

**REPORT TO THE
Twenty-First LEGISLATURE**

**ON S.C.R. NO. 15
Pertaining To The Creation Of A Coordinating
Committee
To Oversee The Care Of Medically Fragile Children**

**Submitted By The Coordinating Committee For Medically Fragile
And Technology Dependent Children
Through the Department of Human Services**

December, 2001

EXECUTIVE SUMMARY:

The Community Coordinating Committee for the Medically Fragile and Technology Dependent Children was created by the twenty first (2001) Legislature through Senate Concurrent Resolution (SCR) No. 15. By creating the Coordinating Committee, the Legislature demonstrated its awareness of the complex medical and other needs of medically fragile and technology dependent children, the need for detailed planning and support in order for children to be safely cared for in the community, and the need for care provided to this vulnerable population to be seamless and family centered.

The Department of Human Services (DHS) and the Department of Health (DOH) were charged with jointly creating the Coordinating Committee. DHS was designated as the lead agency to organize and coordinate the coordinating committee and with the assistance of the DOH, Kapiolani Medical Center for Women and Children, and the Home Care Division of the Healthcare Association of Hawaii (HAH), responding to the issues raised at the summit for policy-makers regarding the care of medically fragile children sponsored by Kapiolani Medical Center on November 14, 2000, and the charge by the legislature, the following was implemented:

- ? Establishment of a steering committee comprised of the chairs of all the work groups, DHS, DOH, HAH, and Kapiolani Medical Center to coordinate the work of the work groups,
- ? Establishment of work groups to address the multi-dimensional needs of this vulnerable population. The work groups are: definition and data; community based services; family support; and human resources/training (attachments: work group reports)
- ? Establishment of charters for each work group

Recommendations of the Coordinating Committee for the Medically Fragile and Technology Dependent Children

- ? The Coordinating Committee believes that much work is needed before the goal of a seamless system of care is achieved. Committee members have a deep interest in this goal and recommend that the coordinating Committee and work groups continue.
- ? The Coordinating Committee believes that the primary focus of care delivery must be to optimize the quality of life for the child and his/her family. Therefore, to emphasize this focus on the child, the Coordinating Committee will change its name from Community Coordinating Committee for Medical Fragile and Technology Dependent Children to Community Coordinating Committee For Children Who are Medically Fragile and Technology Dependent.
- ? The Coordinating Committee believes that the services that children who are medically fragile and technology dependent receive in the home and community setting must be of high quality. Recognizing that there is a great need for the development of community based standards of care and monitoring procedures, a major thrust of the work for the next year will be in developing these standards and determining indicators of quality. However, we feel that for the safety of children and adults, all agencies that provide home care services should be licensed by the State of Hawaii.
- ? The Coordinating Committee acknowledges the expertise of the DOH's Public Health Nurses (PHNs) in managing the home and community based care of children. Especially on the neighbor islands, PHNs

serve as the “safety net” case managers for children who do not have access to agencies that are qualified to provide case management services. Currently, Hawaii Medicaid reimburses case management services provided by both private case management agencies and PHNs. There is agreement among the Coordinating Committee members that more training is needed to increase the access to quality case management and skilled nursing services. However, Medicaid is prohibited from directly reimbursing for training and education. Therefore, the Coordinating Committee supports the DOH’s Public Health Nursing Branch’s efforts to submit bill HTH 11 for the establishment of the public health nursing services special fund to receive and expend Medicaid funds for staffing and training.

- ? The Coordinating Committee strongly supports the principle of care which is family centered and that parents are the experts in the care of their children. The case manager, therapists, providers of specialized equipment, physicians, and parents must work cooperatively as a team. Therefore, the Coordinating Committee recommends parent representation on each of the work groups.

