$816,092
Rental subsidies		\$30,000
Electricity and phone		\$2,500
Heat		\$2,500
Total		\$851,092
Service cost per child		\$106,387

Housing

Costs assume eight rental three-bedroom units at \$1020/month. A scenario that includes debt service on a small \$38,700 thirty year loan at 6% interest is included. This budget does not include rent and utility payments for the medical center, which could be included in the operating budget and used to reduce rents. Rents are based on HUD's Fair Market Rent for a three-bedroom home in Hartford. The housing operating cost budget was generously estimated by the Corporation for Independent Living.

Operating Budget - Housing

Supportive Housing for Families with Medically Complex Children

		Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7	Year 8	Year 9	Year 10	Year 11	Year 12	Year 13	Year 14	Year 15
INCOME			2%	2%	2%	2%	2%	2%	2%	2%	2%	2%	2%	2%	2%	2%
8 Three Bedroom Units	\$1,020	97,920	99,878	101,876	103,913	105,992	108,112	110,274	112,479	114,729	117,023	119,364	121,751	124,186	126,670	129,203
1 Service Unit	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Vacancy @	5%	(4,896)	(4,994)	(5,094)	(5,196)	(5,300)	(5,406)	(5,514)	(5,624)	(5,736)	(5,851)	(5,968)	(6,088)	(6,209)	(6,333)	(6,460)
Other		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
NET INCOME		93,024	94,884	96,782	98,718	100,692	102,706	104,760	106,855	108,992	111,172	113,396	115,664	117,977	120,336	122,743
EXPENSES																
Insurance		4,500	4,590	4,682	4,775	4,871	4,968	5,068	5,169	5,272	5,378	5,485	5,595	5,707	5,821	5,938
Materials & Supplies		1,200	1,224	1,248	1,273	1,299	1,325	1,351	1,378	1,406	1,434	1,463	1,492	1,522	1,552	1,583
Maintenance & Repairs		10,800	11,016	11,236	11,461	11,690	11,924	12,163	12,406	12,654	12,907	13,165	13,428	13,697	13,971	14,250
Maintenance Contracts		1,800	1,836	1,873	1,910	1,948	1,987	2,027	2,068	2,109	2,151	2,194	2,238	2,283	2,328	2,375
Property Taxes		21,600	22,032	22,473	22,922	23,381	23,848	24,325	24,812	25,308	25,814	26,330	26,857	27,394	27,942	28,501
Refuse Removal		18,000	18,360	18,727	19,102	19,484	19,873	20,271	20,676	21,090	21,512	21,942	22,381	22,828	23,285	23,751
Extermination		2,160	2,203	2,247	2,292	2,338	2,385	2,433	2,481	2,531	2,581	2,633	2,686	2,739	2,794	2,850
Snow Removal		3,500	3,570	3,641	3,714	3,789	3,864	3,942	4,020	4,101	4,183	4,266	4,352	4,439	4,528	4,618
Grounds Maintenance		2,500	2,550	2,601	2,653	2,706	2,760	2,815	2,872	2,929	2,988	3,047	3,108	3,171	3,234	3,299
Water & Sewer		1,200	1,224	1,248	1,273	1,299	1,325	1,351	1,378	1,406	1,434	1,463	1,492	1,522	1,552	1,583
Electricity (common only)		1,200	1,224	1,248	1,273	1,299	1,325	1,351	1,378	1,406	1,434	1,463	1,492	1,522	1,552	1,583
Heat (vacant units only)		200	204	208	212	216	221	225	230	234	239	244	249	254	259	264
Management Fee	10%	9,302	9,488	9,678	9,872	10,069	10,271	10,476	10,686	10,899	11,117	11,340	11,566	11,798	12,034	12,274
Accounting Fees		4,000	4,080	4,162	4,245	4,330	4,416	4,505	4,595	4,687	4,780	4,876	4,973	5,073	5,174	5,278
Legal		1,200	1,224	1,248	1,273	1,299	1,325	1,351	1,378	1,406	1,434	1,463	1,492	1,522	1,552	1,583
Provision for Doubtful Accounts		800	816	832	849	866	883	901	919	937	956	975	995	1,015	1,035	1,056
Operating Reserve		1,350	1,377	1,405	1,433	1,461	1,491	1,520	1,551	1,582	1,613	1,646	1,679	1,712	1,746	1,781
Replacement Reserve	\$ 500 unit/yr	4,500	4,590	4,682	4,775	4,871	4,968	5,068	5,169	5,272	5,378	5,485	5,595	5,707	5,821	5,938
TOTAL EXPENSES		89,812	91,609	93,441	95,310	97,216	99,160	101,143	103,166	105,230	107,334	109,481	111,670	113,904	116,182	118,506
Net Operating Income Before Debt Service		3,212	3,276	3,341	3,408	3,476	3,546	3,617	3,689	3,763	3,838	3,915	3,993	4,073	4,155	4,238
Projected Debt Service																
	Principal	Term	Rate													
\$	38,700	30	6.0%	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784	2,784
Feasibility Study of Supportive Housing for Families and Children with Complex Medical Conditions																
Net Operating Income After Debt Service		427	492	557	624	692	762	832	905	979	1,054	1,131	1,209	1,289	1,370	1,453
Debt Service Coverage		1.15	1.18	1.20	1.22	1.25	1.27	1.30	1.32	1.35	1.38	1.41	1.43	1.46	1.49	1.52

