Florida Developmental Disabilities Council Inc.

Children in Nursing Homes

Final Report

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Executive Summary

The intent of this project was to assist the Florida Developmental Disability Council (FDDC) to research options for serving children with medically fragile conditions in skilled nursing facilities and living in the community. The main focus of this project is to better understand the system of care and services that will help avoid placement of children in nursing homes, promote policies that ensure that their care is appropriate while in the nursing home, and address the system coordination and services necessary to allow children with medically fragile conditions to live in the community. The project also included assisting FDDC staff in crafting legislative responses to the issue. To achieve these goals, the consultant and the FDDC staff spent many hours reviewing documents, rules and regulations; talking to medical staff, parents, trade association staff and state agency personnel about the issue; visiting a medical home at the St. Joseph's Hospital in Tampa and visiting nursing homes.

Major actions taken

The major actions taken in this project included:

- Providing technical assistance on a regular basis regarding state policy, systems of care, legislative action, and rule development associated with children with medically fragile conditions and young adults with these conditions who are transferring to adult service systems.
- Researching other state's approaches to serving this population
- Reviewing the use of Early Periodic Screening Diagnosis and Treatment (EPSDT), state plan, TEFRA options and Home and Community Based (HCBS) waivers to meet the needs of families with financial resources that exceed Medicaid traditional limitations
- Provided information about opportunities in the Patient Protection and Affordable Care Act
- Assisted in the development of proposed rules, legislative bills, and legislative proviso language
- Assisted in meetings with state agency leaders and the Florida Health Care Association
- Provided an overview of the observations made about the skilled nursing home situation and the community system of care
- Provided recommendations for system change.

Specific contract objectives/services to be provided met or not met, and why

All the objective/services outlined in the contract were met. Please see the above Project Status Report

Outcomes met or not met, and why

The work associated with this project directly influenced the new policies that AHCA put into place. Through the project, FDDC was able to provide AHCA with constructive and helpful suggestions for improving the system.

During the project, FDDC and the consultant worked very hard to achieve some important legislative changes including modifying the current Model Waiver, obtaining provisions for families that do not meet Medicaid eligibility, and modifying the rules for the Pediatric Skilled Nursing facilities. These legislative changes were not successful this year, however the ideas were introduced and received a favorable response. The timing was problematic and the intensity of the legislative session due to deliberations on Medicaid Expansion left little time or energy for other issues.

Goal and objectives met, not met, and why

All the goals and objectives of the contract were met. Please see above status report.

Recommendations for future action.

The project resulted in 10 recommendations. These are listed below.

Recommendation 1: Permanency Planning

The ongoing reviews of children in the skilled nursing facilities should include a process similar to the Texas permanency planning process. Given the resistance by some state agencies to question parental decisions, it may be necessary to have this process required legislatively as in Texas.

Recommendation 2: Pediatric Skilled Nursing Facilities Rule Revision

There were several excellent components in the proposed bill language that should be added to the existing rule on Pediatric Skilled Nursing Facilities which is a section in the overall Skilled Nursing Facilities regulation. The additional language should require:

- Referral of children birth to age 3 to Early Steps to facilitate the child's return home.
- Standardized assessment at the time of admission of the child's level of cognition, development, social-emotion, education, behavior, function, physical health, therapeutic needs and family relationship.
- The assessment be updated at least quarterly and must include an evaluation of the least restrictive setting possible for the child and the services needed to support the child and family in that least restrictive setting.
- A plan of care is developed by an interdisciplinary team, addresses the findings from the assessments, and integrates the education program into the overall plan.
- An interdisciplinary care plan team includes expertise in medical care, child development, education, therapies, and mental health including infant and early childhood. If a child receives services from a community agency or organization, they will be invited to attend care plan meetings.
- All therapists are trained and experienced in pediatrics.
- Medical protocols are in place to reduce the use of enteral feedings and ventilators whenever possible.
- The plan of care is reviewed quarterly with a status report to the parents on a quarterly basis.
- The assessment, plan of care, and status reports are shared with the CMAT.
- Each child is referred to the local educational program for an IEP, and AHCA and the CMAT will be notified if a school program is not provided.
- An early childhood specialist is on staff or under contract to work with children as determined necessary by the plan of care. This work will be in addition to the education program, and will ensure that the programs are integrated throughout the day and are developmentally appropriate.
- The facility has policies and procedures that promote ongoing relationships with the families.

Recommendation 3: Applications for the Developmental Disabilities Waiver

A policy should be established that requires that all families with children residing in skilled nursing facilities who are screened or documented to have an Intellectual or Developmental Disability be notified of the DD waiver, the benefits of applying for that waiver, and assistance in applying for eligibility. APD should strongly consider including this population as a priority population.

Recommendation 4: Establish Medical (Health) Homes for Children with Medically Fragile Conditions

Special medical expertise is necessary to create the optimal discharge planning process and ensure that all necessary services are in place prior to discharge home. Additionally, high quality ongoing care must be available. As recommended by New York State, the health home provides that best avenue to render and coordinate extensive medical care. The State Plan option for Medicaid funded health homes should be explored and funds requested to establish these services. The health home should be responsible for ensuring that the assigned private duty nurses and other health care staff have the competencies to render the care to the child. Another option is to investigate the possibility of using incentives for Pediatric Accountable Care Organizations as a way to increase health homes for this population.

Recommendation 5: Ensure ongoing care coordination by funding intensive care coordination

To ensure that intensive case management is available for children with medically fragile conditions, the Medicaid State Plan requirements should be modified to include intensive care coordination as a specific service for this population. This could be accomplished through a Targeted Case Management program or by adding coverage under a health home State Plan amendment. The intensive care coordination program should be available at the time of hospital or skilled nursing facility discharge to help establish a smooth transition to the community and should be able to be continually available to the child and family to provide coordination and support. The intensive case manager should be able to coordinate services for the managed care program and any waiver services creating the critical integration between acute and long-term care.

Recommendation 6: Obtain a HCBS Waiver for Medically Fragile Children and Adults

Either a new HCBS waiver should be requested, or the current Model waiver should be expanded to include critical family support services and home modifications. Most importantly, the eligibility criteria should include children living in the community who need waiver services to avoid an institutional placement. Optimally the waiver would include persons 21 years and older to ensure that there will be no break in services. The additional services should be incorporated into the existing 1915(b) (c) waiver to enable the Medicaid health plans to adequately serve this population.

Recommendation 7: Modify the current Medical Foster Home state plan service to include the characteristics of the Family-Based Alternative Model

The current Medical Foster Home service restricts eligibility to children in foster care and is dependent upon the recruitment of individual foster parents. The CMS program is responsible for the training and oversight of the parents. A model such as the Family-Based Alternative allows provider organizations to recruit, train, and provide oversight to the homes. The model also embraces and facilitates the role of the birth parents. This modification to the Medical Home service would open more opportunities for children who are currently living in skilled nursing facilities to live in a family home.

Recommendation 8: Children turning 21 years of age with medically fragile conditions should have immediate access to the DD HCBS waiver or the LTC plan.

If the young adult has a developmental disability and has been receiving either private duty nursing or personal care assistance they should have immediate access to the DD waiver due to the fact the lack of continuation of services will result in a serious medical crisis for the individual. The Aging Out provisions previously instituted through the Aging and Disabled Adult waiver or similar procedures must be continued as the state moves into managed care. AHCA should conduct ongoing monitoring of the services to this population in the managed care program. If it appears that the continuity of care between the children's and adult's program is problematic, or if community options are not being offered, the agency should consider creating a HCBS waiver for persons with medically fragile conditions without an age limit

Recommendation 9: Add another level of care of Adult Family Care and Small Group Homes to serve persons with medically fragile conditions as a service in the Long Term Care managed care program and encourage the development of these homes under the DD HCBS Waiver.

Although Adult Family Care is an available service under the Long Term Care managed care program, the licensure description doesn’t appear to cover persons with complicated medical conditions. In order for the managed care plans to successfully provide diversions from skilled nursing facilities for this population there must be a community living option for persons who do not have their own home or live with natural support caregivers.

The DD HCBS waiver has some flexibility in the array of services that can be provided. To provide options for transitioning adults with me /DD conditions, APD should consider expanding adult foster care as a residential option.

Review of Four States Provision of Home and Community Based Services Waivers

The project included an analysis of three states' use of Home and Community-Based Services (HCBS) or TEFRA. Because of Florida's size, large states were selected for review, California, Illinois, and New York, with Texas added later in the project. In addition to wanting to understand the general waiver configuration, the purpose of the review was to determine how states addressed the needs of children whose parents' income exceeded the levels for traditional Medicaid and SSI. The first three states all use the HCBS for this purpose. Texas has a Medicaid Buy-In program which is discussed later in the paper. None of the four states used TEFRA as a means to serve children. However, the use of TEFRA is discussed under a separate section of the report. The operation of the HCBS waiver is discussed below, by state, for 10 topics required by the contract.

California

The purpose of the HCBS Nursing Facility/Acute Hospital (NF/AH) Waiver is to provide Medicaid (Medi-Cal) beneficiaries with long-term medical conditions, who meet the acute hospital, adult or pediatric sub-acute nursing facility (NF), distinct-part NF, adult or pediatric Level B (skilled) NF, or Level A (intermediate) NF level of care with the option of returning to and/or remaining in their home or home-like setting in the community in lieu of institutionalization.

The goals of the waiver are to: 1) facilitate a safe and timely transition of Medi-Cal eligible beneficiaries from a medical facility to their home and community utilizing NF/AH Waiver services; 2) offer Medi-Cal eligible beneficiaries, who reside in the community but are at risk of being institutionalized within the next 30-days, the option of utilizing NF/AH Waiver services to develop a home program that will safely meet their medical care needs; and 3) maintain overall cost neutrality so that the costs of the participant's selected NF/AH Waiver and state plan services do not exceed the Medi-Cal institutional cost at the participant's assessed level of care and facility type. Services include:

California HCBS NF/AH Waiver Services	
Case Management	Family/Caregiver Training
Habilitation Services	Medical Equipment Operating Expense
Personal Emergency Response Systems (PERS)	Personal Emergency Response (PERS) Installation and Testing
Continuous Nursing and Supportive Services	Private Duty Nursing - Including Home Health Aide and Shared Services
Personal Care Services (WPCS)	Home Respite
Community Transition Services	Transitional Case Management
Environmental Accessibility Adaptations	Facility Respite

Table 1

It should be noted that many of the services shown above are typically state plan or Early Periodic Screening Diagnostic and Treatment (EPSDT) services for children. Because this waiver provides services for adults it includes services that, for adults, exceed state plan services.

Define and determine eligibility for services

The Department of Health Children's Services (DHCS) is responsible for the evaluation and waiver eligibility determination. The DHCS staff consists of registered nurses (RN) and the nurses' supervisor who is also a RN. The nurses must conduct an evaluation visit and determine the level of care using an instrument specified by California rules. The program serves children and adults.

Provide for alternative home settings when the family is unable to adequately care for the child in their home

Continuous Nursing and Supportive Services (CNSS) may be provided to waiver participants residing in a Home and Community-Based Continuous Care Facility (HCBCCF) and must be available to waiver participants 24 hours a day, 7 days a week. The HCBCCF waiver program, licensed as a Congregate Living Health Facility (CLHF), is a residential facility with a non-institutional, homelike environment and serves as an alternative setting for individuals who require institutional level of care but choose to receive their medical services in a home or community setting. The facilities are limited to no more than 12 beds. Adult care homes and group homes do not appear to be an option.

Determine medically necessary services for the child

The Department of Health nurse completes an evaluation through a face to face intake visit with the potential waiver participant. The nurse utilizes this evaluation to determine if the participant meets one of the NF/AH Waiver's levels of care and documents the type, frequency and amount of waiver and state plan services that the participant is currently receiving or the primary care physician has ordered. The information from the initial visit is documented on the Case Report. This report also includes medical justification to support the level of care and the need to receive the type, frequency, and amount of services that are currently authorized or being requested to ensure the health and safety of the participant to return and/or remain safely in their home and community.

Upon the determination of the participant's level of care and need for services, the nurse provides information to the participant and/or their legal representative/legally responsible adult and/or circle of support on the services available through the NF/AH Waiver and the waiver's institutional cost limit for the participant's level of care. The nurse works with the participant and/or their legal representative/ legally responsible adult and/or circle of support, the participant's primary care physician, and the waiver case manager/coordinator in identifying the state plan and waiver services that meet the participant's care needs but do not exceed the participant's institutional alternative cost limit. The plan of treatment that is developed includes both the waiver and the state plan services suited to meet the medical needs of the recipient. The primary care physician signs and approves the plan of treatment which authorizes the medically necessary services.

Coordinate service delivery among multiple programs and payment structures

Coordination of services is provided for through case management. Additionally, there is a comprehensive transition to the community service that provides support as the person moves into the community.

Provide support to families

The following services are designed to provide support to the families. They are:

<u>Home Respite</u>

The Home Respite benefit is intermittent or regularly scheduled medical and/or non-medical care supervision provided to the participant in their own home to do the following:

1. Assist family members in maintaining the participant at home;
2. Provide appropriate care and supervision to protect the participant's safety in the absence of family members or caregivers;
3. Relieve family members from the constantly demanding responsibility of caring for a participant; and
4. Attend to the participant's medical and non-medical needs and other daily living skills, which would ordinarily be performed by the service provider or family member.

The purpose of Home Respite is to temporarily replace non-medical care that was provided to the participant by their legal representative/legally responsible adult(s), and/or circle of support for a scheduled period of time as previously authorized by the department.

Waiver participants whose complex medical care needs meet the acute hospital facility level of care, requiring frequent evaluation by a licensed provider(s)—who is skilled in and knowledgeable of evaluating the participant's medical needs and administering technically complex care as ordered by the participant's primary care physician—are not eligible to receive Home Respite services provided by an unlicensed provider.