Accomplishments:

SCR No. 15 charged the coordinating committee to “make changes and improvements to the system of care where such changes can be implemented voluntarily and within the scope of present state and federal law and regulations. The following are some of the changes made:

- ? The Medicaid Agency developed standards for Medicaid case managers for medically fragile and technology dependent children. Beginning May 1, 2001, Medicaid has enrolled agencies that meet these standards as Medicaid providers and is directly reimbursing them. The Medicaid case manager is the primary case manager of the child who resides in the community and the key to the seamless system of care.
- ? The Medicaid Agency developed standards for home care agencies that provide skilled nursing and personal care services to children who are medically fragile and technology dependent. Beginning December 1, 2001, it has expanded the number of home care agencies that can provide these services.
- ? Recognizing the shortage of qualified pediatric nurses in the State and specifically in home care, beginning November 1, 2001, the Medicaid Agency increased the reimbursement for skilled nursing services provided by qualified home care agencies that provide services to children who are medically fragile and technology dependent.
- ? The Medicaid Agency developed and is testing scoring tools to quantify the level of case management and skilled nursing services needed by an individual child. The Medicaid Agency and the Definition and Data Work Group are planning to test the tools and their validity in identifying children who are medically fragile and technology dependent.
- ? The Coordinating Committee has created another work group to explore the uses of telemedicine in improving the coordination of care in the community for children who are medically fragile and technology dependent.
- ? The Coordinating Committee has developed and implemented a consolidated interagency family resource manual to be kept in the child’s home. Included in this manual are medical information,

community resources, routine and emergency care instructions, life support documentation, and other information of importance to the family and caregivers. The Coordinating Committee is working on making this information available through a secured web site.

- ? Streamlined authorization processes for services, equipment and supplies have been developed to assure completeness and efficiency and to ensure that all needed resources are provided. The Community-Based Services work group is planning to implement and refine these processes.
- ? Hospital discharge protocols have been modified to include community care providers early in discharge planning to ensure a seamless delivery of services.
- ? The steering committee formed the work groups, which are composed of a broad spectrum of committed key stakeholders from the community.

The following are attached:

- ? The general charter for the coordinating committee and work groups, which focused on issues derived identified at the November 14, 2000 summit for policy makers
- ? The reports of the individual work groups
- ? Listing of the membership of the coordinating committee and the work groups

The Coordinating Committee appreciates the Legislature's foresight in creating the committee and the Legislature's continuing support of the committee's activities.

**GENERAL CHARTERS FOR THE
COORDINATING COMMITTEE AND
WORK GROUPS**

ACTION STATEMENTS
Compiled from the recommendations of the break out groups
At the Medically Fragile Children's summit

Organized by Work Group Assignments

Charge by the Legislature:

- ? “Document the needs of medically fragile children and make recommendations to create a seamless system of care.”
- ? “Nonetheless make changes and improvements to the system of care where such changes can be implemented voluntarily and within the scope of present state and federal law and regulations.”

Overall System Recommendations for general membership and all work groups:

- ? Have a leadership council from different agencies to advocate for these children
- ? Integrate state agencies in helping with transition from hospital to home (KMC, DOE, DHS, DOH) -- should have transparency of source to consumer.
- ? Improve inter/intra agency coordination
- ? Enhance system flexibility and timeliness
- ? Review laws and regulations to understand constraints, but also areas where there is flexibility, or areas which require advocacy
- ? Secure feedback from care coordinators and providers from Neighbor Islands
- ? Look at successful systems nationwide.
- ? Streamline processing to avoid rejections/denials
- ? “Blend” funding of services matching resources to needs (seamlessly)
- ? Statewide agency – legislative funding

Work Group 1: Definition and Data Work Group:

- ? Establish the working definition for the population for the committee
- ? Quantify this population and their needs
- ? Contrast costs in various settings.
- ? Present data to decision-makers for system-wide changes.

Work Group 2: Community based Services

General Action statements:

- ? Document needs and make recommendations for methods
- ? Integrate medical, developmental, education, placement, supplies-- planning and delivery
- ? PHN should be central point of contact
- ? Question: Eligibility and delivery of care for 0-3 services
- ? School should be involved in process for ordering equipment
- ? Work with Hawaiian Electric to develop special programs for continuous electrical coverage and financial support.

Equipment:

- ? Need common definition of medical equipment needs – school use vs. home and school
- ? Need to develop clear criteria for medical supplies; Vendors also need criteria.

Case Management:

- ? One case manager should follow individual throughout his or her life span, as long as needed.
- ? There should be an identified case manager with authority to access the needed services
- ? Case management agency should be independent from service agency.
- ? Eliminate duplication of case management services.
- ? Define case management services
- ? Develop uniform case management training.
- ? Move to EPSDT case management system
- ? Question: What authority does home care coordinator need to acquire services/supplies?