Childcare

This budget assumes no extra costs for medical personnel and is based on operating costs for childcare centers that serve children with complex medical conditions. The budget assumes 70 children enrolled -- 24 infants or toddlers and 46 preschool children. The budget is based on 52 weeks a year, 5 days a week, 10 hours per day operation. This budget assumes no center-based subsidies or reimbursements and no private fundraising. Revenues are based on state Care 4 Kids rates and three openings on average at any time, at the preschool rate. Costs of medical staff are included in the previous service budget.

Childcare Annual Operating Costs

Expenses

Payroll		
24 infant/toddlers @1:4 ratio – plus – 46 preschool @ 1:8 – plus one aide + one teacher	2 head teacher FTEs @ \$14/hour	\$58,240
	6 teacher FTEs @ \$13/hour	\$162,240
	6 aide FTEs @ \$10/hour	\$124,800
Executive Director		\$50,000
Administrative assistance		\$25,000
Curriculum/Finance		\$20,000
	Payroll Subtotal	\$440,280
Payroll total	Plus fringe @22%	\$537,142
Supplies non-food		\$3000
Food – assumes Dept. of Educ. food program participation		\$2100
Utilities		\$10,000
Heat		\$9,000
School supplies – toys, equipment, books		\$4000
Phone		\$2100
Building maintenance & repairs		\$20,000
Office supplies		\$4500
Insurance		\$10,000
Training		\$1000
Misc.		\$1000
Total Non-payroll		\$ 66,700
Operating total expenses		\$603,842
	<i>Revenue</i>	
24 infant/toddlers	@ \$200/week	\$249,600
43 preschool slots	@\$160/week	\$357,760
Total revenue		\$607,360
Net income		\$3,518

Maintenance of the transportation and accessible playground options

It is assumed that staff at both the service/medical center and at the childcare center will be licensed to drive a 9 to 11 passenger accessible van at no extra operating cost. Maintenance on the van is expected to cost \$6,000/year.

It is expected that maintenance of the accessible playground will be included within the childcare's maintenance line item.

Capital Costs

Specific locations, environmental issues, housing requirements, and a host of other factors can strongly influence capital costs. Being conservative, all costs are based on new construction. If rehab options are available, costs could be lower, however new construction is most likely to fit the needs of children with complex medical conditions and their families.

Housing

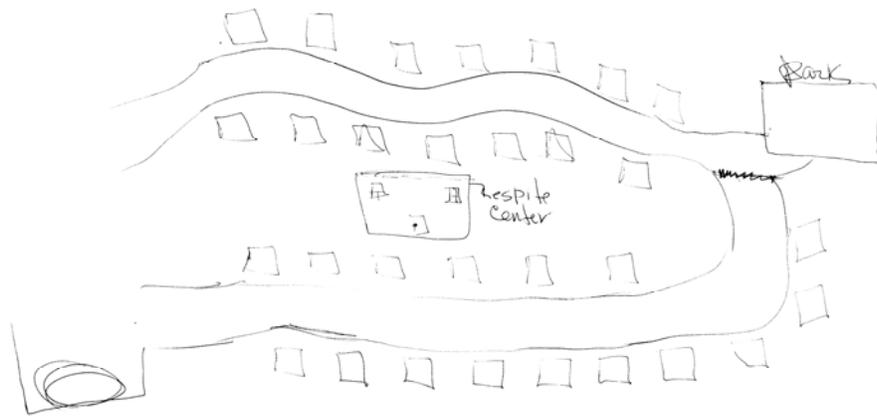
Approximate costs are given for two options. Both are based on eight housing units and another unit for the medical center. All would be designed as affordable, accessible housing, allowing for space and other requirements according to industry standards. Those standards include parking, public and private open space, building shape, building appearance, landscaping, location, and building and unit layout.²⁹ Housing costs were generously estimated by the Corporation for Independent Living.

Both options could be modified to better suit the needs of children with complex medical conditions with the addition of built-in overhead tracks to accommodate lifts and other equipment as well as special tubs accessible from three sides and accessible to a gurney. The tracks would cost approximately \$11,000 per unit and could be placed in both the medical center and the residential units. The tubs would cost an extra \$3,000 for the tub and another \$3,000 for installation per unit.