Facility Respite

The Facility Respite services are provided to participants unable to care for themselves and are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the participant. The services are provided in a continuous care facility known as a Congregate Living Health Facility (CLHF) to do the following:

1. Provide appropriate care and supervision to protect the participant's safety in the absence of family members;
2. Relieve family members from the constantly demanding responsibility of caring for a participant; and
3. Attend to the participant's medical needs and other adult daily living skills, which would ordinarily be the responsibility of the service provider or family member.

Family/Caregiver Training

Family/Caregiver Training services are training and counseling for families and/or unlicensed caregivers of waiver participants. Training for family members includes instruction about medical treatment, use of durable medical equipment, and how to provide medical care services and specialized dietary plans for the participant in the absence of the paid care providers. All family training must be included in the participant's primary care physician signed Plan of Treatment.

Unlicensed caregivers are evaluated to determine specific training necessary to meet the participant's unique needs and the services to be provided. It should also assist the family, participant, and/or circle of support in ensuring the unlicensed caregiver has the necessary skills, competencies, and qualifications to provide those services. All unlicensed caregiver training must be included in the participant's primary care physician signed Plan of Treatment.

Family/caregiver training services that are provided in the home must be rendered by a registered nurse.

Manage costs

Limits on cost and cost validation measures are set in the waiver. The cost limits are set to ensure that costs for in-home services are not greater than what their cost would have been at an institution. As part of the intake process, an agency registered nurse conducts an intake and evaluates the individual's needed level of care and checks the services ordered by the primary care physician. If these costs are more than the costs set (in the waiver application) for the level of service the individual ought to be receiving (as determined by the nurse) and no cost reduction agreement can be reached with the caregiver, the intake is denied. Limits also are placed on the total number of participants served by the waiver.

Transition children at age 21

There is no upper age limit for this waiver, so there is no transitional need.

California Interview

To augment information obtained over the Internet, the consultant conducted an interview with staff from the Long Term Care Division of the California Department of Health Services on April 12, 2013. Staff included the Bureau Chief for Long Term Care and the nursing manager. Below is a summary of the interview:

The NF/AH Waiver has evolved over time. In 2007 California combined several different waivers that served persons at various levels of care into one waiver. However, to maintain access to the different populations represented by the levels of care, the state reserved a certain number of slots by level of care as formerly reflected in each of the previous waivers. The reason for making this policy decision was that state officials and advocates were concerned that the enrollees with the lower level of care needs would fill all the waiver "slots" creating a potential backlog in the acute care and nursing home settings. The policy helps to assure that the state is able to respond to the individuals who are ready to step down from the hospital or nursing home. Each level of care has a specific cost limitation. The current levels of care with their cost limitations are as follows:

- NF-A (intermediate) at $29,548
- NF-B (basic skilled) at $48,180
- NF-B, Pediatric at $101,882
- NF-Distinct Part (these programs are a distinct part of a general acute care hospital) at $77,600
- NF-Sub acute, (more intensive care before stabilization) Adult at $180,219
- NF-Sub acute, (more intensive care before stabilization) Pediatric at $240,211
- Acute Hospital at $305,283

The current capacity across all levels of care is 3,448 and they are serving 2,350. The program has a waiting list of 670 persons for the intermediate and basic skilled levels of care.

Persons with intellectual/developmental disabilities (I/DD) are included in the waiver. Inclusion of this population is not a duplication of the Developmental Disabilities (DD) waiver in that the DD waiver does not cover the higher acuity level of care reflected in the NF/AH waiver. Also, the DD program is responsible for covering the costs associated with DD issues through a special state appropriation to comply with a California law, Lanterman Act, which entitles people with developmental disabilities to services.

Because of the availability of Early Periodic Screening Diagnostic and Treatment (EPSDT) children are usually on the waiver for one of two reasons: the family income exceeds the financial limitations for Medicaid and the NF/AH waiver allows the child to gain access to Medicaid eligibility, or because they need an out of home living environment other than an institutional setting. According to the interviewees, very few children require out of home care due to the extensive availability of in home services.

California has a robust EPSDT program, and most of the needs of the children are met through this program. Therefore, most of the persons served are adults. The program has an array of basic services and supplemental services, such as private duty nursing (California calls it shift nursing). The supplemental services are provided through the State's Title V program known as Children's Medical Services.

Each child is assigned a Medicaid nurse who is responsible for coordinating both the services through EPSDT and the waiver. For "continual" state plan services, such as private duty nursing and personal care assistance, the total cost of these state plan services must not exceed the cost limitation that is set by level of care shown above. According to the interviewee, this limitation is established in their state plan.

The HCBCCF provides out of home services for children who need out of home care but whose families do not want them to live in an institutional setting of a skilled nursing facility or an Intermediate Care Facility/DD. These facilities can be up to 12 beds and are licensed as CLHFs. The waiver states that the facility must provide a home-like setting for individuals enrolled in the NF/AH Waiver choosing a CLHF as their place of residence. The program must provide inpatient care that includes the following array of services: medical supervision, 24-hour skilled nursing services and supportive care, pharmacy, dietary, social, and recreational services.

Illinois

The HCBS waiver program for children is authorized by Illinois Public Aid Code 305CS 515-2(7). The law specifically provides that medical assistance be available to persons who are under 21 years of age and would qualify as disabled as defined under the federal Supplemental Security Income Program, provided medical service for such persons would be eligible for federal financial participation under the waiver. In January 2012, the state served 519 children under this waiver, although they have the waiver approval to serve 700.[1]

Define and determine eligibility for services

The state determines that the child is eligible for the services as follows:

- The person requires a level of care provided by a hospital, skilled nursing facility, or intermediate care facility, as determined by a physician licensed to practice medicine in all its branches;
- It is appropriate to provide such care outside of an institution, as determined by a physician licensed to practice medicine in all its branches; and
- The estimated amount which would be expended for care outside the institution is not greater than the estimated amount which would be expended in an institution.

The state has chosen in the past to exempt parental income in the HCBS waivers for medically fragile children. Children served through the waiver are eligible to receive all medically necessary state plan services. In the 2012 legislative session, a bill passed that capped the parental income at 500% of poverty. This results in an income cap of $115,250 for a family of four. Co-payments were also established.[2]

The process for eligibility determination for the waiver is described below:

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[1] Information based on Report of Medicaid Services for Person who are Medically Fragile, Technology Dependent by HFS, January 2012 and the filed 1915(c) waiver for MFTD 2007.

[2] Fiscal policy center *At Voices for Illinois Children*.

A home care consultant or care coordinator performs the initial evaluation. Professional qualifications for these positions include: registered nurse, social worker, or speech therapist. Nursing care coordinators are required to have a bachelor's degree and two years of public health or specialized nursing experience. They must be licensed as a professional registered nurse in Illinois. Social work care coordinators must have a Master's degree from an accredited school of social work and at least three years of experience with social work agencies. Speech and Hearing care coordinators must have a Master's degree in Speech-language Pathology, Audiology, or Communication Disorders and two years of experience in a speech/hearing program, including the Clinical Fellowship year.

The Illinois MFTD level of care instrument has been developed with the assistance of a Quality Improvement Organization. Level of care instruments used by other states were studied. A tool was tested and adopted specific to Illinois from level of care tools used by Oregon and Virginia. The level of care tool assesses both technology and nursing needs (medical fragility). Points are assigned to technology and nursing services. A minimum of 50 points is required. Once completed, the level of care and other medical information is sent to Health Family Services for review and approval. Admission to the waiver is contingent upon an applicant requiring one or more of the services offered in the waiver in order to avoid institutionalization.

Establish the necessary array of services

Waiver services include the following:

Illinois MFTD Waiver Services	
Respite Care	Placement Counseling
Environmental Modification	Family Training
Special equipment otherwise not covered by Medicaid State Plan	Medically Supervised day care

Table 2

These services are provided in the participant's home or in a Children's Community-Based Health Care Center Model, licensed by the Illinois Department of Public Health. If providing respite in the home, respite services must be provided by appropriately qualified licensed nurses and certified nurse's aides, employed by an approved private duty nursing agency. If providing respite in the Children's Community-Based Health Care Center Model, nurses and certified nurse aides will be employed by the Center. The State does not permit respite and private duty nursing services to be provided simultaneously. The Children's Community-Based Health Care Center Model is a designated site which provides necessary technological support and nursing care provided as respite care in a stand-alone facility. It is licensed by the Illinois Department of Public Health as an Alternate Health Care Model. The model provides respite for a period of one to fourteen days for those individuals, under age 21, who are in the waiver, and who are clinically stable. Care is to be provided in a home-like environment that serves no more than 12 children at a time, offering an alternative setting for waiver services normally provided in the child's home.

The state authorizes home health agencies to provide in home services. However, only a specialized group of nursing agencies services the technology-dependent pediatric population with shift nursing care. There are 45 such agencies throughout the state. Also, appropriately qualified staff—including RNs, LPNs, and certified nurse assistants—provide respite care for this population. The nurses must be employed by a state approved agency unless the respite care is provided in a community-based health center and the nurses are employed by the health center.

Provide for alternative home settings when the family is unable to adequately care for the child in their home

Alternative home settings are not included in the waiver.

Determine medically necessary services for the child

Eligibility includes individuals under the age of 21 who, because of the severity of their physical illness or disability would require the level of care in a nursing facility or long-term care hospitalization without the support of the services provided under the waiver. The waiver participants do not include individuals under 21 who require institutionalization solely because of a severe mental or developmental impairment.

The Division of Specialized Care for Children (DSCC) is operated by the University of Illinois. The DSCC care coordinators assess the participant for physical health, mental health, social services, respite, and educational needs. Information is gathered from the participant and family, nursing agency, physician, medical specialist, and Early Intervention Program or the school, if appropriate. In the development of the plan of care, the care coordinator includes the expectations of the family for the child in the home and community and consideration of the family and caregivers' supports and employment schedules. Care coordinators conduct an initial home assessment upon admission to the waiver, and then at the three-year evaluation or if the family relocates. The home assessment is performed to identify safety risks and home modification needs. As an ongoing assessment of need, the DSCC care coordinator contacts the family each month regarding the health and safety of the participant.

Coordinate service delivery among the multiple programs and payment structure

DSCC care coordinators identify and assist the family with accessing community resources to meet the child's or family's needs beyond waiver services. Care coordinators also participate in Individual Education Plans (IEP) meetings, if the family wants support. Nursing hours (non-waiver service) and respite are prescribed by the week to allow the family some flexibility. The nursing agency and the family determine when services will be provided. In the event of an acute illness or change in available supports, additional nursing hours may be approved to prevent hospitalization. The case manager contacts the family each month regarding the services the child is receiving, including nursing.

If services cannot be provided by the nursing agency or living with the parents is considered by the physician as unsafe, the back-up plan is for the child to be admitted to the hospital or skilled nursing facility. It does not appear that the state has other residential options for the children.

Families are informed to call the care coordinator if the child becomes acutely ill and the physician has requested an increase in nursing services. A Health Family Services nurse and physician review plans of care to determine if the services meet the participant's needs or if there is a need for a change in the plan of care.

Provide support to families

Family supports are provided to persons who live with or provide care to a person served on the waiver, and may include a parent, spouse, siblings, relatives, foster family, or in-laws. Training includes instruction about treatment regimens and use of equipment specified in the plan of care. Updates as necessary are required to safely maintain the participant at home. It may also include such training as Cardiopulmonary Resuscitation (CPR). All family training must be included in the participant's written plan of care.

Counseling services are provided on a short-term, issue-specific basis for family or individual for the purpose of maintaining the participant in the home placement. This service is prescribed by a physician based upon their judgment that services are necessary to maintain the child in the home placement. This service must be provided by a licensed clinical social worker (LCSW), a licensed clinical psychologist, or an agency certified by the Department of Human Services, Division of Mental Health or Department of Children and Family Services to provide Medicaid Rehabilitation Option services (State Plan services).

Respite services as described above are also available.

Managed costs

The DSCC care coordinator completes the Cost Estimate form, which includes the projected cost of care and services. This information is included in a packet sent to Health Family Services along with the assessment of care and the services needed. The Health Family Services physician and nurse consultants determine whether the individual cost limit will meet the needs of the participant. The plan of care is developed with input from the attending physician. If the cost of home care is greater than the institutional cost, the attending physician is consulted to ensure that the participant can be cared for safely in the home under the cost limit. DSCC provides utilization review as well.

The state uses a blended rate for the cost comparison of the waiver, using both hospitalization and skilled nursing facility costs. Recent legislative action will cap the family income at 500% of poverty and require some level of cost sharing.

Transition children at age 21

The waiver only serves participants up to the age of 21. As participants move to adulthood, adult HCBS waivers and other long-term care services are available as long as the child has a medical need for the service. Adult waiver service models typically offer mixes of care provided by both non-licensed and licensed professionals.

Three state agencies are involved in transition activities. They are the Division of Specialized Care for Children (DSCC), the Department of Healthcare and Family Services (HFS), and the Department of Human Services-Divisions of Rehabilitation Services (DRS) and Developmental Disabilities (DDD). These agencies work together to help MFTD waiver participants transition to adult services as they approach their 21st birthday. The goals of transition planning include:

- Making sure everyone involved has a chance to learn about and discuss transition activities,
- Making sure transition works the same way for all people served,
- Helping participants direct their transition as much as possible and helping them to be as independent as possible,
- Making sure everyone understands what is happening,
- Keeping track of participants who leave the MFTD HCBS waiver, and
- Giving families information to make the transition process better.