Discharge Planning:

- ? Integrated discharge planning with hospital and community
- ? I.D. Medically Fragile patient (for Medicaid) – submit documentation with 1144
- ? Need for a designated coordinator for home care
- ? Everyone should be involved with the process of discharge (payers, providers, vendors, etc)
- ? Clarify role of each service provider once child is home
- ? Simulate home situation while the child is still in the hospital
- ? Parents should be trained on equipment they are to use in the home
- ? Discharge date projected...therefore all equipment ordered in advance to meet d/c needs – resolve reimbursement issues to permit this.
- ? No discharges on Fridays
- ? Start discharge planning early
- ? Attending physician at KMC should relate information to neighbor Island PCP--NOT to be given by MSW, Resident, etc.
- ? Do peer review of discharges of Medically Fragile children
- ? Incorporate social aspects of discharge planning

Work Group 3: Family Support

- ? Assure clear understanding by parents of what has transpired in order to obtain services
- ? Resource list/guide for parents, providers
- ? Development of web site; develop web site re: “Myths and Misconceptions
- ? Knowledgeable person to interpret system
- ? A policy manual for parents that includes rights
- ? Listen to parents
- ? More family support services to address family fatigue

Work Group 4: Human Resources/Training:

- ? Comprehensive look at nursing shortage crisis—not enough human resources.
- ? Identify level of expertise that is needed for all settings and health care providers; responsibilities
- ? Need a credentialing program for home health nurse (develop competencies and standards)
- ? Strengthen nursing resources for 0-3 programs
- ? Discrepancy between hospital/home care nursing
- ? Salaries too low
- ? Regulations
- ? EPSDT training for all islands
- ? Educate community re: guidelines via web site, etc.
- ? Focus on educating hospital physicians
- ? Legal guidance to help develop a training system
- ? Education for those receiving requests
- ? Question: Is there a need for skilled nursing in infant development programs?
- ? Reimbursement issue—need payment enough to attract and retain qualified personnel

WORK GROUP REPORTS

Report
Definition and Data Work Group

CHARTER:

- ? Establish the working definition for the population for the committee
- ? Quantify this population and their needs
- ? Contrast costs in various settings
- ? Present data to decision-makers for system-wide changes

ACTIVITIES:

- ? The majority of activities were centered on defining the population.
- ? Defining the population is key to accurate assessment of resources need to support children who are medically fragile and technology dependent in the community.
- ? Defining the population is critical to tracking and monitoring the resources needed and identifying the gaps in resources.
- ? Defining the population is essential to validating the appropriateness of interventions.
- ? The goal is to identify essential data elements that will be collected and would clarify and quantify the needs of children who are medically fragile and technology dependent.
- ? Steps taken to achieve this goal:
 1. The Med-QUEST Division has developed and implemented an assessment tool to quantify skilled nursing services that children who are medically fragile and technology dependent need and has implemented a database based on the assessment. (see attached database and assessment tool)
 2. The Work Group will review and modify this database.

Attachments

Home Skilled Nursing Scoring Tool

NAME:	Last	First	M.I.	Birthdate	I.D. Number
	Nursing Intervention			Frequency/Complexity	Points
1	Ventilator			Continuous	50
				Intermittent	30
2	Tracheostomy				30
3	Oxygen therapy				20
4	Nebulized Medications			TID or less	10
				>TID	20
5	Vascular access catheter				40
6	Parenteral nutrition			Continuous	40
				Intermittent	30
7	Gastrostomy/jejunostomy/nasogastric tube			Gravity feedings	20
				Pump feedings	30
8.	Ileostomy/colostomy				10
9	Urinary bladder catheterization			Intermittent or continuous	10
10	Orthopedic appliance			Splint/cast (each)	5
				Complex (describe)	10
11	Isolation/reverse isolation				30
12	Enteral Medications			8 doses/day or less	5
				>8 doses/day	10
13	IM/SQ medications			4 doses/day or less	10
				>4 doses/day	15
14	IV medications			4 doses/day or less	15
				>4 doses/day	20
15	Monitor (Apnea, Pulse Oximeter, C-R)				20
16.	Special Skin Care (Burn, decubiti)			Localized	5
				Extensive (describe)	10
17.	Wound Care (describe)				10
18.	Less than 6 months since initial discharge (discharge date: _____)				40
19	Less than 3 months since subsequent discharge (discharge date: _____)				30
20	Other Specialized nursing interventions: _____ _____				
<u>Total Points</u>					

Comments and explanations _____

Provider: _____ Date: _____

Community Service Workgroup

Recommendations:

Create a system that utilizes one (1) case manager for each Medically Fragile and Technology Dependent Child.