²⁹ Accessibility Requirements for Buildings, HUD, and Affordable Housing Design Advisor, www.designadvisor.org
Feasibility Study of Supportive Housing for Families and Children with Complex Medical Conditions

Option 1 -- Detached single family, one-floor homes

This proposal includes one separate home for the medical center. All are assumed to be in close proximity in a residential neighborhood. This option was the most highly favored by parents. One mother sketched her vision of the project:



Option 2 – Row townhouses

A nine-unit townhouse with all units attached is proposed -- eight residential units and one medical unit. This option minimizes land needs while maintaining a residential, neighborhood environment.

Architectural plans for this option are attached in Appendix F. Plans secured by the Corporation for Independent Living of Wethersfield, Connecticut and produced by Gleysteen Design LLC of Cambridge, Massachusetts.

Supportive Housing for Families with Medically Complex Children Development Budget -- Housing Option Two

Sources

Grant Funds		\$ 2,090,141
Loan Funds		38,700
State Housing Tax Credit Contribution		400,000
Total Sources		\$ 2,528,841

Uses

Acquisition		\$ 300,000		
Construction/Renovation				
- Site Improvements		100,000		
- Unusual Conditions		-		
- Demolition		-		
- Construction - New				
Townhouse	Units	Square Ft	Cost/sf	
	8	1,400	\$ 80	896,000
	1	1,600	\$ 90	144,000
- Accessory Buildings				-
- Environmental Abatement				-
- Other				-
- Other				-
Subtotal				1,140,000
- General Requirements			5.00%	57,000
- Overhead & Profit			20.00%	228,000
- Bond Premium				17,500
- Building Permit & Other Fees				20,000
- Appliances				27,000
- Other				15,000
Subtotal				364,500
Total Construction				\$ 1,504,500
Construction Contingency			10.0%	\$ 150,450
Architect				
- Design/Contract Documents				85,000
- Contract Administration				15,000
Survey/Engineering				22,000
Environmental Assessment				3,500
Property Taxes				1,500
Carrying Charges				2,800
Insurance - Liability				3,000
Construction Loan Interest				20,000
Appraisal				1,500
Loan Origination Fee			2.00%	41,803
Legal				18,500
Cost Certification				2,000
Title Insurance				3,500
Title Bringdowns				1,200
Recording Fees				1,000
Developer's Overhead			2.5%	54,431
Developer's Fee			12.5%	272,157
Soft Cost Contingency			1.8%	10,000
Capitalization of Replacement Reserve				5,000
Capitalization of Operating Reserve				10,000
Subtotal				\$ 573,891
Total Uses				\$ 2,528,841
Feasibility Study of Supportive Housing for Families and Children with Complex Medical Conditions				-

Childcare option

This option is for a childcare center accommodating 70 children – infants, toddlers and preschool ages, both medically complex and typical children. The upper range of estimates for space per child is used to allow for equipment and other needs of children with complex medical conditions. No extra costs are allowed for medical equipment at the center. Childcare centers that care for children with complex medical conditions do not have such installed equipment; each child's needs are unique and are best served by portable equipment purchased to fit their specific needs at their current stage of development. It is assumed that any medical equipment costs would be either shared with the medical center above and/or covered by each child's insurer. Costs per square foot include all costs of building a new center including land acquisition costs, development and building, contingency fees, furnishings and appliances. Two sources of capital costs were solicited³⁰; the higher end of the resulting range was used for this estimate. As some costs may be shared with the housing development, this estimate may be high. As always, it is important to stress that many factors can significantly alter this estimate.

Childcare capital cost estimate	
70 children @ 90 sq ft/child	6300 sq ft
6300 sq ft @ \$125/sq ft	\$787,500

Licensure as a childcare center in Connecticut requires 35 sq ft of indoor useable space per child, 75 sq. ft. outdoor play space per child, one bathroom designated for staff only, one toilet and wash basin with hot and cold running water per 16 children, two staff on premises at all times, staff qualifications and ratios, background checks for staff through fingerprinting, workers' compensation insurance and compliance with building, zoning, fire and local health codes.³¹

Accessible playground option

Costs of accessible playgrounds vary widely depending on the number and ages of children who will use them. Inclusion of the childcare option will require more space and an emphasis on structures for younger children. Again, some costs may be shared with housing and/or childcare development.

Costs of several options were provided by Boundless Playgrounds, Inc. The first two cited here were professionally installed in school environments. All playground options listed exceed the ADA requirements of accessibility. The first

³⁰ Bruce Waters, KinderCare, Inc., and David Wasch, Children's Investment Partnership

³¹ DPH

is 100% accessible – the entire student population at the school has one or more disabilities. This project was 12,200 sq ft and included several enhancements such as a greenhouse and a small, accessible golf course for the children. The second example includes a 14,000 square feet playground with a sensory garden enhancement. The third example is a very large 26,000 square foot playground in a public park. While this project used volunteer builders, the percentage of the budget devoted to installation was higher than the other two.