For up to three to five years before a participant reaches age 21, Department of Health Services (DHS) case managers and DSCC care coordinators work with families to develop a transition plan. The following is reviewed:

- Participant's medical needs,
- Services available from different state programs,
- Services available to help families make a gradual transition to the adult service programs and adjust to any differences in the services prior to age 21,
- Need for educational and vocational planning and services, and
- Need for assistive technology services and devices;

To ensure that the transition goes smoothly, DSCC and DHS staff discuss transition when the participant reaches age 14. At that time, DSCC sends a letter telling the family about adult programs. Parents are asked to sign a release of information so DSCC can share information about the child with DHS. When the participant reaches age 15, the DSCC sends the family information about the vocational rehabilitation (VR) program. When the participant reaches age 16, DHS makes a home visit along with the DSCC care coordinator. When the participant reaches age 17, a DHS-DRS Vocational Rehabilitation transition specialist will contact the family. The family will also receive information about Centers for Independent Living and other adult supports or services. When the participant reaches age 18, families are given the opportunity, separate from this waiver, to try out some of the adult individual self-directed services, as appropriate, in an effort to help the participant make a gradual change to the adult services program. The choice to move to another HCBS waiver will be offered at least annually until the participant's transition is completed. When the participant reaches age 21, they are no longer eligible for the MFTD children's waiver, but are likely to qualify for one of the programs mentioned above.

Illinois Interview:

An interview was conducted on Friday April 26, 2013 with the Manager of the Waiver unit in the Illinois Medicaid office. The state is operating under an extension of their 2007 approved waiver. The waiver serves about 550 children, including children with developmental disabilities. There are about another 500 children who are considered technology dependent who do not meet the threshold for waiver services who are served through the EPSDT access to shift nursing. In Illinois, the state plan does not include shift nursing. To access the service, the family/child has to go through the Medicaid EPSDT pre-authorization process.

Children on the waiver receive care coordination through the Universities Division of Specialized Services. The care coordination is intended to coordinate both State Plan, EPSDT and waiver services. However, Medicaid approves the level of shift nursing through a prior authorization process. Care coordination is provided to children receiving their nursing services through the EPSDT program only. Children without shift nursing and not on the waiver do not receive care coordination.

The legislature recently changed the financial eligibility for families at 500% of poverty. The state is working with CMS on the waiver modification but moving slowly. The legislation also required the families pay a co-pay. The state has not addressed this issue yet with CMS. According to the interviewee, CMS is not opposed to the 500% cap on the family earnings. The state has never collected any information on the financial level of families. Therefore, they have no way to determine how many families may be affected by the cap of 500% of poverty. Delays in getting the necessary data and other issues in Illinois have resulted in the CMS approval of a waiver extension rather than a new waiver.

Although the waiver states that the cost of care will be capped at the institutional cost, the provision is not rigidly enforced. The cap on costs is determined by the combination of state plan, EPSDT, and waiver services. The state is more concerned with overall cost neutrality than with the costs of individual situations. The challenges confronted when trying to cap children's services due to the EPSDT requirements were also discussed.

The state's Alternative Health Care Delivery Act provides for the operation of the Children's Community-Based Health Care Center, which cannot exceed 12 beds. This program provides for respite care for up to 14 days and transitional services when the child is being discharged from a hospital or skilled nursing facility. The program is not available as an alternative home. The state does not have an alternative medical foster home option.

Although the state has well defined practices, transitions for "aging out" populations are very difficult. There is a waiver for adults operated by the Illinois Rehabilitation Agency. The adult waiver does not have the range of services that are available to children through the combination of waiver, EPSDT and state plan services, resulting in a loss of available services. However, shift nursing is available in the adult wavier. Through the consumer directed model, individual licensed nursing are enrolled providers rather than only being enrolled through home health agencies.

For children, the home health agencies must meet additional standards to provide shift nursing. Since shift nursing is only provided to children through EPSDT it has its own rate. The rate is about $36 per hour for an RN in the Chicago area, $32 for LPN. In the rest of the state, it is $28 per hour for an RN and $25 for an LPN. Eligible children may receive services through the medically fragile waiver or the DD waiver. Because the bulk of costs are in the state plan and EPSDT, it is not really an issue as to what waiver they are served under. Although allowable for adults, the state does not permit individual licensed nurses to provide shift nursing care to children. The state officials believe that children are more vulnerable and should be served by an agency.

New York

New York has five waivers for children living at home with complex medical conditions. These waivers are assembled in two sets. Care at Home (CAH) Waivers I and II are operated by the Department of Health. They provide medical assistance to families with children living at home who have severe disabilities or complex medical conditions. The I and II refer to levels of care, with CAH I serving children who meet the admission criteria for a nursing home and CAH II serving children who require hospital level of care which is based primarily upon the use of ongoing medical technology.

The CAH Waivers III, IV, and V are operated by the Office of Developmental Disabilities and are restricted to children with developmental disabilities whose parental income exceeds traditional Medicaid and SSI financial levels. [3]

The New York State 2012-14 Enacted Budget directed the Department of Health (DOH) and the Office of People with Developmental Disabilities (OPWDD) to review the care of medically fragile children and make recommendations regarding several aspects of their care, including how to transition the population to managed care. The report recommends that both populations be transitioned to managed care within the next two years.

New York State has defined the medically fragile child as an individual who is under 21 years of age and has a chronic debilitating condition or conditions, who may or may not be hospitalized or institutionalized, and is:

- technology-dependent for life on health-sustaining functions, and/or
- requires a complex medication regimen or medical interventions to maintain or improve their health status, and/or
- is in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health, or development at risk.

The definition above was created through the Medically Fragile Children Work Group Report and includes conditions that may go beyond those defined in their current waiver. The state has determined that they are currently serving 13,000 children who meet the definition of medically fragile at a cost of $900 million dollars.[4]

Define and determine eligibility for services

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[3] Based on Medically Fragile Work Group Report by DOH, OPWDD, February 2013; conversation with OPWDD staff, and the filed 1915(c) waiver 2009.

[4] *Medically Fragile Children Work Group Report, February 2013, State of New York*.

Eligibility for CAH I and II is as follows:

- Under the age of 18 and unmarried
- Meets the categorical eligibility criteria for SSI
- Requires a level of care provided by a skilled nursing facility or hospital
- Capable of being cared for safely in the community

Eligibility for CAH III, IV, and VI for persons with I/DD conditions

- Under the age of 18
- Have a developmental disability
- Have complex health care needs
- Requires level of care provided by an intermediate level of care and not hospitalized.

Eligibilities for CAH I and II are handled by CAH coordinators in the local state offices. The CAH Coordinator completes a home assessment to determine if the child can be safely and cost effectively cared for in the family home. The home assessment includes a review of the physical structure of the home for accessibility and whether the home has adequate electrical wiring for the special medical equipment. The Coordinator also assists the family to complete a full application at that time. Documentation is obtained to demonstrate that the child meets the eligibility for the level of care. A Pediatric Patient Review Instrument is completed to determine and show the medical needs of the child.

Eligibility for the III, IV, and VI waivers is in accordance with the developmental disabilities eligibility determination process use by the OPWDD agency.

An earlier version of the waiver required that the child have been in a hospital setting for 30 days or a skilled nursing facility for 60 days prior to being eligible for the waiver. Also in the earlier version, only children not eligible through the existing Medicaid program were eligible for the program. With the waiver revisions in 2007, both of these provisions were eliminated.

Because the CAH Waivers III, IV and VI are operated as a developmental disability waiver and follow the general principles of a developmental disabilities HCBS waiver, the details of the CAH Waiver discussed below is focused on CAH I and II.

Establish the necessary array of services

The array of services for all CAH Waivers includes:

New York Services for CAH Waivers
Case management
Home and vehicle modifications
Respite mare
Five palliative services, including:
o family palliative care education
o pain and symptom management
o bereavement services
o massage therapy

o expressive language

Table 3

All other services are provided through the State Plan and the EPSDT federal requirements.

Provide for alternative home settings when the family is unable to adequately care for the child in their home

Both sets of the CAH waivers are for children living at home only. The developmental disability waivers include alternative home settings when the family is unable to care for the child and the child has a developmental disability. It does not appear that out of home services are available to children without developmental disabilities.

Determine medically necessary services for the child

The CAH Coordinator works with the family to develop a plan of care for the child that includes all the services needed by the child and must address:

- Description of all the services needed, including the physicians orders that show the medical necessity of the services
- Monthly budget which includes both State Plan and waiver services
- Case Management Plan

The plan of care is updated every 120 days or when an event occurs requiring a plan of care adjustment. The physicians orders must be updated every 60 days and the Pediatric Patient Review Instrument every year.

Coordinate service delivery among the multiple programs and payment structure

The CAH Coordinator is responsible for intake and eligibility determination. The case manager provides ongoing support. The case manager assists the parent in preparing for the plan of care meeting, assists in identifying insurance benefits and other resources, and assists in accessing all services including State Plan and waiver services. The case manager is responsible for coordinating all services, including waiver services and State Plan services. The services are specified on the Plan of Care. Services are provided through DOH enrolled providers.

Provide support to families

The case manager is responsible for assisting the family in locating services. Additional respite care is available as well as palliative care services if necessary.

Managed costs

There is a monthly budget limit or cap for Medicaid costs for each CAH program. The budget caps are based on needs of the child and vary for each CAH program:

- The monthly budget cap for **CAH I** is based on the monthly Medicaid costs for care in a skilled nursing facility. It is currently set at $9,000 per month.
- The monthly budget cap for **CAH II** is based on the monthly Medicaid costs for care in a hospital. It is currently set at $14,500 per month.
- A final budget is developed to show all of the monthly costs for care and services at home. The budget also shows who will pay for each item of care or service. For example, private

insurance may pay for necessary medical equipment, and Medicaid may pay for the hours of nursing care provided each month.

- Prior Approval for medical necessity is required for some medical procedures and supplies, such as durable medical equipment, prosthetic or orthotic appliances, and certain medications.

Transition children at age 18

This waiver only covers children up to the age of 18, requiring that youth transition to the Nursing Home Transition and Diversion (NHTD) Waiver. This waiver provides supports and services to assist adults with physical disabilities between the ages of 18 and 64—or those who are 65 and older upon application—to safely integrate into or remain in community living. The NHTD HCBS program is administered by the New York State Department of Health through contractual agreements with Regional Resource Development Centers and Quality Management Specialists. Waiver participants may either transition from a nursing facility or other institution to a community setting or participate in the program to prevent institutionalization (diversion).

When youth are transitioning from the CAH waiver to the adult waiver, Regional Resource Development Specialists and Service Coordinators collaborate to review the applicant's history, if any, of prior state plan and waiver services. This collaboration helps develop an understanding of the strengths and needs of the applicant, as well as the availability of informal and formal supports and informs the development of the waiver service plan and ensures that the person's needs are addressed.

The NHTD waiver offers a variety of services, including service coordination, assistive technology, community integration counseling, peer monitoring, positive behavioral interventions and supports, community transitional services, structured day program, wellness counseling, home and community support services, respiratory therapy, day program, respite care, home modifications, and nutrition counseling.

Texas

The Medically Dependent Children Program (MDCP) HCBS Waiver provides supports to families and primary caregivers of individuals who wish to move from a nursing facility to the community or to remain in the community. Without MDCP waiver services, these individuals would require nursing facility or hospital care. Texas uses the MDCP waiver to provide services to children and young adults (under age 21) in the least restrictive environment possible. These environments include the individual's or a family member's home or a foster family home. The program attempts to serve children and young adults with disabilities in a cost-effective manner through a process that does not supplant the family role and is designed to support permanency planning for all program individuals. MDCP strives to:

- enable children and young adults who are medically dependent to remain safely in their homes,
- offer cost-effective alternatives to placement in nursing facilities and hospitals, and
- assist families in their role as the primary caregiver for their children and young adults who are medically dependent.

The services include:

Texas MDCP Waiver Services
Respite
Financial management services

Adaptive aids
Flexible family support services
Minor home modifications
Transition assistance services

Table 4

Most services are available either through the traditional method or consumer-directed care.

The program operates in tandem with the Money Follows the Person Demonstration (MFPD) which is available for the MDCP. The program is intended to eliminate barriers and enable Medicaid-eligible individuals to transition from nursing facilities and receive necessary long-term services in the setting of their choice. To access the MFPD funds, the individuals must reside continuously in an institutional setting for at least 90 calendar days prior to the waiver program eligibility date and are enrolled from a Medicaid-certified nursing facility. Individuals who participate in MFPD must transition from a nursing facility to a waiver program. Children may be served by the waiver without prior residence in a nursing facility.

The state currently serves approximately 7,175 children up to the age of 21. As of April 30, 2013, their interest list (waiting list) held 27,184 children. This represents the greatest number of identified children with medically fragile conditions in any of the states.

Define and determine eligibility for services

For an individual to be determined to need waiver services, an individual must require:

- provision of at least one waiver service, as documented in the service plan,
- provision of waiver services at least monthly or, if the need for services is less than monthly, the participant requires regular monthly monitoring which must be documented in the service plan.

The level of care assessments are performed by registered nurses who may be employed by the operating agency.

Medicaid or the Department of Aging or Disability Services (DADS), or a home and community supports agency contracted with Medicaid or DADS. Registered nurses licensed by the state, with experience in pediatrics and who have completed a level of care training within the last two years, are eligible to complete the evaluations. For individuals to qualify for nursing facility care (skilled nursing facilities), their medical conditions and health care needs must be such that they require institutional care under the supervision of a physician. Individuals must meet the level of care and medical necessity criteria for nursing facility admission as specified in the Texas Administrative Code and must have a medical condition of sufficient seriousness that the individual's needs exceed the routine care which may be given by an untrained person and requires nurse supervision, assessment, planning, and intervention on a regular basis. When completing the eligibility determination, the registered nurse completes the individual's medical necessity and level of care assessment. This assessment is submitted to the State's contracted Medicaid Management Information System, where registered nurses and physicians review the assessment, verify the level of care, and calculate the Resource Utilization Group in accordance with state-established criteria. The process is the same for level of care initial evaluations and reevaluations.

In addition to the clinical requirements, the child must be eligible for Medicaid. For children whose parents' income exceeds the financial requirements, the Medicaid Buy-In for Children (MBIC) program is an acceptable Medicaid eligibility category to apply for MDCP. The Medicaid Buy-In for Children program was implemented by the Health and Human Services Commission (HHSC)—Texas Medicaid—effective Jan. 1, 2011, to provide Medicaid to children with disabilities up to the age of 19 with family income up to 300% of the Federal Poverty Level (FPL). The Medicaid Buy-In program is also an acceptable categorically eligible type of Medicaid for eligibility purposes for 19 and 20-year-old individuals applying for MDCP.