? Establish criteria for this role that covers:

- ? Standards of Care
 - o Participation with child to begin pre-discharge
 - o Following a schedule of interaction with client
- ? Scope of Services
 - o Clearly defined areas of authority
 - o Channels of communication with payors
- ? Licensure
- ? Standardized fee schedule for services
 - o Streamlining reimbursement
 - o “Batching” of 1144’s
 - o Standardized scoring tools for objective allocation of resources
- ? Quality Assurance/Performance Improvement

Activities:

- ? Explored areas of concern
- ? Addressed the charges set forth by the Legislature

Accomplishments:

- ? Greater appreciation of individual roles in the process
- ? Constructive suggestions for meeting mandates
- ? Established a working dialog with State personnel involved in this exercise

We are fully committed to working with all members of the Medically Fragile and Technology Dependent Child task force in achieving the goal of a seamless transition from hospital to community.

We recommend the community case manager (CCM) establish a relationship with the client prior to hospital discharge to transition services from hospital to community. The CCM is the most pivotally important contact to assure seamless delivery of services. In pursuit of this ideal, the CCM needs to have the authority to access services in a timely manner and across the spectrum of providers and payors. Coordination of services is essential to the success of this endeavor.

Having the CCM as the key person enables all providers of service to have a single point of contact. With this, then, is accountability for the seamless delivery of services. Also, having one person being responsible for coordination of all services enhances the efficiency of community care. The scope of the CCM’s authority needs to be defined on a State level to assure consistency of service across the State.

It is important that reimbursement be commensurate with the services provided. Community care of this population has the potential to be the most cost effective venue if it is approached along the same guidelines as have been successfully implemented in the adult population (the RACCP Program).

Involving the CCM early in the discharge planning process enhances successful transition from the hospital to community. Having vendors and service providers participate in the discharge planning process just prior to discharge establishes their presence in the process and builds the foundation for the team to support the MFC in the community. Clearly defined expectations and acknowledgement of the role of the CCM as the “Captain of the Ship” now set the stage for seamless delivery of service.

Another strategy that has been found to be effective is having a staff RN from the discharging facility accompany the MFC home on the initial discharge. We have also learned that we also need to identify a contact person from each vendor to address emergency needs.

The discharge binder that is initiated in the hospital becomes the database for the service providers in the community. We recommend that statewide standards be developed and adopted for documentation, time constraints, and for storage of documents that have been thinned from the binder. Agency concerns about sharing their documentation space with other agencies needs to be addressed at a statewide level.

We recommend that standardized 1144's for specific needs be implemented. (see attached) The feasibility of assigning new cost codes to these “batched” 1144's should be studied. It is the feeling of this committee that this would be a more efficient and cost effective way to ensure that families receive needed equipment and supplies in a timely manner. Family concerns about delays in obtaining the equipment and supplies could be partially addressed by doing this. Within a clearly defined scope of authority the CCM will be the responsible person in deciding the urgency of requests that fall out of the “batched” 1144's. The CCM will advocate for the MFC to expedite this process. A contact person needs to be identified so that the CCM can address issues in the timeliest manner. As part of the “batching” process it would be specified that the request is for home, school, or other use. We recommend that data supporting the most cost effective modalities be used in justification. (? Use of liquid O₂ vs. O₂ concentrator) Quality of life and ease of care need to be valid criteria in approving supplies and equipment.

The EPSDT scoring tool should serve as the standard of care for services for this population. This will provide for objective allocation of resources and further enhance statewide application of community based care.

We need to agree, on a statewide basis, who constitutes this population. Just as the EPSDT scoring tool is the standard of care, a statewide definition would be the initial screen for entry into services.