Accessible Playground Capital Costs			
	<i>Example 1</i>	<i>Example 2</i>	<i>Example 3</i>
Play equipment	\$120,100	\$205,000	\$172,400
Installation	\$40,000	\$49,000	\$58,000
Surfacing & Installation	\$30,400	\$49,000	\$74,000
Site Preparation	\$10,000	\$20,000	\$37,400
Professional Services (e.g. landscape architecture, legal, contractor)	\$28,500	\$49,000	\$145,000
Play Value Site Amenities		\$14,000	\$24,000
Site purchase, rent or lease	N/A	\$14,000	N/A
Perimeter landscaping	\$5,000	\$30,000	\$73,200
Other site amenities (e.g. pathways, benches, fences)	\$154,300	\$32,000	\$23,000
Total	\$388,300	\$462,000	\$607,000
Location	School	School	Public park
Playground Size	12,200 sq ft	14,000 sq ft	26,000 sq ft
Equipment as % of budget	31%	44%	28%
Installation as % of budget	33%	24%	34%
Surfacing as % of budget	25%	24%	43%
Items of note	Greenhouse, golf course	Sensory garden	Sensory garden

Transportation option

A nine to eleven passenger van that can accommodate two wheelchairs costs \$38,900 from Ride Away. This is the cost for a new van; apparently used vans are rarely offered for sale.

Comparison costs

As described in the Introduction, the state spends \$328,270 per year for each child at the Hospital for Special Care. As these charges are Medicaid-eligible, the state's net cost of care is \$164,132 annually for each child.

Children with complex medical conditions in DCF's custody can easily reach costs of \$164,252 per child. An indeterminate share of these costs are reimbursed by the federal government.

Within the assumptions used in the Operating Costs section, this facility's housing and childcare costs are balanced by revenues generated from those services. The costs of medical care per child are estimated at \$106,387 per child. These costs are Medicaid-eligible, making the state's net cost per child \$53,193. Accounting for interest on bond debt of \$1.5 million (assuming grants for the balance of funding), adds \$10,313/child for a total of \$63,506. At the current Department of Social Services (DSS) rate of \$37.74/hour for Extended Nursing by an RN, used extensively by children with complex medical conditions³², the state would save money for any child previously receiving 4.6 hours/day of nursing care or more. Many children on Medicaid are approved for over 16 hours/day of skilled nursing care. This figure does not include the benefits to families of stable, affordable, accessible housing, easing caregiver stress, the possibility of employment for both parents, access to care management, support from other families and some measure of control over the systems of care that serve their families. The benefits to children with complex medical conditions of consistent medical care provided in a dedicated setting with staff accountable to their parents cannot be measured. It is expected that these improvements in care will lead to better health status and reductions in unnecessary acute hospitalizations, at a daily rate of \$1,848, saving the state far more.

³² DSS

Annual costs of care for children with complex medical conditions			
		<i>Total cost</i>	<i>State net cost</i>
Hospital for Special Care		\$328,270	\$164,135
DCF custody		\$164,132 or more	N/A
Supportive Housing		\$106,387	\$53,193
Interest on bonds	Assumes \$1.5 million 20-year state bond debt @ 5.5% interest divided by 8 children	\$10,313	\$10,313
Total cost/child		\$116,700	\$63,506
State savings/child/year			\$100,629

Funding Sources

Housing

Various sources of funding are available, both state and federal, for accessible, affordable housing. Some are limited to building and capital costs, some are available for operating costs, and some can serve in either category.

Section 8 Vouchers

The Section 8 program provides low-income families, elderly people and people with disabilities resources to rent decent, safe, affordable housing. Four families interviewed offered that they have Section 8 vouchers currently. Tenants typically pay 30% of their income to rent; the Section 8 subsidy pays the balance. The subsidies are long-term and are considered permanent housing³³. Two types of Section 8 assistance are relevant to this project – tenant based vouchers and project based rental assistance. Tenant based vouchers are available through Public Housing Authorities and, in some cases, through non-profit organizations.

³³ *Opening Doors*, May 2002, The Technical Assistance Collaborative
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Families must be low or very low income to qualify, which meets the circumstance of the families interviewed and interested in participating in this project. A certain number of Section 8 vouchers are or can be set aside for families with disabled members. Project-based vouchers are dedicated by Public Housing Authorities for a specific set of units that owners agree to construct or set aside a portion of the units for eligible families³⁴. In 2002 the state of Connecticut obtained 200 Section 8 vouchers specifically for people with disabilities allowing the Corporation for Supportive Housing and the state to develop over 300 units of permanent supportive housing for homeless people and those with disabilities at risk of homelessness.³⁵