Provide for alternative home settings when the family is unable to adequately care for the child in their home

Texas does not provide out-of-home care as a specific service under the MDCP. If the child lives in a foster home that is licensed by the state's Protective and Regulatory Services and meets all other eligibility criteria, the child may receive services through the waiver. The services would be provided just as they would in a traditional home. It appears that the children must be under the state's child protection program to be eligible for foster home care. The DADs waiver has a service for children called the Family-Based Alternative care program that is available for children with I/DD conditions whose parents are not able to address their needs at home but want their child to receive services in a family-based setting. There is no comparable service for children who have a medically fragile condition but do not have I/DD.

The state has an aggressive program for monitoring and addressing permanency for all children with developmental disabilities living in institutions. In 2001, the Texas Legislature passed S.B. 368, requiring that the HHSC monitor child (defined in the legislation as a person with a developmental disability under the age of 22) placements and ensuring ongoing permanency plans for each child with a developmental disability residing in an institution in the Texas. S.B. 368 requires that every child residing in an institution have a permanency plan developed and updated semi-annually. The primary goal of permanency planning for children under age 18 is to reunite the child in the birth family or an alternative family. Permanency planning laws in Texas are designed to ensure that children who are placed in institutions are placed there on a temporary basis. The objective of the permanency planning process is to ensure that the child will live in a long-term nurturing relationship with a family as soon as possible. To the maximum extent possible, the child will maintain a relationship with the birth family. As a result of this work, as of January 2013 only 76 children resided in nursing facilities.

While the state makes every effort to encourage reunification of children with birth families, there are some instances when this is not in the best interest of the child or family. In those situations, the preferred alternative for a child may be a support family, also known as a family-based alternative. As referenced above, family-based alternatives are defined in S.B. 368 as "a family setting in which the family provider or providers are specially trained to provide support and in-home care for children with disabilities or children who are medically fragile." While active recruitment of families continues, the number of children in need exceeds the current availability of support families.

Determine medically necessary services for the child

The individual, the parent/guardian, the DADS case manager, DADS regional nurse or home and community support services agency nurse if applicable, and those chosen by the individual, develop the individual plan of care. Texas state law requires that providers be involved in the creation of the plans. The DADS case manager must make initial contact and meet with an individual within 30 days of the individual's release off the interest list (waiting list) or request to apply for MDCP. The DADS case manager must complete the service plan within 30 days of the initial meeting with the individual. A re-evaluation is conducted annually and a service plan is developed for services for the next year. The individual, parent/guardian, designated representative, or provider on behalf of the individual can request changes in the service plan at any time. The DADS case manager or regional nurse discusses the requested service plan changes with the individual or the individual's representative and approves or denies the changes. The information gathered during the medical necessity and level of care assessment is used in developing the service plan. The DADS case manager works with the individual and representative to set goals to address caregiver relief, health care, social, and other support needs identified for and by the individual during the initial assessment. They develop a plan to achieve each goal, including those goals requiring non-waiver services that are otherwise important to the individual's health and well-being. The service plan must be consistent with the desires of the individual. The DADS case manager must educate the individual and representative about all waiver services as part of the service plan development. The service plan must reflect the goals, needs and preferences of the individual. The individual or representative must sign the plan to indicate understanding of, and agreement with, the service plan. If the individual does not agree with the service plan, the individual or representative may file an appeal.

The service plan includes services (listing units, frequency, etc.) and the roles of the individual, DADS case manager, providers, family, and informal caregivers in achieving the goals and meeting the individual's needs, including health care needs. The DADS case manager is responsible for monitoring and overseeing the implementation of the service plan. The DADS regional nurse may assist with monitoring and overseeing the service plan. Monitoring and implementing the service plan requires that the DADS case managers maintain contact with the individual and their representative to ensure appropriate service delivery. The service plan can be updated at the request of the individual, the representative, or the provider when the individual's condition changes. The service plan can be updated to reflect changes resulting from utilization review, and the individual may appeal any changes.

Coordinate service delivery among multiple programs and payment structures

As part of care coordination, the DADS case manager must give the individual information about community organizations or third party resources that are otherwise important to the health and well-being of the individual and make referrals as necessary. The DADS case manager, with support from the DADS regional nurse or HCBS agency nurse as applicable, is responsible for organizing necessary services to achieve the individual's goals, including those goals requiring non-waiver services that are otherwise important to the individual's health and well-being. The DADS case manager must contact the individuals in person or by telephone at least every six months. The individual's access to services and satisfaction with services are reviewed during the six months contact. The backup plan is reviewed at each six month contact. Although the requirements imply a high level of service coordination, the every six month contact requirement brings the intensity of the case management program into question.

There are several different types of services that can be accessed for children under 21 who are Medicaid eligible. These include:

- The Comprehensive Care Program (EPSDT)
- Primary Home Care
- Day Activity and Health Services
- Personal Care Services

These services are outside of the waiver requiring careful coordination to ensure that all services are in place without duplication. The services are described below:

Comprehensive Care Program

The Comprehensive Care Program (CCP)—which was formerly called the EPSDT program—may be a source of home nursing for children eligible for Medicaid through Supplemental Security Income (SSI) or some other Medicaid-eligibility route. The case manager is required to inquire about any services the applicant is currently receiving or has requested from CCP. These services are taken into account during the MDCP care planning process. If the MDCP applicant is not currently authorized to receive private duty nursing services through CCP, the case manager may assist the family in applying for CCP services, if appropriate. The CCP hours for the week do not have to be exhausted before MDCP hours for other services are utilized because CCP offers private duty nursing while MDCP offers respite services and flexible family supports and child care support. In some situations, CCP services maybe approved to follow a child to school.

Primary Home Care and Day Activity and Health Services

The child may also receive Primary Home Care and/or Day Activity and Health Services. Primary Home Care is a non-technical, medically related personal care service prescribed by a physician as part of a client's plan of care. Primary home care is available to eligible Medicaid clients whose health problems result in functional limitations in performing activities of daily living. The service is provided by a supervised Personal Care Attendant, who performs tasks based on individual need. Day Activity & Health Services are available through licensed Day Activity and Health Services facilities that provide daytime services, up to 10 hours per day, Monday through Friday, to individuals residing in the community. The facilities address physical, mental, medical and social needs.

Personal Care Services

Personal Care Services are also available to Medicaid recipients under the age of 21 who are eligible for the Texas Medicaid program and may receive these services in addition to receiving MDCP services. Since Personal Care Services address different needs than those met by MDCP services, the applicant's/individual's decision to access Personal Care Services does not affect the MDCP services authorized by DADS case managers. For applicants receiving both Personal Care Services and MDCP, close coordination between DADS and Personal Care Services case manager is necessary to ensure the individual plan of care accurately reflects all services being received. The DADS case managers are required to coordinate services with Personal Care Services case managers for individuals who are receiving both Personal Care Services and waiver services.

The use of Medicare, Medicaid, private insurance, home health services provided by a community agency, personal care provided by friends or relatives, and other community services must be explored to determine if any of the individual's needs can be met through these resources. Staff must ensure that requests for services must first be sought through these resources.

As is evident above, Texas has numerous different programs that can be coordinated to provide a comprehensive individual plan of care. However, some of these services are very similar with slightly different eligibility requirements which require that the case manager be very familiar with multiple programs. Although the programs are all available, the individual plan of care must ensure that services are comprehensive but not duplicative.

Provide support to families

To provide support to families, the waiver includes a broad range of services entitled “flexible family support services” which are intended to promote community inclusion in typical child/youth activities through the enhancement of natural supports and systems. To accomplish this, flexible family support services providers may provide personal care supports for activities of daily living and instrumental activities of daily living, skilled care, non-skilled care, and delegated skilled care supports to support inclusion. This service may be reimbursed if part of an approved service plan and if delivered in a setting where provision of such supports is not already required or included as a matter of practice.

Flexible family support services are a diverse array of approved, individualized, disability-related services that support independent living, participation in community-based child care, and participation in postsecondary education. Flexible family support services may be used only when the primary caregiver is working, attending job training, or attending school. Flexible family support services may not be used in place of child care that is paid for by the primary caregiver. An individual may receive a maximum of 1,875 hours of flexible family support services per service plan year. Exceptions to the service limit will be granted on an individual basis if the need for flexible family support services is greater than 1,875 hours. DADS will grant an exception to the 1,875 hours if there is evidence indicating that exceeding the service limit is necessary to protect the individual's health and welfare. If an exception is granted, it is subject to the individual cost limit for the waiver. Requests for exceptions are submitted to the DADS case manager, who can consult with the DADS regional nurse as needed.

The State allows an individual to select a relative or legal guardian, other than a spouse, to be their provider for adaptive aids, flexible family support services, financial management services, minor home modifications, and respite. The relative or legal guardian must meet the requirements to provide waiver services and cannot be the parent or legal guardian of an individual who is under age 18. The controls that are in place to ensure that payments are made only for services rendered are the same controls the state has for any of the waiver services. There are no additional service limits when a relative provides the services. The State ensures waiver services provided by a relative are in the best interest of the individual through the development of the service plan and the requirement for DADS to approve the service plan.

Manage costs

The service plan is developed in the same manner for the individuals who receive services through the traditional service option and those who elect the consumer-directed program and as described above. Once developed, DADS enters the amount of the cost of the service plan into their accounting system. The budget is the estimated cost of the services in the approved service plan and, if relevant, the consumer-directed services reimbursement rates. DADS's staff perform reviews of each agency provider every two years and consumer-directed service agencies at least every three years to monitor that services in the service plan are delivered. DADS annually aggregates data and reports the results to Medicaid. Medicaid discusses with DADS any significant findings and together with DADS reviews remediation activities and prepares improvement plans as needed.

Cost limits for waiver services are set at 50% of the reimbursement rate that would have been paid for that same individual to receive services in a nursing facility. Note that the cost of the other services listed above, such as the Comprehensive Care Program, are not included in the cost limits. The cost limit is the maximum dollar amount available to an applicant for MDCP services per individual plan of care effective period. Cost limits are also set by a system of allocating costs by participant called the Resource Utilization Groups (RUG). The assigned RUG is calculated from the Medical Necessity and level of care assessment. If the case manager determines that the cost of MDCP services is within the individual plan of care cost limit, MDCP is determined to be a feasible alternative to nursing facility care. The case manager may continue with MDCP eligibility determination. The case manager must deny MDCP services if the applicant's initial individual plan of care is not under the cost limit.

Transition children at age 21

Currently, young adults who are approaching age 21 are referred to the Community Based Alternative program which is the Texas HCBS waiver for elderly persons and persons with disabilities or the Texas Star Plus, depending upon what part of the state they live in. The Texas Star Plus managed care program is an integrated acute care and long-term care program that incorporates the Community-Based Alternative waiver in the Regions that it is operational. As with the Florida system, this waiver has an interest list (waiting list). Youth transitioning from the MDCP waiver are automatically enrolled in one of the two adult waivers and do not have to be placed on the interest list. Managed care plans also include Primary Home Care and/or Day Activity and Health Services. In 2012, Texas reduced the waiting list for the CBA and Star Plus Waiver by 49,641 persons. In April 30, 2013 there were 8,264 persons waiting for the CBA with another 5,790 waiting for the Star Plus Waiver.

The state has transitioning requirements in place to ensure that the work is initiated several months in advance to transfer the young adult to the Community-Based Alternative program or Texas Star Plus, whichever is operation in the specific area of residence.

Adult Foster Care (AFC) is available for adults and provides a supervised, 24-hour living arrangement in an adult foster home for people who are unable to continue living independently in their own homes because of physical, mental, or emotional limitations. Adult Foster Care providers and residents live in the same household and share a common living area. With the exception of family members, no more than three adults may live in the foster home unless the state licenses it. The person receiving services pays the provider for room and board. There are three levels of care which include various levels of nursing supervision. These services could be very helpful in transitioning persons who are medically fragile.

The 2013 Legislature authorized the Texas Medicaid program and DADS to seek a waiver for adults with medically fragile conditions and expand the Money Follows the Person program for adults.

States Medicaid State Plan Services (EPSDT)

The contract for the project required that the report include a discussion of how states are using the EPSDT requirements to provide services for children with medically fragile conditions. State Plan services are services in the state's Medicaid State Plan that are provided to all Medicaid recipients who meet the medical necessity requirements for the services. The federal EPSDT requirements are found in 42 USC § 1396d(r) (542), which states that "in addition to specified screening, diagnosis, and treatment, law requires other necessary health care, diagnostic services, treatment, and other measures described in law to 'correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan.'" Therefore, even if the state has not established a service in their State Plan, if a child medically requires the service it must be provided. Some states refer to their children's benefit package as the EPSDT services. States are required to cover private duty nursing and personal care for children. States are permitted by Medicaid to establish limitations on services, but for children they cannot impose limitations if the child's medical needs exceed those limitations.

States that do not have HCBS waivers for children with medically fragile conditions may provide all necessary services through the EPSDT provisions. If the state has a TEFRA waiver for children who meet the institutional level of care, the state would be able to allow families whose income exceeded the Medicaid financial eligibility requirements to enroll in Medicaid and then receive the full array of medically necessary services through EPSDT. The state of Washington provides services for children with life limiting or threatening diagnosis to receive several benefits, such as symptom management, grief support for the family, and case management through state plan services that are approved and managed through the EPSDT system.[5]

For children in HCBS waivers, the vast majority of Medicaid costs are borne by the state plan Medicaid services or those provided in addition to the state plan through the EPSDT program. This fact is demonstrated in the chart below which shows the state plan/EPSDT costs and the waiver costs for California, Illinois, and New York. The California numbers include adults; therefore, the waiver costs are greater and the state plan/EPSDT services are less because fewer state plan/EPSDT services are offered to adults, creating a greater cost burden on the waiver.