Because of the unique nature of the State of Hawaii we need to acknowledge that equipment and supply needs cannot be met consistently, statewide. Families on the Neighbor Islands often face great hardships in receiving the services that are routine on Oahu. Also, Neighbor Island families have substantially more challenging transportation needs.

This committee has questions regarding the question of training, for whom is this intended the family? the CCM?, the vendors?

There should be a state level person (probably through Med Quest Division) who is responsible for monitoring, Q. A. identifying areas for performance improvement and establishing a process of addressing concerns and issues. This process needs to be operated in the context of collegiality with the shared goal of delivering the best possible service for this population.

COORDINATING COMMITTEE FOR MEDICALLY FRAGILE: FAMILY SUPPORT WORK GROUP REPORT
CHAIRPERSON: RUTH OTA

FAMILY NEEDS IDENTIFIED THROUGH THE FOLLOWING SOURCES:

1. Literature Search by Ratliff, Clark, University of Hawaii School of Nursing and Dental Hygiene
2. Needs identified by a panel of parents at the Medically Fragile Summit sponsored by Kapiolani Medical Center for 2000, and needs identified by Family Support Work Group and other parents
3. SUMMARY REPORT: Survey, "Your Voice Counts" by Family Partners, a collaborative project of Family Voices; was mailed to families in 20 states between March, 1998 and April, 1999 and 2,220 families responded.

LITERATURE SEARCH (RATLIFFE, ET AL)	NEEDS IDENTIFIED BY FAMILIES AT MEDICALLY FRAGILE SUMMIT AND OTHERS	SURVEY: YOUR VOICE VOICES AND BRANDEIS
<p>ROLE CONFLICTS</p> <ul style="list-style-type: none"> ? Ongoing changes between being the parent and expert caregiver ? Challenges to learn how to be a parent ? Be a teacher, supervisor to health professionals who come into their home. ? Family being the expert care giver, but not seen/regarded as a part of the care team ? Conflicts between parents as caregivers and professionals 	<p>INCREASED DEMANDS ON FAMILIES:</p> <ul style="list-style-type: none"> ? Fears, anxieties, shock, disbelief with child's diagnosis and caring for such a sick child ? Emotional strain on siblings and decreased time with siblings impacting on family dynamics ? Ill prepared to having to be an expert immediately ? Expected to be an expert in isolated community with limited resources ? Conflict as to who is the "expert" ? Having to constantly keep up with being sure that supplies, equipment, medications are available ? Feelings of isolation with high demands for expert caregiving ? Feel like we are just another family "on paper" trying to get help and support. ? Are a real family struggling to maintain a "normal life" 	<p>INCREASED DEMANDS ON FAMILIES:</p> <ul style="list-style-type: none"> ? Having a child with significant family involvement ? Mothers are providing care at home i.e. PT, feeding, etc. ? Parents coordinate and manage a lot of health care themselves. ? Case Managers never seem to have to talk to different people ? Case Manager only manages things I ask for; not things I need; other parents get 99.9% of the information ? States managed care caseworkers' recommendations; managed care caseworkers examine each request through documentation rather than cost to system

<p>FINANCIAL BURDEN</p> <ul style="list-style-type: none"> ? Financial worries over equipment, supplies, care delivery ? Major job changes as direct result in having medically fragile child ? Good insurance coverage could not shield families from life altering charges ? Dealing with equipment agencies, insurance and government agencies problematic 	<p>FINANCIAL BURDEN:</p> <ul style="list-style-type: none"> ? High electrical and phone bills ? Taking time off from work; fear of losing jobs ? Humiliating process to go through the Medicaid application process ? Not knowing what services family is eligible for that can impact on family finances ? High cost of services tied in with dissatisfaction with services ? Burden of in/out of KMC for NI families and cost for travel, housing, etc ? Having to spend hours on phone dealing with insurance companies, medical equipment vendors, therapy service agencies ? Authorization process is a “nightmare,” resulting in delays to no supplies/equipment and not getting the services due to delays or denials ? Frequent changes of medical equipment companies 	<p>FINANCIAL BURDEN:</p> <ul style="list-style-type: none"> ? Two thirds reported work and/or stopped condition ? Half of families reported majority incurred out Exceeding \$1,000 at \$5,000. ? Delays in getting re insurance companies
<p>CARE BURDEN</p> <ul style="list-style-type: none"> ? Overwhelming with need for technical skills, complicated procedures, machines ? Sense that “one is never off”. Even if there is a care professional in the home, level of trust is insufficient that parents are “never off.” ? Never ending task of supervising, teaching care professionals ? Feeling that it is not worth it to go out. 	<p>TRAINING/EDUCATION/RESOURCES</p> <ul style="list-style-type: none"> ? Intensity of care at home; overwhelming demands of care; emotional struggle to see child struggle every day; emotional strain on siblings and other family members ? Some parents are ill-prepared to care for child at home-family needs consistent/ongoing training in hospital so better prepared at home ? Need help in community for unexpected events/more training– someone who can provide the expert support and assistance ? Lack of trained professionals/inadequately trained nurses; unfamiliar with child’s condition ? Unprofessional manner of personnel ? Parents have to orient, train, supervise professionals 	<p>PROBLEMS FAMILIES ARE SERVICES:</p> <ul style="list-style-type: none"> ? 48% had problems getting home health care professionals ? Having unreliable professionals ? Being denied payment for number of hours ? Difficulties getting coverage cap on number of visits by health plan, lack of getting referrals for specialists ? 23% had difficulties specialty doctors; find necessary skills and payment for specialist