Home Funds

Created in 1990, HOME is a federal block grant to state and local governments to create affordable housing for low-income households. Within very broad guidelines, states and localities are free to design how HOME funds are used. Funds can be used to build or rehabilitate housing for rent including the costs of acquiring land and buildings, renovations as well as new construction. HOME funds can be made available as grants or loans and can be used for units from efficiencies to multi-bedroom apartments and single-family homes. HOME funds cannot be used for on-going operating costs. The program includes maximum per unit subsidy limits. Residents in HOME-funded projects must fit within income guidelines – the incomes of the families polled and interested in this project fit easily within the HOME requirements. HOME financed projects have total rental cost limits that specific to each area, but for Connecticut are far below the \$1020 assumed in the housing operating budget. Other sources of operating or individual-based subsidies must be found to make the HOME program a feasible funding option. Since 1992 the state of Connecticut has received \$97,945,000 as of June 30, 2003 in HOME funds directly. There are 6 local jurisdictions in Connecticut that receive federal HOME Funds – Bridgeport (\$17,688,000 since 1992), Hartford (\$23,399,000 since 1992), New Britain (\$6,979,000 since 1992), New Haven (\$17,812,209 since 1992), Stamford (\$5,141,000 since 1992), and Waterbury (\$9,517,000 since 1992).³⁶

State Bond Funds

Several state bond fund accounts have funded similar projects in the past. A few examples include Fund 3975, the Urban Acts Grants, has funded many similar projects to purchase a building or improvements to existing facilities. These funds flow through DSS or DECD. There is currently over \$78 million undistributed in

³⁴ US Dept. of Housing and Urban Development

³⁵ *Opening Doors*, 2002, The Technical Assistance Collaborative

³⁶ US Dept. of Housing and Urban Development -- HOME income requirements – at least 90% of residents must have incomes no more than 60% of the HUD-adjusted median for the area, at least 20% must have incomes no more than 50% of the median, and no resident can exceed 80% of the area median, HOME income limits are published each year
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this fund (authorized but not allocated. Fund 1873, Grants to Local Governments and Others, provides funding to “neighborhood facilities” including homeless shelters, domestic violence shelters, multi-purpose human resource centers, food distribution centers and childcare centers. Fund 1873 has a balance of \$3,165,000 unallocated. Fund 1800, Housing Assistance, flows through DECD and has historically targeted elderly housing but has funded projects for low-income and disabled housing.³⁷

State Housing Tax Credit Program

The Housing Tax Credit Contribution Program (HTCC) provides state tax incentives to businesses for grants to housing initiatives by non-profit organizations to develop or manage housing for very-low, low- and moderate-income families. The incomes of the families polled for this study easily fall within HTCC guidelines. Companies receive a dollar-for-dollar reduction in their state tax liability in exchange for financial support of affordable housing up to a maximum of \$400,000. CHFA allocates \$5 million in HTCC credits annually.³⁸

Federal Low-Income Housing Tax Credits

These funds are federal tax credits granted to developers of low-income housing who then sell the credits to companies that in turn receive a reduction in their federal tax liability. Eligible projects must either have 20% of units rented to tenants with incomes below half the HUD area median income, or have 40% of residents with incomes below 60% of the HUD area median income. The amount of the tax credit can be increased by setting aside 100% of units for low-income tenants. Again, the families interviewed and interested in moving into this project would easily fit within these guidelines.³⁹

Federal Home Loan Bank Affordable Housing Program

Ten percent of the Bank’s net earnings fund the program, which provides grants and low-interest loans through member institutions. Funds can be used for rental housing in which at least 20% of units are for households with incomes at or below half the HUD area median income. Funds can be used for the direct costs of producing or financing affordable housing in New England. Supportive services and commercial space associated with the development are ineligible for this funding; this exclusion may apply to the medical unit.⁴⁰

³⁷ Office of State Comptroller

³⁸ CHFA, www.chfa.org

³⁹ *ibid.*

⁴⁰ Federal Home Loan Bank of Boston, Affordable Housing Program

Community Development Block Grants

Since 1974, HUD has provided CDBG grants to states and local communities for a wide variety of affordable housing programs, to provide services to the most vulnerable and to expand business opportunities. Each grantee must develop and follow a detailed plan for citizen participation, which could be served by the Parent Advisory Committee. At least 70% of the funds must be used for activities that benefit low- and moderate-income people. In 2003, the state of Connecticut was granted \$15,537,000 in CDBG funds; 22 Connecticut communities were granted a total of \$33,862,000.⁴¹

Medical and care management service funding

Medicaid serves as the primary funder of care for children with complex medical conditions in Connecticut. While the project, as described above, does not require any waiver of Medicaid rules or regulations, other services could be included and reimbursed under a Home and Community-Based Services (HCBS) Waiver. HCBS waivers allow states to develop and implement creative alternatives to placing people in hospitals and other facilities. Under the waiver, Medicaid could reimburse not only for nursing care, but also for care management services, homemaker/home health aide services, personal care services, respite care and “other” services requested by the state⁴². If the childcare center can be designated as part of the child’s “home”, as is the case in Massachusetts, Florida and Georgia, eligible services provided there would be reimbursed through Medicaid⁴³. Connecticut currently has nine HCBS waivers and two more are pending. None of Connecticut’s waivers target children but many other states have HCBS waivers covering similar populations with similar services.⁴⁴ DSS, as Connecticut’s designated Medicaid agency, must apply for any waiver.