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[5] *Concurrent Care for Children Implementation Toolkit*, Appendix 4.

State	State Plan/EPSDT Costs	Waiver Costs
California	$ 54,046	$ 27,713
Illinois	$ 146,077	$ 4,464
New York	$ 141,662	$ 7,410
Texas	$ 60,257	$15,449

Table 5

Each of the four states use state plan services extensively for children who have medically fragile conditions. However, each state applies the EPSDT provision differently.

California calls all their services to children EPSDT services. These services include all services covered by their Medicaid program (Medi-Cal). In addition to regular Medi-Cal benefits, a beneficiary under the age of 21 may receive additional medically necessary services. These additional services are known as EPSDT Supplemental Services and include private duty nursing services from a RN or a Licensed Vocational Nurse (LVN), Case Management, Pediatric Day Health Care, and Nutritional and Mental Health Evaluations and Services. Other services if identified can be provided; however, the ones listed above are routinely available based upon medical necessity criteria.

In Illinois the majority of the services are covered under the state plan program with the exception of shift nursing (private duty) nursing which they refer to as EPSDT supplemental shift nursing. The Medicaid office prior authorizes all shift nursing services.

New York covers all their services for children under the EPSDT program with a specific manual that outlines the EPSDT benefit. These services include home health and private duty nursing. The program also covers out of home care for children with developmental disabilities and mental health disorders but does not cover out of home care for children who are medically fragile. In addition to the Care in Home waiver in New York, there is a long-term care waiver for individuals of any age who are eligible for nursing home care.

Texas refers to their EPSDT program as the Comprehensive Care Program (CCP) which includes services beyond those in the basic Medicaid program. Private duty nursing and medical coordination for children with special health care needs are included under this program. According to the Texas Medicaid website, children 20 years old and younger are eligible for any medically necessary and appropriate health care services that are covered by Medicaid, regardless of the limitations of the state's Texas Health Steps (Medicaid program for children) program.

Options Available through the Patient Protection and Affordable Care Act

In March 2013, the National Council on Disabilities published *Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers*. The information in this section of the report is taken primarily from that document. There are several provisions in the Patient Protection and Affordable Care Act (PPACA) that are available to states to expand services for people with chronic disabilities in home and community-based settings. Below is a brief summary of these options:

- Children with pre-existing conditions cannot be denied coverage.
- Young adults up to age 26 can stay on or join their parents' health insurance plan.
- Health insurance plans can no longer have lifetime and annual limits, as of January 2014.
- Medicaid must cover hospice care and treatment.

- Section 2403 of the PPACA extends the Money Follows the Person (MFP) Demonstration Program through 2016. At this time, 42 states and the District of Columbia have participated in the program. States receive a temporary increase in their federal matching ratio for transitioning people from institutions to the community. Unfortunately, Florida chose not to apply for the program.
- The State Balancing Incentive Payment Program is authorized under Section 10202 of the PPACA and provides states with enhanced federal financial participation for increasing the share of Long Term Services and Supports (LTSS) devoted to home and community-based services. The increase in federal financial participation is based on the state's baseline of persons in institutions to those in community services.
- Section 2401 of the PPACA authorizes a new State Plan option for community-based attendant services. This option, known as Community First Choice, must be provided as an entitlement service. Therefore, it is very unlikely that Florida would use this option.
- Section 2402 of the PPACA authorizes the Medicaid Home and Community-Based Services Plan Option, also known as the Section 1915(i) provision. This State Plan option allows states to target benefits to a particular group of individuals with disabilities and modify the income eligibility criteria. Few states have done so because of the fiscal unknowns associated with offering a group of services as an entitlement. Florida has used this option for services for adolescents in the Juvenile Justice system with mental health issues.
- Section 2703 of the PPACA established a new Health Home State Medicaid Plan Option. This option allows states to provide a comprehensive system of care coordination for Medicaid beneficiaries with two or more chronic illnesses or disabilities. Health home providers are responsible for coordinating and integrating all primary, acute, behavioral health, and long-term services for enrollees. The state Federal Medical Assistance Percentage rate for this new coverage option is 90% for the first two years the State Plan amendment is in effect.
- Pediatric providers may be recognized as Pediatric Accountable Care Organizations if they demonstrate a coordinated delivery system. Incentive payments offered to these organizations are designed to encourage more providers to offer higher standards of care while achieving cost savings.

Originally the Governor's office was opposed to using any of the PPACA options for services in Florida. However, now that the Governor publically supported Medicaid Expansion, some of these options may be available in the future. Unfortunately, the Florida 2013 Legislature voted against the Medicaid Expansion.

Findings and Recommendations

The main focus of this project is to better understand the system of care and services that will help avoid placement of children in nursing homes, promote policies that ensure that their care is appropriate while in the nursing home, and address the system coordination and services necessary to allow children with medically fragile conditions to live in the community. The project also included assisting FDDC staff in crafting legislative responses to the issue. To achieve these goals, the consultant and the FDDC staff spent many hours reviewing documents, rules and regulations; talking to medical staff, parents, trade association staff and state agency personnel about the issue; visiting a medical home at the St. Joseph's Hospital in Tampa and visiting nursing homes. Without question, this is a complicated issue that is impacted by the state system of services, the medical community, and the circumstances that parents and their families face on a daily basis. Although small in number, these children are one of the most vulnerable groups of children in the state, with very high costs of care. Their medical, social, and educational needs are both extensive and require highly trained staff to address them. The responsibilities of the parents and their immediate natural resources at times can be exhaustive. Yet, the vast majority of parents are dedicated to the nurturing care of their children. The general findings from these activities are included in the information that follows.

Understanding the Need

Children Enrolled in Medicaid, Community-Based

Per a request from FDDC, Medicaid provided data on services and costs of care for children considered medically fragile by the Agency. The data is based on State Fiscal Year 2011/2112. Children included in the data set may have been only partially served through the year. Therefore, the data may underrepresent the full annual cost of serving children. The information below reflects estimates based on the type of services paid for by the Agency. In general the data showed the following:

Medicaid Services to Children Who Are Medically Fragile (2011/12 claims data)
5,866 children were identified as medically fragile.
The average expenditure per child was $76,230.
Total expenditures for this population were $447,165,035.
Of these children, 3,789 were SSI recipients and another 111 eligible through Medically Needy (estimated) constituting less that 2% of the children serviced.
The remaining children appeared to be eligible through the general Medicaid financial eligibility category.
31 children were on HCBSs waivers (likely DD Waivers) representing .53% of the children.
3,434 children were in the Children's Medical Services program.
Over 50% of the children were hospitalized during the fiscal year with 31 the average number of days in the hospital. This by far represents the greatest proportion of the expenditures.
Expenditure data showed the following trends: • Primarily hospital related costs and in-home nursing made up about 75% of the total costs. • There appear to be about 2,724 children who were on some type of enteral feeding. • About 263 children were on ventilators during the fiscal year. • At least 1,230 children received in-home nursing care with an average expenditure per child of $60,379.

Table 6

On May 15, 2013 in an AHCA communication release, the Agency stated that 1,788 families have chosen to keep their children with medically fragile conditions at home at a cost of $94, 952. These families are obviously a subset of the children/families included in the AHCA data set provided to FDDC and likely represent the children that receive in-home private duty nursing on a regular basis.

Total Need

This project focuses on the needs of a subset of children with chronic conditions, those that are technology dependent which refers to the use of medical devices without which- if they were to fail or be discontinued- would result in adverse health consequences and hospitalization. Examples include ventilators, intravenous catheters, tracheostomy tubes, enteral feeding devices, colostomy bags and urinary catheters. The number of children who are classified as technology dependent is very small. There is very little usable data to help project the number of children who are dependent upon technology. One estimate from a 1987 study by the Federal Office of Technology stated that about 1 in 1,000 children would meet that category. Another study 1990 study, *Stress in Families with Medically Fragile Children,* estimated that about .16 percent of the population would meet this category. It is clear that the number of children who are technologically dependent is on the rise, making these estimates likely very low. However, using them as a gross estimate, and given that Florida has about 5 million children under 21 living in the state, the number of children who are dependent on technology may range from 5,000 to 8,000 children. This is probably low. North Carolina estimated in a special report by the State Center in 2005 for Health Statistics that .32 percent of children below the age of 4 were technology dependent. These numbers are more accurate because they were based off hospital claims data but they are for a small age range of young children. Using these numbers the count would be 16,000. This number is probably a better estimate but based upon 10 year old data.

New York completed their report on children defined as Medically Fragile in February 2013. Their definition of Medically Fragile is similar to the definition of Technology Dependent used in this report. However, they also include a group of children with medical complications who require ongoing assessment or interventions to prevent adverse health outcomes. Using claims data, they found that the number of children meeting the definition was 12,868 for a total cost of $907,500. However, closer examination showed that 55% of the children were served in managed care with costs of only 14% of the total. The remaining 5,855 children were served in fee-for-service programs. Given the current managed care exclusions and the relatively low estimated cost for children in managed care, it is likely that these children represent children with fewer chronic and complex conditions. Interestingly, the New York estimated for the fee-for-service population of 5,855 is almost the exact number that Florida estimated from a claims data analysis of the fee-for-service population of 5,866.

The burden of care for families who are not eligible for Medicaid can be very high if they do not have a comprehensive health insurance policy. Children from families with incomes around 250% to 300% of poverty may meet the financial eligibility for SSI. Above that financial level, families in Florida only have the Medically Needy eligibility category available to obtain Medicaid (which may be difficult for a family to meet) or the DD waiver if their child also has an Intellectual/Developmental Disability (I/DD). It is well known that the DD waiver has an extensive waiting list. The chart below shows that the majority of children in the financial bracket of 251% of poverty to 400% of poverty are served through employer insurance. There are 66,500 children or 9% of the children uninsured which is 3% higher than the national average. Employer-based insurance often does not have extensive coverage of home health services, especially private duty nursing on a regular basis. Families in this income bracket will be eligible for health insurance through the Federally Facilitated Exchange beginning in January 2014. However, the benchmark plan upon which Florida's essential benefit plan is based has only limited home health coverage. The level of "habilitation" services remains undefined at this time. Therefore, there is a large group of children whose families have limited resources who do not have access to broad health care coverage. An FDDC review in January 2013 showed that 39 states have programs to allow families to access Medicaid either through the TEFRA option (which does not consider parental income when determining financial need) or through HCBS waivers for this population (which also does not include parental income in determining eligibility). As discussed earlier in the report, Texas uses a different strategy. The Medicaid Buy-In allow families with incomes at 300% of the SSI financial level to purchase Medicaid coverage. Florida's Model waiver which serves only one small diagnostic group had only five slots in January of 2013.

Table 7 provides estimates of the sources of the health insurance coverage for children in Florida and in the United States as a whole.

Health Insurance Coverage of Children with Incomes from 251-399% of Federal Poverty Level (FPL), states (2010-2011), U.S. (2011)View 50-State Comparison				
	FL #	FL %	US #	US %
Employer	500,100	67%	10,457,500	73%
Individual	NSD	NSD	761,400	5%
Medicaid	132,700	18%	1,942,700	14%
Other Public	NSD	NSD	243,300	2%
Uninsured	66,500	9%	859,600	6%
Total	751,300	100%	14,264,600	100%

Table 7

To determine the need for either a new waiver or to address the needs for an expansion of an existing waiver, the consultant and FDDC staff have tried to estimate the number of children that might need an access to a waiver because of their parents' financial levels. The New York HCBS waiver for children with medically fragile conditions and I/DD serves up to 600 children. This waiver serves only families whose income exceeds the traditional medical eligibility thresholds. Given the similarity in population estimates, and because most of the children observed in Florida also have an I/DD, the number served of 559 could be used as a rough estimate of about how many children in Florida do not currently meet the financial eligibility criteria and need access to a waiver for Medicaid and waiver services.

Observations on the Current System – Children in Skilled Nursing Facilities

The impetus for this project was concern about children living in skilled nursing facilities. At the beginning of last fiscal year, there were about 230 children serviced in nursing homes. As of May 9, 2013, the number had dropped to 191. Also, there initially were 6 skilled nursing facilities with pediatric beds. One has closed, and a second one in Tampa is closing soon, leaving just four facilities in operation. The consultant and FDDC staff toured two skilled nursing facilities and observed that the majority of children also have an intellectual or developmental disability.

According to Agency for Health Care Administration (AHCA) press releases, their staff have contacted the parents of the children living in these facilities to determine if they would be interested in having their children return home with services and supports. Only 1% of the families were interested in pursuing this option. According to conversations with skilled nursing facility staff, many parents are very involved with their children, visiting as often as possible and with ongoing communication. Unfortunately, there is a group of children whose families are not involved and who receive very little contact with their families. AHCA is firm on their position that parents have the right to choose a placement for their child and that failure to respond to AHCA's request for information does not constitute any indication of abandonment. Currently, there is no avenue to obtain interested adult advocacy for these children. Therefore, they remain in the skilled nursing facilities with only the staff to advocate for their needs.

The current rules for skilled nursing facilities do not require that the facility staff provide outreach to attempt to encourage and enable family connections. Although some of the staff do a great job of this, it should be an established ongoing responsibility of the facility to encourage as much communication and contact with the family as possible. Of course, staff can only do so much. If the parents are not responsive the staff cannot force the issue.

The skilled nursing facilities are responsible for meeting all the medical needs of the children. The occupational, physical, respiratory, and communication/language therapies are provided by the facilities. The school system is responsible for the educational program. A small percentage of the children attend school off-site. The majority receive “home-bound” services for a set number of hours per week based upon the recommendation of the local school district. Many of the children are fed through enteral methods, most often through a gastrostomy tube. Given the number of children receiving enteral feeding, it is important to have policies in place to monitor the use of the enteral feeding to ensure that it is the least restrictive type of feeding possible and to encourage practices to strengthen, if possible, the child’s ability to eat and drink orally. Also, there were several children on respirators/ventilators. Again, it is not clear what the policies are for aggressively trying to wean the children from these devices for periods of the day and perhaps totally as they mature.