<ul style="list-style-type: none"> ? Different caregivers providing the services and doing procedures differently ? Unresolved system challenges prevent adequate care by systems ? Worries about maintenance of child's complex ADLs; maintenance of family life routines ? Deterioration of family structure ? Mod. High % of mothers scored at risk for depression experience ? Emotional support from family, friends, church important, but unreliable. ? Coping with other's attitudes and values ? Tremendous stress involving in feeding children before giving in to "gastrostomy feeding." 	<ul style="list-style-type: none"> ? Lack of regulation or monitoring of personnel of agencies providing the care in the home. ? High turnover of personnel from agencies, which puts more demands for training on parents ? Families are not informed about resources available – have to find out from someone else. ? Feelings of isolation ? It takes a long time for agency personnel to get to know the child so as to know exactly what to do – it is only during this phase that parents are comfortable in leaving child with agency personnel. ? Trained non-licensed personnel can provide the "nursing services" to reduce the care burden and giving family choices as to providers 	<ul style="list-style-type: none"> ? 21% had problems v medications; getting difficulty getting app considered "experim ? Dissatisfied with or nutritional suppleme equipment; disposab
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>INDEPENDENCE</p> <ul style="list-style-type: none"> ? Difficulties being continually isolated in the home ? Social contacts and social supports decrease, which increases the isolation ? Difficult to do anything SPONTANEOUSLY outside the home. There is much preplanning. ? If child left at home, problem of lack of trained, trusted care provider. ? Learning for child is important-going to school can be problematic ? Power conflicts between health care provider and parents 	<p>OTHER</p> <ul style="list-style-type: none"> ? Demands are so great that it limits social contacts ? Teachers may not be trained to work with child to focus on ADLs 	
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--

RECOMMENDATIONS BY FAMILY SUPPORT WORK GROUP AND ADAPTED FROM: Ratliffe, Clark; Harrigan, Rosan
“Medically Fragile Children: An Integrative Review of the Literature and Recommendations for Future Research, “University
Dental Hygiene

THEMES FOR ACHIEVEMENT

	THEME: EMPOWERMENT	THEME: FINANCIAL	THEME: REDUCE CARE BURDEN/STRESS	T C
FAMILY	<ul style="list-style-type: none"> *Parents as “experts” of care; parents knowledgeable about child’s needs and care *Support so parents are motivated to care for child at home *Training provided as though parents were at home **Parents with standard of performance 	<ul style="list-style-type: none"> *Standardized guidelines as to equipment, supplies with build in uniqueness based on needs of child *Streamline authorization processes so those who know what the needs are can make decisions *Hooked into all benefits *Written financial plan before 	<ul style="list-style-type: none"> *Consistent, skilled case manager to work with family *Trained, skilled personnel to provide care in the home *Research use of non-licensed personnel in 	* w a; * h h * *