Childcare funding options

Again, some are appropriate for capital costs and some are specific to operating costs.

Several state bond fund accounts are appropriate to fund the costs of building childcare centers. Fund 1843 is specifically earmarked for childcare facilities. The current unallocated balance in Fund 1843 is \$2,585,652. Fund 1843 described above has funded childcare centers in the past and currently has a balance of \$3,165,000 in unallocated funds.

⁴¹ US Dept. of Housing and Urban Development

⁴² US Centers for Medicare and Medicaid Services

⁴³ *Child Watch Coalition – Our Vision for the Future*, 11/20/02

⁴⁴ US Centers for Medicare and Medicaid Services

Several sources of private, foundation funds supporting childcare centers exist, both for capital and/or operating costs. The Connecticut Children's Investment Partnership (CIP), funded in part by the William Caspar Graustein Memorial Fund, provides grants for non-profit organizations to develop new childcare centers. CIP offers technical assistance, design consultants, and no-interest loans for pre-development costs, which can include land acquisition, and professional costs.⁴⁵

DSS provides various forms of assistance to childcare centers and directly to parents. Care 4 Kids subsidizes childcare for low-income families with children under age 12.⁴⁶ Childcare providers are paid directly by the state. The families surveyed all fall within Care 4 Kids income eligibility limits. DSS also provides enhancing grants for staff training (a critical component in a center caring for children with complex medical conditions), equipment, and repair safety problems. DSS has accreditation grants which pays accreditation fees for centers that serve children with disabilities ages 3 to 5 receiving special education services and that have a history of working with school districts to serve such children. DSS can lend up to \$10,000 to centers to develop, expand, or improve facilities including project planning and design, legal and financial fees, permits and insurance, meeting state and local codes, and minor renovations. DSS can provide funding to towns and nonprofit organizations to purchase property, plan or construct childcare centers. DSS can guarantee between 20% and 50% of bank loans made to childcare centers for construction, rehabilitation or facility improvements.⁴⁷ As described above, under a home and community-based services Medicaid waiver, DSS could fund the costs of care for children with complex medical conditions in the childcare center.

The State Dept. of Education reimburses nonprofit and public centers for part of their meal and snack costs. Businesses can claim a corporate or other business tax break of up to \$50,000 for contributing to the acquisition, construction, or reconstruction of a nonprofit childcare center designated by a town.⁴⁸

Playground funding options

State bond Fund 1873, Grants to Local Governments and Others, flows through DEP for various park and recreational improvements including accessible playgrounds for schools and non-profits⁴⁹. Many communities fund the full costs of accessible playgrounds with private fundraising efforts⁵⁰.

⁴⁵ Connecticut Children's Investment Partnership, Hartford

⁴⁶ DSS

⁴⁷ *Financial Assistance for Day Care Centers*, OLR, 2002-R-0938

⁴⁸ *ibid*

⁴⁹ Office of State Comptroller

⁵⁰ Boundless Playgrounds, Inc.

Other issues to be considered

Choice of Lead Agency

It is critical to engage a lead agency with both a demonstrated commitment and history of serving/listening to families and very good ties to the community where the project will be built.

A common theme voiced by families was “No one listens. They nod their heads, but they don’t listen.” Parents need assurances that their children’s needs will remain the focus of the project. There must be a sincere understanding that is not only symbolic, that parents really are the best experts on what they need to care for their children. Programs that are not premised on this philosophy often fail. A commitment to ceding control to parents and the Parent Advisory Committee is paramount. As one father stated, the Committee has to have a real role in running the project, or “it would be just like fighting with the insurance company.” Support for busy parents in this role that is non-directive is critical as is extensive experience in facilitating communications and conflict resolution.

It is also critical that the lead agency be respected and connected to its community. Group homes, foster homes and childcare centers serving children with complex medical conditions have encountered significant community resistance. Projects that avoid those problems include the community and community leaders at the earliest stages of development, accommodate their concerns when possible, and continue community outreach and engagement on a regular basis after the project is built and operating. Community Builders is currently developing two similar congregate housing projects to serve grandparents raising grandchildren. In one city, the project has sailed through local processes, has been endorsed by local leaders and even received local CDBG funding. The lead agency on this successful project is a well-respected, well-established local non-profit agency that already provides senior housing in the same neighborhood. The other project has encountered significant roadblocks at virtually every stage of development and is currently on-hold. The lead agency on this project is mired in city politics and budget cuts⁵¹.