Although the number of children in the skilled nursing facilities has declined, there is the probability that other children will be admitted. The majority of referrals for skilled nursing facilities come through the hospitals. These referrals go to Children’s Medical Services (CMS) to determine a level of care. According to policy, an interdisciplinary team called the Children’s Multidisciplinary Assessment Team (CMAT) makes a recommendation regarding the level of care. The team should include the physician, the parents, and representatives from CMS, AHCA, and Agency for Persons with Disabilities (APD) if the child has I/DD condition, and DCF if the child is served by child welfare. Our discussions with CMS indicated that in the past a full team may not always have been assembled and the full range of options may not have been explained to the parents. For example, it is not clear that during the CMAT parents are made aware of the range of services available through APD. Many children are currently in nursing homes who are likely eligible for a DD Waiver, but an application for the waiver has only been completed on about 47 of the children, indicating that families may not be aware of the possibility of DD waiver services.

Prior to admission to an institution, CMS is required to complete a Pre-admission Screening and Resident Review (PASRR) Level I screen which is used to determine if there is a primary diagnosis of serious mental illness or a developmental disability. Children are required to have a Level II screen if they have such a primary diagnosis. The Level II screen results in a determination of whether nursing facility residence is appropriate, alternatives to nursing facility residence if appropriate, and the services which the individual needs for emotional disorder or developmental disability. APD is responsible for completing the PASRR Level II screen, while DCF Substance Abuse and Mental Health must complete these for children with emotional disorders. Based upon discussions and observations in two nursing homes, it appears that the majority of children should have received a Level II screen. At the completion of this project, FDDC staff had requested information about the completion of the Level II screens for children currently in the skilled nursing facilities. It is not clear to what extent APD identifies the level of services that should be provided in the nursing facilities and the extent that this information is shared with the skilled nursing facility and monitored by AHCA.

State Level Improvements – Skilled Nursing Facilities

Over the last year, state agencies have put in place several practices designed to address the needs of children in nursing homes.

These are briefly summarized below:

- Initially visited each child and contacted all the families to determine if they would like to bring their child home.
- Assigned nurse care coordinators for every child. The coordinators visit each pediatric facility monthly.
- CMS now reviews the care of every children in nursing facilities every six months.
- DCF has added additional oversight and approval protocol for the admission of a child in the child protective system to a skilled nursing facility.
- Submitted a request to the Centers for Medicare and Medicaid Services to increase the model waiver by 15 slots to help children move to the community from the nursing facilities. It is assumed that AHCA has initiated this action because some of the children in the nursing facilities will not be Medicaid eligible when placed in the community. However, Medicaid has not confirmed this.
- Revised the PASRR handbook.

Recommendations for Additional Improvements – Skilled Nursing Facilities

Permanency Planning

Although the state agencies have addressed many of the issues related to children in skilled nursing facilities, there remain concerns. FDDC's position is that children should live with families and the use of skilled nursing facilities, if medically necessary, should be short-term. Long-term care in an institution should not be considered an acceptable solution for children. This presents something of a policy dilemma, given that state officials maintain that placement of the child in a skilled nursing facility is the sole prerogative of the parent and that according to AHCA's press releases, only 1% of the parents are interested in finding another living solution for their children.

Research revealed that unlike Florida, Texas has, since 2001, provided a system of permanency planning for children with developmental disabilities under the age of 18 in institutional settings regardless of parental legal status. The goal of the permanency planning requirement is to ensure that institutional placements are on a temporary basis with the objective to have all children living in a long-term relationship with the birth family or an alternative family. The planning process is comprehensive, requiring a description of the following areas:

- Child's characteristics, skills, and abilities, and medical condition
- Permanency or relationships
- Continuity of services needs if living with birth family
- Previous living environments
- Identification of supports and services to live in the community
- Plans to support community living

For a variety of reasons, some children cannot return home to their birth parents. In these cases, the DADS waiver has "Family-Based Alternatives", a service discussed above in the Texas discussion. This program will be discussed further below.

According to a Resource Coordinator working for a HCBS provider, Every Child Inc. Texas, the permanency planning process can be difficult if the family member is not at all interested in working with the reviewer. The reviewer is responsible for completing the permanency plan regardless of family involvement. In situations where the reviewers have not been able to get any response from the designated contact person, the case is referred to Child Protective Services. Sometimes Child Protective

Services is able to locate another interested family member. Also, in these cases, the policies encourage that an adult advocate be appointed to help address the needs of the child.

Recommendation 1: Permanency Planning

The ongoing reviews of children in the skilled nursing facilities should include a process similar to the Texas permanency planning process. Given the resistance by some state agencies to question parental decisions, it may be necessary to have this process required legislatively as in Texas.

Pediatric Skilled Nursing Facilities Rule Revision

The project provided an opportunity to work with the Florida Health Care Association to address the need to create statutory requirements for the operation of pediatric skilled nursing facilities. Currently, the requirements are articulated in rule rather than statutorily. FDDC made several legislative attempts for improved services and supports in the skilled nursing facilities. The proposed legislative bill did not pass. These issues still remain important. There has been some discussion about revising the existing rule to address them.

Recommendation 2: Pediatric Skilled Nursing Facilities Rule Revision

There were several excellent components in the proposed bill language that should be added to the existing rule on Pediatric Skilled Nursing Facilities which is a section in the overall Skilled Nursing Facilities regulation. The additional language should require:

- Referral of children birth to age 3 to Early Steps to facilitate the child's return home.
- Standardized assessment at the time of admission of the child's level of cognition, development, social-emotion, education, behavior, function, physical health, therapeutic needs and family relationship.
- The assessment be updated at least quarterly and must include an evaluation of the least restrictive setting possible for the child and the services needed to support the child and family in that least restrictive setting.
- A plan of care is developed by an interdisciplinary team, addresses the findings from the assessments, and integrates the education program into the overall plan.
- An interdisciplinary care plan team includes expertise in medical care, child development, education, therapies, and mental health including infant and early childhood. If a child receives services from a community agency or organization, they will be invited to attend care plan meetings.
- All therapists are trained and experienced in pediatrics.
- Medical protocols are in place to reduce the use of enteral feedings and ventilators whenever possible.
- The plan of care is reviewed quarterly with a status report to the parents on a quarterly basis.
- The assessment, plan of care, and status reports are shared with the CMAT.
- Each child is referred to the local educational program for an IEP, and AHCA and the CMAT will be notified if a school program is not provided.
- An early childhood specialist is on staff or under contract to work with children as determined necessary by the plan of care. This work will be in addition to the education program, and will ensure that the programs are integrated throughout the day and are developmentally appropriate.

- The facility has policies and procedures that promote ongoing relationships with the families.

Applications for the Developmental Disabilities Waivers

Based upon observations and interviews, it appears that the majority of children in the skilled nursing facilities are eligible for APD services through the Developmental Disabilities Waiver. Yet, according to APD staff, fewer than 50 of the children are formally known to APD (likely on the waiting list). It is unknown whether the families have been apprised of the possibility to apply for the waiver and how waiver services could assist the child locate community services. APD has residential programs that are able to serve this population and could provide alternative community options. Additionally, APD has expressed interest in developing smaller alternative family-based homes for children with medically fragile conditions. Also, for children the primary cost of care is the responsibility of AHCA through the Medicaid State Plan services rather than waiver expenditures. APD received funds this year to provide services to several hundred people on their waiting list. Children living in skilled nursing facilities should be a priority population.

Recommendation 3: Applications for the Developmental Disabilities Waiver

A policy should be established that requires that all families with children residing in skilled nursing facilities who are screened or documented to have an Intellectual or Developmental Disability be notified of the DD waiver, the benefits of applying for that waiver, and assistance in applying for eligibility. APD should strongly consider including this population as a priority population.

Observations on the Current System – Children Living in the Community

The majority of Florida's children with medically fragile conditions live at home with their families. AHCA has estimated that about 5,866 children with medically fragile and technology dependent conditions are living with their families and receiving Medicaid services, while only 191 or about 3% of the identified children are served by a skilled nursing facility. This fact highlights the need for a highly competent and functional community-based system to support the children and their families' needs. The children's complex conditions require extensive and highly professional services usually involving multiple medical specialties, pediatric nursing, pharmacy, social work, educators, and allied medical professionals. Failure to provide the necessary medical interventions and services when needed could result in death or increased disability.

In Florida, as in other states, no one agency has responsibility for this population. APD has responsibility for those children with developmental disabilities enrolled in their program. The Department of Health, Children's Medical Services is responsible for children in the CMS Network. The Department of Children and Families is responsible for medically fragile and technology dependent children who are under child protective services. AHCA is responsible for ensuring that all children who are Medicaid beneficiaries receive all Medicaid necessary services.

The involvement of multiple agencies results in the assignment of multiple case managers. Every agency has their own case manager (by multiple names) that are responsible for coordinating the services of their particular agency but not all services as a whole. Unlike the other four states discussed above, the DD waiver support coordinators are not responsible for developing a comprehensive plan of care that includes services from all the agencies, including State Plan services. Instead, they are responsible for developing a support plan that primarily addresses services provided through the waiver. Given this situation, families may deal with multiple case managers and uncoordinated care. During the time of the project, the different roles and responsibilities of the various organizations were not fully delineated in one place, such as in an interagency agreement.

Most children with medically fragile conditions are identified in pediatric hospital units. They are either identified at birth, at the time of an accident, or when their needs escalate and they have repeated hospitalizations. Most of the children are discharged home. The parental responsibilities can be enormous. The acuity of hospitalized children has increased over time, as have the medical conditions present at discharge. Children are now sent home to continue complex interventions that in the past were done only in a hospital setting, such as oxygen, tracheostomies, enteral feeding tubes, intravenous infusions, dialysis, and other complicated medical regimens. The homes of the families have been described as having a Pediatric Intensive Care Unit in your living room.[6]

One of the most important steps in ensuring ongoing community living is the discharge process. Interviews with Children's Hospital medical staff revealed that the hospitals are often responsible for arranging for all the equipment and parental training on the equipment before discharge. The state agencies have very little involvement in this process unless the child is enrolled in CMS. According to hospital staff, the hospital is primarily responsible for these functions. The primary reasons for failure of home care are the lack of community resources, inadequate financial resources and insurance coverage, and the emotional depletion of the family. If the hospital doesn't have a medical home for this population (and most do not), the child and family may be left pretty much on their own without nursing case management or other services and supports.

As part of the research for the project, the consultant and FDDC staff visited a Medical Home for children in complex medical conditions in Tampa, Florida at St. Joseph's hospital. This medical home provides a full array of services, coordinates all medical care, and is integrated with the CMS care coordination program. The Children's Hospital Medical Director was the founder of the program and has been able to cover the cost of the medical home through reduced readmissions and improved overall care. The Medical Director stated that it is essential for children to have access to high quality medical care if home care is to be successful. He believes that all the Children's Hospitals in Florida should have a medical home for this population. A Medical Home for children with medically fragile conditions is currently operational at the Miami Children's Hospital. In January, 2013 the University of Florida announced the opening of the Wolfson Center for the Medically Complex Child in Jacksonville. The project team also interviewed the Medical Director of this center as part of the research.

In addition to the coordination of care, when professional staff were interviewed, the quality of community services came up repeatedly as a concern, especially the quality of the private duty nursing. There are no current requirements for any type of special training or pediatric experience. There also is concern that the home health agencies may not be able to provide the level of services necessary.

Access to care is dependent upon financial resources which, for most families, means adequate insurance coverage. Although often criticized as inadequate and lacking the appropriate array of medical providers, the Florida Medicaid program provides the best coverage for children with medically fragile conditions. Families financially eligible for SSI or other traditional Medicaid coverage have access to the array of EPSDT services, such as private duty nursing, that are often not covered in commercial insurance. Also, due to the EPSDT safeguards, the state cannot set arbitrary limits on the services and must provide medically necessary services. However, families whose financial situation exceeds the SSI limits (about 250% to 300% of poverty) are not eligible for Medicaid. Their income levels also make them ineligible for the Florida Child Health Insurance Program, Healthy Kids. Ironically, if the child is placed in an institutional setting, the parents' income is not considered as part of the Medicaid eligibility determination due to the federal Institutional Care Program (ICP) requirements.

The Centers for Medicare and Medicaid Services provides states with options to address this situation. The two most frequently used Medicaid programs are the TEFRA option and the HCBS waivers. With

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[6] Elias, E. R., & Murphy, N. A. (2012). *Pediatrics, 129,* 996-1005.

the TEFRA option, states may disregard the income of families whose child meets the clinical criteria of Medicaid covered institutional care. The child becomes Medicaid eligible and has access to all the Medicaid State Plan services. HCBS waivers eligibility determination operates in much the same way. Since persons entering the program are also eligible for an institutional program and choose to waive placement in the institution for community living, they are also eligible for Medicaid in the community. This provision is often referred to as "the child is a family of one". Currently, these options are unavailable in Florida. Florida has not adopted the TEFRA option nor does the state have a waiver for children with medically fragile conditions. The current Florida Model waiver has only 5 slots to serve a very specific diagnostic category and is basically unavailable. Although many children are eligible for the DD waiver, the long waiting list has made that possibility almost impossible unless the family is having a very serious crisis. The other option, the Medically Needy program, is difficult to understand and potentially forces families into very difficult financial constraints.

The current Medicaid service array for children with medically fragile conditions addresses many of the critical needs for services, but does not address areas such as family support, home modifications, and alternative living environments if the child cannot live safely at home. Florida does not have such a HCBS waiver, so services are not available for children living in the state. Of the greatest concern is the lack of an alternative family home for those children whose parents do not want them to be served in an institution but who cannot address the child's needs on their own in their home. There are many reasons that this can be the case. The physical structure of the home must be able to accommodate the equipment, and the electrical system must be appropriate for the advanced equipment and physically accessible. The parents also must have the ability to manage the multiple responsibilities associated with the care and the continual presence of health care providers in their home. For some families, home care is just not an option. Yet, the families would like their children to live close to them and to be able to be involved in their lives. Medical foster homes provide this type of out-of-home program. In Florida, this service is available only to children who are in out of home legal status within the child welfare system, leaving other families and children without an alternative living option.