	<p>for care followed by agency personnel</p> <ul style="list-style-type: none"> **Parents as trainers or mentors **Parents as final decision maker as to needs for child; who provides the care **Individual needs for parents with limited capacities 	<p>discharge</p> <ul style="list-style-type: none"> *Partners with insurers *More flexibility for supplies *Standard timely process to address denial of services 	<p>care in the home with strong involvement of family (Nurse Practice Laws will need to be researched)</p> <ul style="list-style-type: none"> *Individual stress management plan for each family member *Family stress management plan *Local support groups of similar families *Respite care of high quality *Day Care of high quality 	<p>d c * c * r h * b d * o * f a * a st</p>
CHILD	<ul style="list-style-type: none"> *Attending School *Developmentally appropriate IEPs, normalizing child's life as much as possible *Mobility *Communication *Up to date assistive technologies *Integrate the various therapies into everyday life functions at home and at school. This should start in hospital 	<ul style="list-style-type: none"> *Need for equipment at home as well as while attending school *Availability of supplies at home and school *Coverages to normalize child's environment at home and at school *Coverages for special nursing care, therapies, other special training 	<ul style="list-style-type: none"> *Consistent, compassionate, trained care givers at home and at school *Mobility throughout the home and community 	<p>* * P o a * f * c</p>

<p>HEALTH CARE PROVIDER</p>	<ul style="list-style-type: none"> *Education in culturally competent family centered care *Facilitate empowerment of family *Integrate principle of families as experts and partners *Help family develop performance standards for care of child *Respect family choices and preferences *Be sure agency staff knowledgeable of resources available 	<ul style="list-style-type: none"> *Help family through the maze of insurance systems *Help family to get signed up for benefits *Inform family of all the resources available *Advocate for parents with insurers and other bureaucracies 	<ul style="list-style-type: none"> *Assess family stress and respond *Assess provider stress and problem solve *Set up/facilitate support groups *Provide counseling *Involvement of physician/other personnel who know the child and family 	<p>* P ? ? ? * p a b * p * n ir c</p>
<p>HEALTH CARE SYSTEM</p>	<ul style="list-style-type: none"> *School Special Education support in having trained teachers and educational assistants *Improved facilities in schools to meet the needs of children 	<ul style="list-style-type: none"> *Insurers and payers partners with families *Facilitate the authorization/reauthorization process—once child is medically fragile condition does not generally change *Supporting families probably cheaper *Research needed on costs 	<ul style="list-style-type: none"> *Respite care both short term and long term *Day care with trained providers *Community counseling services 	<p>* * fa ir * p * c * th p c</p>

Report
Human Resources Work Group

Community Coordinating Committee For Medically Fragile and Technology Dependent Children

12/7/01

Charter (Summary):

Identify human resource manpower needs now and for the future
Identify education and training needs
Identify level of expertise needed in all settings
Develop standards for provision of services, looking at applicable laws, etc.
Identify strategies for developing manpower, training
Quantify costs and benefits
Quantify impact on reimbursement

Activities:

Met and reviewed assigned recommendations from the summit and initial meeting.

Began identifying action strategies for following areas:

- ? Identifying manpower requirements
- ? Identifying shortage areas
- ? Identifying factors in the shortage areas, primarily home health.
- ? Identifying new service sectors requiring training
- ? Identifying new training needs
- ? Identifying sources of training standards and curricula

Created another working group which will explore a “leapfrog” approach using technology and telemedicine options as a potential avenue to extend the limited trained human resources.

Accomplishments:

None to report at this time.

Recommendations:

Request data committee results upon completion to support manpower documentation.

Feedback/comments?

**LISTING OF THE MEMBERSHIP OF
THE COORDINATING COMMITTEE
AND WORK GROUPS**

**COMMUNITY COORDINATING COMMITTEE FOR MEDICALLY
FRAGILE AND TECHNOLOGY DEPENDENT CHILDREN**

MEMBERSHIP – (final)

NAME	AGENCY
Abel, Gigi	Abel Case Management
Aoki, Dr. Byron	KMCWC
Arnobit, Violetta	Ace Medical
Boardman, Elise	KMCWC, Case Management
Bojorquez, Melissa	HMSA
Bowman, Barbi	Castle Home Care
Carey-Goo, Pam	KMCWC
Castonguay, Bonnie	KMCWC, Quality Management
Chun Oakland, Suzanne	Senator
Conjugacion, Sandra	Special Education Center of Hawaii
Connor, Angie, MD	DD Council
Gallagher, Dr. Thomas	Chief, Exceptional Family Member Program
Harrigan, Dr. Roseanne	Dean, School of Nursing and Dental Hygiene, UH-Manoa
Hayashi, Miki	Nursing Dept., KCC
Hill, Judy S.	Nursefinders
Hing, Linda	Total Home Care
Honbo, Lynette, MD	Med-QUEST, DHS
Hudson, Frankie	Hawaii Home Infusion Assoc.