Strategy to implement

Advocacy begins with families

It is critical to build a consensus among policymakers and advocates supporting this project. It is important to first engage families’ support in advocating for the project. This must be a thoughtful and purposeful coordinated initiative. Given the strong positive response by polled families for this report, this should be easily

⁵¹ Community Builders, Inc.

done. After a solid base of family support is constructed, reaching out to both policymakers and the wider advocacy community is advised.

Structure the project to attract the broadest range of potential agents

Given the wide range of skills and experience needed in building and operating this model of supportive housing, it is best not to require all functions be performed by one applicant. Allowing applications for one or more of the various functions involved – development and construction, medical and care management service provision, property management and childcare center operations – will ensure the best selection of candidates, especially those with experience serving families of children with complex medical conditions.

Families should design the program from the beginning

Once approved, it is critical that parents of children with complex medical conditions be intimately involved in selecting among competing proposals, more than just including one or two parents on the selection committee. A process could include an initial screen by agency staff to eliminate proposals that do not meet basic program requirements, and a committee of parents who then select among those that pass the initial screen. The parents should have support and assistance from both state agency representatives, but also from advocates, researchers and others. However, parents have the only final votes on the proposals.

The first job after selection of a lead agency and a proposal must be to create the Parent Advisory Committee. This committee should advise on all aspects of program development including site selection, building design, staff requirements and job descriptions. The process to develop the rules for residents' responsibilities and rights should begin very early – it may seem premature to begin before the project is built, but the experience of Coop Initiatives demonstrates that the process helps residents understand their roles, the intricacies of group living and creates a sense of community necessary for success.

Building codes

Building codes and local approval processes for residential and commercial projects differ greatly. Similar projects have encountered significant resistance in planning and zoning processes. This project is considerably more likely to be approved if it can retain residential coding. It is critical that the medical center and its permanent fixtures be as much like a home and as little like a hospital as possible. This was also the strong preference of families.

Childcare centers are usually coded as commercial use. Siting of the childcare center must be carefully considered.

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Special Education

Since parents will be living with their children, whatever town hosts this project could be liable for the special education costs for all the children in the project. Under current law in a typical group home, the town where the parents live is responsible for those costs. The state reimburses towns for costs above five times the average per pupil cost -- between \$36,000 and \$71,000 per child. However, state statute has been changed in the past to accommodate children living in a "foster home, group home, hospital, state institution, receiving home, custodial institution or any other residential or day treatment facility" (CGS Chapter 164, Sec. 10-76d). According to legal aid sources, a similar change in law to keep the liability with the town where the family lived before moving should not be difficult. This change in state law would be critical to ensuring local acceptance of any project.

Appendix A – Advisory Committee Members

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Appendix B – Sources Contacted (in addition to Advisory Committee)

- 35 parents of children with complex medical conditions living in Connecticut
- Over 20 foster parents caring for children with complex medical conditions in Connecticut
- Ann Louise Blanchard, CT Legal Services
- Barbara Sprague, Director, CIB group home in Middletown
- Iris Thompson, YNHH Title V program
- Marty Legault & David McKinley, Corp for Independent Living
- Jaci Fricks, Hospital for Special Care
- Jim Standish, Hospital for Special Care
- Christine Johnson, ARC of Quinnebaug Valley
- Ana Chambers, DPH
- Group home staff, HARC
- Sarah Parker McKernan, LARC
- Sharon Guerette, Marie Vitorelli, DSS
- Jeri Dudics, Chris Malinowsky, DCF Waterbury
- Pat Garrett, YNHH Title V
- Olga Vasquez, CCMC Title V
- Stan Soby, CIB
- Holly Brooks, HARC
- Linda Swanson, RN, DCF
- Joyce Abrams, DMR
- Olga Vasquez, CCMC Title V program
- Andy Wagner, DMR waiver unit
- Full Circle of Care, British Columbia
- Nicki Highsmith and Kamala Allen, Center for Studying Health Systems Change
- Rachael Kline, Families USA
- Maureen Mitchell, VA Family Voices
- Casey Foundation
- Kaiser Family Foundation
- HRSA -- Title V section
- Julie Beckett, Family Voices
- Cynthia Baughn, The House That Kerry Built, Abilene, Texas
- National Association of Hospital Hospitality Houses
- Iowa City city plan, Supportive Housing Needs of Non-Homeless Special Needs
- John Rimbock, assisted living consultant, Oakland CA
- Hiram Zayas, Whispering Pines Residential Services, Nee Buffalo, Mich.
- Cathy Ludlum, Coop Initiatives
- Office of Protection & Advocacy, State of CT