State Level Improvements – Community Services

AHCA has made several policy changes to address the needs of the children in the community by completing the following activities:

- Revised the prior authorization requirements and rules for home health services and Prescribed Pediatric Extended Care and monitored the process for approval for services on a regular basis.
- Required a contractor to visit with the parents of children receiving private duty nursing services in the home to determine their satisfaction with the level of services. At the time of the last report, October 2012, 99.1% of the families were satisfied with the level of services.

Home Health Services

The changes in the Medicaid Home Health Services Coverage and Limitations Handbook (March 2013 draft) added services to address the care coordination of the children who are receiving private duty nursing. These changes are highlighted as follows:

- The Quality Improvement Organization (QIO), eQHealth Solutions, Inc., will provide care coordination services for all Medicaid recipient children who receive private duty nursing in the child's home. The care coordinator will either be a licensed nurse or social worker with experience working with medically complex children. According to an AHCA press release, the maximum ratio of care coordinator to recipients is 1:40.

- The care coordinator will maintain regular monthly contact, either telephonically or face-to-face, with the child's parent or legal guardian, and other health care professionals and individuals involved in the child's care.
- Every six months, the care coordinator will convene a multidisciplinary team comprised of the recipient (if able), the parent or legal guardian, and other medical professionals and individuals involved in that recipient's care.
- The QIO will develop a service plan that includes all services and supports needed to meet the recipient's medical needs in order to safely remain in the home. All services, including private duty nursing, that are subject to prior authorization will be reviewed as a part of this multidisciplinary team process.
- Home health service providers must submit the required documentation set out in the "Requesting Prior Authorization" section of this chapter to the QIO prior to the multidisciplinary team meeting.
- Of particular note, when approving private duty nursing, the team will NOT require that parent's participate to the fullest extent possible in performing skilled interventions that normally could only be provided by a licensed nurse.
- Private duty nursing, personal care services, and home health visit services provided to a recipient enrolled in a CMS Specialty Plan are authorized and claims are processed through the CMS Specialty Plan.
- Parents or legal guardians must provide assistance with activities of daily living and instrumental activities of daily living for their child, to the fullest extent possible. If parents or legal guardians need training to safely perform these tasks, the home health services provider must provide training.

Prescribed Pediatric Extended Care (PPEC) Services

- Parental availability will not be a factor in approving PPEC services.
- Parents and caregivers have the choice between private duty nursing and PPEC services. Even if the child receives PPEC services they will remain eligible for private duty nursing in the home as a wraparound service to the extent that PPEC alone does not satisfy the child's medical needs.
- The agency also modified the transportation policy to reduce the time children are transported on vehicles, unless authorized by the treating physicians.

Recommendations for Additional Improvements – Community Services

The changes described above have the potential to significantly improve community living for children with medically complex conditions. However, there is still room for additional enhancements. These are discussed below.

Medical Coordination and Care

These children and their families need significant assistance at the time of discharge from the hospital and continually thereafter to receive the appropriate level of medical care, social and educational services, and family supports. The American Academy of Pediatrics published article in Pediatrics on April 30, 2012 entitled, *Home Care of Children and Youth with Complex Health Care Needs and Technology Dependencies,* setting out the steps that should be followed at discharge:

- High quality discharge planning from the hospital to home which includes:
  - Comprehensive evaluation of the child, family, and the home.
  - Ensuring the home has the physical structure to accommodate all the equipment needed and ensuring appropriate electrical wiring and capacity.

    - Arranging for all necessary services and equipment.
- Benefit and financial counseling to determine how the family will be able to meet the child's needs.
    - Evaluation of any family insurance to determine scope of coverage and limitations.
    - Determination of eligibility for SSI benefits or other Medicaid coverage.
    - Determination of how the family will be able to cover other financial requirements, such as utility bills, transportation, care for other children, etc.
- Location of a Medical Home that has the capacity to serve the child, coordinate their care, and ensure that the pediatrician has all the information necessary to assume care of the child.
- Arranging for home care nursing, therapies, and developmental/educational programs.
- Arranging for supplies and equipment.
- Ensuring that acute care resources with the capacity to address the needs of the child are available.
- Extensive training for caregivers regarding all the necessary medical procedures that must be completed, the operation and maintenance of the equipment, and all necessary emergency procedures. Ongoing support and assistance are often required.
- A comprehensive developmental/educational assessment and integration of the developmental and academic programs into the overall plan of care.
- Provide the primary care physician with a comprehensive discharge summary that includes details of all the issues and events of the hospitalization and an accurate list of medications, therapies, equipment, and services.

The probability for home care success is enhanced when high quality care coordination and a medical homes are available. New York State in the recent *Medically Fragile Workgroup Report,* published in February 2013, recommends that the state use the PPACA provision to include Health Homes for Medicaid enrollees with chronic conditions under the Medicaid State Plan. New York intends to adopt the option of the Health Home care coordination model for high cost/high need Medicaid enrollees with two or more chronic conditions, and has received approval by the Centers for Medicare and Medicaid Services. The state is developing special requirements for Health Homes for children with medically fragile conditions. Through the Health Home, the primary care provider is responsible for coordinating all the medical specialty care and for providing oversight over the medical services provided to the child. The primary care physician should be very experienced in working with children with medically fragile conditions or have ongoing expert support from a physician who is an expert in this area of medicine.

In New York, the care coordination services will be provided through the Health Homes and will include:

- Comprehensive care management
- Care coordination and health promotion
- Comprehensive transitional care
- Patient and family support
- Referral to community social supports
- Use of health information technology to link services

Florida's current approach to care coordination includes assigning a QIO care coordinator to each child that receives private duty nursing. This is likely to be a temporary solution. The QIO care coordinator will be effective only as long as the child is in a fee-for-service situation. However, starting in January 2014, the number of children in this situation will diminish as most of the children will be enrolled in some type of managed care program. The exception to mandatory enrollment will be for those children receiving DD waiver services (about .53% of the population) and those on the DD waiver waiting list. The 59% that are enrolled in CMS will be enrolled in the CMS Specialty Plan. The other remaining children will either be exempt through the DD waiver provisions or served by other managed care plans, such as Provider Service Networks (PSNs) or HMOs. Under these circumstances, the QIO care coordinator will have little authority. In fact, the current draft of the Home Health Handbook makes it clear that the CMS Specialty Plan and the PSNs will be responsible for authorizing home health services.

The degree of care coordination that is necessary for these children and families cannot be adequately provided under the existing Medicaid payment structure. The managed care plans are required to provide care coordination to high risk enrollees and this service is also part of the CMS services. Yet, the payment structure does not provide for the additional cost associated with this service. Other payment solutions should be sought, either through coverage of the cost in a home health program or providing targeted case management for these children.

Recommendation 4: Establish Medical (Health) Homes for Children with Medically Fragile Conditions

Special medical expertise is necessary to create the optimal discharge planning process and ensure that all necessary services are in place prior to discharge home. Additionally, high quality ongoing care must be available. As recommended by New York State, the health home provides that best avenue to render and coordinate extensive medical care. The State Plan option for Medicaid funded health homes should be explored and funds requested to establish these services. The health home should be responsible for ensuring that the assigned private duty nurses and other health care staff have the competencies to render the care to the child. Another option is to investigate the possibility of using incentives for Pediatric Accountable Care Organizations as a way to increase health homes for this population.

Recommendation 5: Ensure ongoing care coordination by funding intensive care coordination

To ensure that intensive case management is available for children with medically fragile conditions, the Medicaid State Plan requirements should be modified to include intensive care coordination as a specific service for this population. This could be accomplished through a Targeted Case Management program or by adding coverage under a health home State Plan amendment. The intensive care coordination program should be available at the time of hospital or skilled nursing facility discharge to help establish a smooth transition to the community and should be able to be continually available to the child and family to provide coordination and support. The intensive case manager should be able to coordinate services for the managed care program and any waiver services creating the critical integration between acute and long-term care.

Medicaid HCBS Waiver for Children with Medically Fragile Conditions

All of the four large states reviewed for this project have a HCBS waiver for this population. The request to CMS to amend the existing Model waiver will not address the needs of these children. The request is for only 15 additional slots for children who are residing in a skilled nursing facility. This does not provide any relief for families in dire need of access to Medicaid and other family support services. The DD waiver, with its long waiting list, is not a viable solution and does not address the needs of children who do not have an I/DD condition. Also, two of the states reviewed covered all ages in their waivers, which ensures that young adults can have continuity of care when they turn 21. The current Long Term Care waiver for elderly and persons with disabilities is not designed to service persons with medically fragile conditions.

Recommendation 6: Obtain a HCBS Waiver for Medically Fragile Children and Adults

Either a new HCBS waiver should be requested, or the current Model waiver should be expanded to include critical family support services and home modifications. Most importantly, the eligibility criteria should include children living in the community who need waiver services to avoid an institutional placement. Optimally the waiver would include persons 21 years and older to ensure that there will be no break in services. The additional services should be incorporated into the existing 1915(b) (c) waiver to enable the Medicaid health plans to adequately serve this population.

Family-Based Alternative Homes

Currently, the state only has one out-of-home option for children who can't safely live in their parents' home, a skilled nursing facility. This situation is very problematic. It is unknown if the 191 parents whose children currently live in the nursing home would have responded differently to the option of their leaving the skilled nursing facility if they had been offered another out-of-home option. It is likely that some of them would have been interested in discussing options if they knew that their child would be well cared for closer to home.

Of the four states reviewed, only California had an out-of-home option as part of their waiver. The Continuous Nursing and Supportive Services is provided in licensed facilities known as the Continuous Care Facility which is 12 beds or less. Texas has a program known as the family-based alternative that was established in state statute in 2001. The program only services children with I/DD conditions. Even with these limitations the structure of the program is appealing. It is designed to serve children and families who, beyond their control, require out-of-home assistance. The program offers families choice and still provides for a family-based home for the child. Children can be placed in an alternate family and yet remain an integral part of the birth family's life. If desired, birth parents participate in all the planning and decision-making involved in the family option, including selecting an alternative home. Through the efforts of the permanency planning program discussed above and programs such as Every Child, Texas has seen an 88% reduction in the number of children living in large ICF/DDs and a 69% reduction in children in skilled nursing facilities since 2002.

The model for the Family Based Alternatives originated in Michigan and was brought to Texas under the name of Every Child Inc. Texas (Every Child). Every Child is a non-profit Medicaid HCBS Waiver provider that operates shared parenting and support families. The agency recruits, trains, and supports the family-based homes. The Texas Department of Aging and Disability Services licenses the homes. Under this model, the provider organization has primary responsibility for the overall operation of the homes and pays the families as caregivers. Unlike the Florida Medical Foster Home model, the individual homes are not enrolled as a Medicaid provider. The program has been in place since 2000.

The first goal of the program is to work with the birth family to explore possibilities of finding adequate supports to enable a child to return home. If that is not possible, then the second goal is to find a shared parenting arrangement or support family, selected by the birth family to care for their child. The fundamental principle is that children should live in families and that birth parents should be extensively involved in the lives of their children even if they live with another family.

Implementing the family-based alternative requires simultaneous activity in three areas:

- Collaborating with the birth families to explore possible alternatives to institutional care.
- Recruiting and preparing support families or shared parenting arrangements to provide a home for children who can't live with their birth parents or who can't live with their birth parents full time.
- Linking together people, supports, and activities of community agencies as partners in helping families and children thrive.

Shared parenting is a wonderful concept that accepts the fact that some families need out-of-home support yet still want to be very involved in the lives of their children. The following features distinguish shared parenting arrangements:

- Specifically recruited for children with disabilities.

- The parent is paid as a caregiver but the care is provided in a family home.
- The amount of time shared and the conditions under which care is shared between the two families can vary with the family's circumstances and preferences.
- Families who provide shared parenting are carefully screened, certified, and monitored by a community agency that is responsible for assuring the child's care is appropriate through ongoing supervision and support.
- Shared parenting arrangements include a negotiated agreement between the birth parents and shared parents outlining the schedule of care and describing mutual decisions about how to share care.

In situations where shared parenting may not be the best option, family-based alternatives may include the use of a support family. The support family model is distinguished from traditional foster care by several unique components as listed below:

- Families are recruited specifically for children with disabilities.
- Families make long-term commitments to the children and can provide care into adulthood.
- Birth families do not have to give up parental rights to access the support family services.
- Families are matched with the child and birth parents to promote collaborative care.
- Support parents receive specific training about caring for the child and receive ongoing support from the lead agency.

This model has the potential to help many children find homes outside of institutional settings while acknowledging the birth parents' desire to be part of their children's lives. One of the shortcomings of the program is that is available only to children with I/DD conditions. The consultant and a Resource Coordinator from Every Child discussed this issue. The Resource Coordinator stated that the lack of availability for all children with medically fragile conditions was definitely a problem. In fact, the day of the interview, she was trying to assist a family whose child did not meet I/DD criteria. Another issue is that this service is available only through a HCBS waiver which limits access based upon the waiver's capacity.

Recommendation 7: Modify the current Medical Foster Home state plan service to include the characteristics of the Family-Based Alternative Model

The current Medical Foster Home service restricts eligibility to children in foster care and is dependent upon the recruitment of individual foster parents. The CMS program is responsible for the training and oversight of the parents. A model such as the Family-Based Alternative allows provider organizations to recruit, train, and provide oversight to the homes. The model also embraces and facilitates the role of the birth parents. This modification to the Medical Home service would open more opportunities for children who are currently living in skilled nursing facilities to live in a family home.