- Terry Cote, DMR
- Ginny Szondy, Pediatric Services of America
- Lucille Taylor, nursing, Hospital for Special Care
- Cecilia Villanueva, Christus Santa Rosa Children's Hospital, San Antonio, TX
- Raphael Podolsky, Legal Assistance Resource Center
- Marriette McCourt, Medicaid Managed Care Council
- Staff and founders, Kangaroo Corner Childcare Center
- Rhonda Misciagna, Boundless Playgrounds
- Karl Kemper, DCF
- Ken Lewis, Community Builders
- Mary Kempf, Karasik Childcare Center, Montgomery County, MD
- Robert Zavoski, CCMC
- Miriam Clarkson, property management
- Carla Taymans, medical billing
- Deb Swift, Local Initiatives Support Corp.
- Darlene Ragozzine, CT Charts a Course
- David Wasch, Children's Investment Partnership
- Guy Sunny, American Red Cross
- Bruce Walters, KinderCare, Inc.
- Amy Gillman, Community Investment Collaborative for Kids

Appendix C – Parent Interview Guide

Interview guide

Parents of children with special health care needs

Introduce myself

We need your help. A working group of state policymakers and parents of children with special health care needs is exploring the possibility of developing a project of congregate housing for medically complex children and their families. The idea is to allow children to live with their families, and enjoy all the complexities and richness of family life, in a setting that meets their medical needs, as well as meeting the needs of other family members.

The first step in developing this idea is to start with families. We need your input. You are the experts on your child, your family and your experiences. All the information you give us will be kept in the strictest confidence. Nothing will be shared without your permission.

Questions

General

Age of Child

Town

Number of family members in household, ages, relationships

Income

Insurance coverage for child and rest of family – Medicaid, private insurance, HUSKY B, None

Do you own your home or rent or share with someone else or ?

How long have you lived there?

How much do you pay for housing?

How did you choose where you live? What was important to you?

What role did your child's needs play in the decision?

Are you happy with your housing? Does it meet all your needs? If not, which ones?

Needs for services

Degree of child's physical disability

What services do you need now?

Does your child now have skilled care in your home and paid for by your insurance or another agency?

How many hours/week?

How has that changed over time? In response to what – your child's needs change and/or changes in policy/coverage

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Would you say that getting skilled care in your home now is easy, hard, very difficult, impossible?

At any time has your child's special needs prevented you from maintaining employment?

How often is your child admitted to the hospital? Why, when and for how long?

Who is responsible for coordinating your child's care? Do you have help with that?

How do you find services for your child?

How much control do you have over who cares for your child? Do you have choices?

How do you register feedback/complaints now?

What do you now pay for your child's care? All costs – including lost wages, respite, higher housing costs, modifications, DME, etc.

If you have other children, do they have needs that are difficult to meet? E.g. your time, childcare, housing or school issues

Congregate housing

Might you be interested in living with other families with medically complex children in a community independent living situation that would provide, on site, a shared Skilled Care Center for your child's needs that would operate on hours based on your child's and family's needs?

Do you feel that this type of living arrangement would be appealing to families of children with special health needs?

Would you prefer to own or rent such housing?

If you could design such a place, what would it look like?

Contemporary vs. traditional

Formal (like a medical setting) vs. informal (a home)

Urban, suburban, rural

School systems

Close to your PCP, hospital, specialists

Access to public transportation

What services would be included on the menu available to residents and/or others?

Medical care

Daycare – children who live there, staff, and community children?

Respite for your child (so you can take a vacation, etc.)

Respite for medically complex children in the community?

Massage therapy – for children and staff

Fitness center/pool – only for the residents, include the community?

Recreation – trips, movies, etc.

Care coordination – e.g. answering service

Family resource center – library, videos, internet access

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Do you think it would be a good idea to include in the housing residents of families without medically complex children? Seniors? Affordable housing? Is it a good idea to include a diverse population of varying cultures? (this is a sensitive question that I will probably ask “sideways”)

How much space should be private for families and how much shared? E.g. just a lobby (and the medical center) as in apartment buildings or a shared “family room”, resource library, etc.

How should access to families’ space for visitors be handled? E.g. should a visiting sister or aunt have access to the medical center, family room, etc. or should visitors be limited to families’ private space

What would be the best way to have families support each other and share experiences and resources?

Staff

What kind of a relationship with staff would you like to have?

Which qualities/qualifications are most important in staff?

How much of a role in hiring, supervising and evaluating staff should parents have?

How much time would you have to devote to those tasks? How involved would you want to be?

Would you prefer a large pool of staff or a smaller number who only work at this medical center?

Are you willing to help out if the staff need you? Even during the night?

What would be the best way to communicate on a daily basis with your child’s care provider? What is the best way to regularly re-evaluate his/her care plan?

Governance

What role/responsibility should parents have in running the home?

- Developing and modifying standards of care

- Financial information/control

- Management

- Staff – recruitment, hiring, supervision

What process should be created to handle problems fairly?

How would quality assessments and evaluations be designed?

- Family satisfaction survey

- Outcomes

Would you be willing to serve on a Parent Advisory Committee for this project?

We would accommodate your needs and abilities to attend meetings (or not), email (or not), travel, time constraints, etc.