Youth with Medically Fragile Conditions – Transitioning to Adult Services

Introduction

Stage of life transitions are difficult for everyone. For persons with disabilities they can be extremely stressful. One of the most difficult times for persons with disabilities is the transition to adulthood (age 21) which is exacerbated by the inconsistencies between service systems designed to serve children and those for adults. The reduction in the scope of the Medicaid benefit package can present enormous challenges to persons who require daily and ongoing assistance. The federal EPSDT regulations require that states provide an array of services for children including private duty nursing, personal care, and therapies. The state does not have to provide these services as part of their State Plan for adults and in Florida they do not. The services can be offered through HCBS waivers. Of course, all of these waivers in Florida have long waiting lists making access to care very difficult at times.

The Kaiser Family Foundation Report in January of 2007, *Aging out of EPSDT: Issues for Young Adults with Disabilities,* reported that for adults with disabilities, the risk of having basic needs go unmet is substantial. According to the report, research showed that of three million adults living with disabilities in the community who need assistance in daily living skills as many as 33% did not receive the necessary care. Of these individuals, 30 percent reported that they soiled themselves because they had no other choice, while 10% said they had gone to bed hungry because they had no assistance in eating. For young adults with severe physical, intellectual, or mental disabilities who had previously received private duty nursing or personal care services to live at home, the greatest risk is the threat of placement in an institution or having essential basic health and daily living needs go unmet. This situation is a personal crisis for many young adults and their families. To compound the problem, for adults without a home or family home to live in, HCBS waivers may not have supported living environments available that can meet their complex medical needs. For example, young adults "aging out of foster care" who live in Medical Foster Homes may not have an alternative living arrangement available that has the capacity to provide the range of services available in the Medical Foster Home, especially if they do not meet the criteria for the DD waiver.

Adult Services for Persons with Medically Fragile Conditions

Adults with medically fragile conditions who need support from state services do not have many options in Florida. In the past there have been four basic transitional pathways: transfer to either a Developmental Disabilities HCBS Waiver or the Aged and Adult HCBS Waiver, enter an Intermediate Care Facility for Developmental Disabilities, or enter a skilled nursing facility. Most young adults want to remain in the community but there options are limited by the availability for HCBS waivers.

Florida is significantly changing the management of the HCBS waivers for elderly persons and people with disabilities through the Florida Medicaid Reform Long Term Care (LTC) program. The phase-in of the Long Term Care managed care program will begin in August 2013. This managed care program is authorized by the Centers for Medicare and Medicaid Services through a new Long Term Care waiver that rolled the following HCBS waivers into the new program:

- Nursing Home Diversion
- Aged and Disabled Adult
- Assisted Living Waiver
- Channeling Waiver
- Frail Elder Option
- Consumer Directed Plus for Aged and Disabled Adult

The previous package of services under each of the six waivers was consolidated into a new list of services which are shown in the chart below:

LTC Program Minimum Covered Services	
Adult companion care	Intermittent and skilled nursing
Adult day health care	Medical equipment and supplies
Assisted living	Medication administration
Assistive care services	Medication management
Attendant care	Nursing facility
Behavioral management	Nutritional assessment/ risk reduction
Care coordination/ Case management	Personal care
Caregiver training	Personal emergency response system
Home accessibility adaptation	Respite care
Home-delivered meals	Therapies, occupational, physical, respiratory, and speech
Homemaker	
Hospice	Transportation, non-emergency

Table 8

Persons currently receiving services from the six listed HCBS waivers must enroll in one of the LTC Health Plans in their AHCA Region. They will receive their LTC services through either a Health Maintenance Organization (HMO) or a Provider Service Network (PSN) and their state plan services through either another managed care program or through the same health plan that is providing the LTC if that health plan is authorized to provide managed care for state plan services in the Region. The waivers will no longer be managed by the Department of Elder Affairs or the Department of Children and Families. They LTC managed care plans will be under contract with AHCA. The Department of Elder Affairs will be responsible for administering the Comprehensive Assessment and Review for Long-Term Care Services (CARES) instrument to determine eligibility for the LTC services.

These changes are significant and will fundamentally modify how the services are approved and organized. As with the individual waivers, the new LTC program has a substantial waiting list for services which limits the number of young adults who can be enrolled in the program.

The Aged and Disabled Adult waiver has been the primary vehicle for continued services for young adults with disabilities who do not have I/DD conditions. The operation of the Disabled Adult section of the HCBS waiver will be transferred from DCF to AHCA. This portion of the waiver consists of only about 1,700 people, constituting a very small portion of the HCBS waiver component of about 36,000 persons currently served in the community.

To create smooth transitions for eligible youth from the CMS program to the Aged and Disabled Adult waiver, AHCA created a program entitled the Aging Out Program. The description of this program is found in Chapter 3 of the Aged and Disabled Adult Coverage and Limitations Handbook. It is operated directly through AHCA. The Aging Out Program is intended to ensure the smooth and uninterrupted provision of services necessary for the recipient to maintain their optimal level of physical, emotional, and psychosocial well-being while remaining in the community. To be enrolled in the program, the individual must be “aging out” of CMS and have the following characteristics:

- Cognitively intact and oriented to time and place and able to display independence in daily decision making, able to make decisions regarding health care, comprehension, and problem solving;
- Medically complex, with chronic debilitating diseases or conditions of one or more physiological or organ systems that make the individual dependent upon medical, nursing, or health supervision or intervention; and
- Technology Dependent, requiring medical apparatus and procedures to sustain life.

Persons enrolled in the Aging Out Program are eligible to receive all medically necessary services under the Aged and Disabled Adult Waiver after first accessing applicable Medicaid state plan services and generic community services. Each individual is assigned a case manager who is responsible for working with CMS and the individual/family to develop and implement a plan of care and provide ongoing coordination and support. Services include personal care and skilled nursing as well as the necessary therapy services. Based upon a discussion with DCF staff, historically there have been problems with limits imposed on personal care and skilled nursing services. It is not yet clear whether the LTC managed care programs will be more flexible and approve the necessary level of nursing and personal care. The out-of-home living services in the LTC program are Assisted Living Facilities and Adult Family Care Homes. Neither of these facilities appears, based on licensure requirements, to be able to serve persons with medically fragile conditions. Broward Children's Home operates a group home for young adults over the age of 21. This home is funded by a special appropriations. At this time it appears that-other than Broward's Children's Home - skilled nursing facilities remain the only out-of-home choice for young adults over 21 who do not have an I/DD condition and do not have a place to live in the community.

Recent communications with staff from the Department of Elder Affairs indicate that the continuance of the Aging Out Program under Medicaid Reform has not been confirmed. Lack of access to the critical services covered by this component of the Aged and Disabled Adult HCBS waiver could very likely result in institutional placement for young adults with medically fragile conditions. It is unknown how the managed LTC plans will address the needs of this population.

Findings from Review of Other States

Of the four states reviewed for this report, only California had no upper age limit on the HCBS waiver for persons with medically fragile conditions. In a previous project with FDDC, Chrysalis Consulting Group reported that another 6 states also provide adult HCBS waiver services for this population. The states include: Alabama, Maryland, New Mexico, North Dakota, South Carolina and Virginia. Without question, having HCBS waivers for persons with medically fragile conditions available without age limits provides the best option for persons to have ongoing continuity of care. For the best outcomes, providers should have the capacity to work with both children and adults, and out of home services in alternative homes should ensure that the child is able to remain in the home after they turn 21.

The Long Term Care plans currently being phased in across the state, must –according to the language in the intention to negotiate – be able to meet the needs of this population. Most adults with medically fragile conditions live with other persons in the community, usually family members. For these individuals the services provided in the Long Term Care plans should be able to meet most of their needs. However, if the person's community costs exceed the cost of the skilled nursing facility, the Long Term Care plan has a financial incentive to place the person in a skilled nursing facility. Also of concern, is what appears to be extremely limited (or no) capacity to provide community-based alternatives to avoid institutional placement for persons who do not have a home environment available. A Long Term Care plan to serve this population should include alternative residential choices.

States with Adult Family Home Services

Adult foster homes is a growing option to serve elderly persons and persons with disabilities in the community rather than institutional settings. Small, home-like residential settings for this population are known by several names – adult foster care, adult family homes, adult family care, residential care facilities, and sometimes as assisted living facilities. They are usually certified or licensed by state agencies or county-based agencies. States offer an array of settings and supports for individuals that need assistance with activities of daily living, health conditions, oversight, and supervision. The severity of medical conditions of persons served in the homes varies by state. Below is a discussion of three states that provide services in adult family homes for persons with medically complex conditions.

California

The California Department of Developmental Services has a program called Family Home Agency (FHA). FHA and family home services and supports started in 2007 to enable adults with developmental disabilities to enter into partnerships with families that promote self-determination and interdependence.

These not-for-profit organizations are under contract with the Department to approve family homes which offer the opportunity for up to two adult individuals with developmental disabilities per home to reside with a family and share in the interaction and responsibilities of being part of a family. The individual receives the necessary service and supports from the family, agencies and the community to enable the individual to be a participating member of the family and the community where the family resides. The family home arrangement allows the sharing of food, shelter, experience, responsibilities and love. FHAs are responsible for recruiting, training, approving and monitoring family homes, as well as providing ongoing support to family homes. Social service staff employed by the FHA make regular visits to the family home to ensure that necessary services and supports are in place, and that the match between the family and the new family member is viable, and continues to be viable. The adult foster care program is a HCBS waiver services under developmental services and is able to serve persons with medically fragile conditions. The service is not available under the waiver for persons with medically fragile conditions.

Texas

Other states have addressed this issue. In Texas, the Texas Star Plus managed care program includes Adult Foster Care as a service. The individuals live with the family as part of the family home. Depending upon the characteristics of the individuals living in the home, the capacity ranges from three to four persons with disabilities. The individual must pay for their own room and board. In addition to the traditional foster home care and supervision, other services available to adult foster care members are: adaptive aids and medical supplies, nursing services, minor home modifications to accommodate individual needs, therapy services, and dental services. Day services are available as well. The same array of services may be provided in small group homes that serve no more than 8 persons. The Adult Foster Care service has three levels of care. Level II and Level III may be appropriate for persons with medically fragile conditions, with Level III available for very fragile conditions.

Level II services include assistance with tasks that may require the delegation and supervision of registered nurse. Some of the duties listed as examples include:

- Administration of oral medicines through permanently placed feeding tubes
- Positioning and turning
- Invasive procedures, such as inserting tubes in a body cavity or instilling or inserting substances in an indwelling tubes (excludes gastrostomy tube).

In Level III, many tasks must be provided by a licensed registered nurse, or licensed vocational nurse. Persons served have a medical disorder, disease, or both with a related impairment being so complex or of such sufficient seriousness that their needs exceed the care which may be delegated to an unlicensed person. These individuals require timely assessments, planning and intervention by a licensed nurse on a 24-hour basis.

The homes are licensed by the Department of Aging and Disability Services. Texas Star Plus also provides in home and out of home respite for persons who need nursing care.

Oregon

The Department of Health Services provides adult foster home care through the Seniors and People with Disabilities (SPD) Home and Community Based Services waiver.

These services are provided in home-like settings. Each is licensed for five or fewer individuals who are not related to the foster home provider. Homes may specialize in certain services such as serving ventilator-dependent residents or persons with other types of medically fragile conditions. For homes that serve persons who are ventilator-dependent, licensure requires that the home have awake staff 24 hours a day; that the home and staff are fully trained in providing all the care necessary; and back-up generators are available. A registered nurse must work in the home who is trained in the care of ventilator-dependent individuals. The registered nurse services include but are not limited to the provision of medical consultation for and supervision of resident care, skilled nursing care as needed, and delegation of nursing care to caregivers. The provider must have physician, RN, and respiratory therapist consultation services available on a 24-hour basis and for in-home visits as appropriate. Oregon serves about 3,000 elderly and persons with physical disabilities in these homes. It appears that homes are both individually and agency operated.

Recommendations for Transitioning Young Adults with Medically Fragile Conditions to Adult Services.

Access to Adult Waivers

Young adults with medically fragile conditions will need services beyond those provided in the Florida Medicaid state plan for adults. To receive these additional services they will need to be served on a HCBS waiver. Florida's HCBS waivers with the responsibility of serving this population include the new LTC managed care plan waiver and the Developmental Disabilities waivers. Both of these resources have long waiting lists. These young adults can't wait for services. They need immediate enrollment on one of the waivers to receive critical nursing and personal care.

Recommendation 8: Children turning 21 years of age with medically fragile conditions should have immediate access to the DD HCBS waiver or the LTC plan.

If the young adult has a developmental disability and has been receiving either private duty nursing or personal care assistance they should have immediate access to the DD waiver due to the fact the lack of continuation of services will result in a serious medical crisis for the individual. The Aging Out provisions previously instituted through the Aging and Disabled Adult waiver or similar procedures must be continued as the state moves into managed care. AHCA should conduct ongoing monitoring of the services to this population in the managed care program. If it appears that the continuity of care between the children's and adult's program is problematic, or if community options are not being offered, the agency should consider creating a HCBS waiver for persons with medically fragile conditions without an age limit.

Services included in the HCBS for adults with medically fragile conditions

In order to reduce the number of persons served in the institutions and to provide options for persons with complicated medical conditions, states should have small residential options for persons to live safely in the community. Adult foster homes and small group homes offer that option. They can be operated either individually or through a provider agency. Given the medical complexity of this population, consideration should be given to included agency operated as an option. These programs can also offer out of home respite care if necessary as well.

Recommendation 9: Add another level of care of Adult Family Care and Small Group Homes to serve persons with medically fragile conditions as a service in the Long Term Care managed care program and encourage the development of these homes under the DD HCBS Waiver.

Although Adult Family Care is an available service under the Long Term Care managed care program, the licensure description doesn't appear to cover persons with complicated medical conditions. In order for the managed care plans to successfully provide diversions from skilled nursing facilities for this population there must be a community living option for persons who do not have their own home or live with natural support caregivers.

The DD HCBS waiver has some flexibility in the array of services that can be provided. To provide options for transitioning adults with me /DD conditions, APD should consider expanding adult foster care as a residential option.