Iwaishi, Dr. Louise	
Kabel, Joya	Nursefinders
Kusunoki, Laurie	
LaFontaine, Susan, Mgr.	KMCWC, Rehab Services
Lee, Cory	Dtr. Of Professionals Kokua Nurses
Lopes, Dwayne	KMCWC
McMannen, Kii	Office of Senator Chun-Oakland
Mendoza, Nancy	Respiratory Home Care Specialist
Mitsunaga, Dr. Richard	
Morton, Willow	Vice President, KMCWC
Nishimura, Cynthia	Med-QUEST, DHS
Odo, Mrs. Winifred	Program Director, Kulana Malama
Okuna, Jeff	Kaiser Permanente
Ota, Ruth	Chief, PHN, DOH
Paeste, Gina	Parent
Parlin, Leolinda	Family Voices of Hawaii
Pereira, Sheena	Case Manager, KMCWC
Peters, Linda	Kaiser Permanente
Powers, Dr. Gerald	CCOH
Poyzer, Rose Ann	Vice President of Homecare and Hospice Division

Rosen, Linda, M.D.	Family Health Services Div., DOH
Ratliff, Clark	UH School of Nursing
Ruhland, Marie	Hilo Medical Center
Saruwatari, Ken, MD	
Schuetter, Tom	Pacific Island Medical, Owner
Shacter, Joe	Planner, DD Council
Silverman, Madi	DHS, Social Services Div.
Smalley-Bower, Helen	Parent
Smith, Frank R., MD	DHS-Med-Quest
Suenaga,. Ryan	Kaiser Permanente
Steelquist, Laura	Hawaiian Islands Medical
Taketa, Sachi, <i>for Hamamoto, Patricia</i>	DOE
Teeuwen, Carolyn	HMSA
Vanderford, Dr. Paula	KMCWC, Director Pediatric ICU
Wong, Newton	Apria Healthcare
Yamamoto. Dr. Kara	KMCWC, Pediatric Unit
Yagi, Leland	Island Nursing
Yuskauskas, Anita, Ph.D., Chief	DOH Development Disabilities Div.

WORK GROUP TABLE

COMMUNITY SERVICES WORK GROUP

***=Co-Chairperson**

Name	Agency
*Abel, Gigi	Abel Case Management
Arnobit, Violeta	Ace Medical
*Boardman, Elise	KMCWC Case Management
Conjugacion, Sandra	Special Education Center of Hawaii
Hill, Judy S.	Nursefinders
Honbo, Lynette	Med-QUEST, DHS
Hudson, Frankie	Hawaii Home Infusion Association
Lee, Cory	Dtr. Of Professionals Kokua Nurses
Lopes, Dwayne	KMCWC Respiratory Care
McMannen, Kii	Office of Senator Chun-Oakland
Mendoza, Nancy	Respiratory Home Care Specialist
Nishimura, Cynthia	Med-QUEST, DHS
Pereira, Sheena	Case Manager, KMCWC
Peters, Linda	Kaiser Permanente

COMMUNITY SERVICES WORK GROUP (CONTINUATION)

Poyzer, Rose Ann	VP-Homecare & Hospice Div. Healthcare Assn of HI
Silverman, Madi	DHS, Social Services Div.
Steelquist, Laura	Hawaiian Islands Medical
Suenaga, Ryan	Kaiser Permanente
Teeuwen, Carolyn	HMSA
Wong, Newton	Apria Healthcare
Yagi, Leland	Island Nursing
Yuskauskas, Anita	DOH Development Disabilities Division

DEFINITION AND DATA WORK GROUP

Name	Agency
Bojorquez, Melissa C.	HMSA
Castonguay, Bonnie	KMCWC Quality Management
Harrigan, Dr. Roseann	Dean, School of Nursing & Dental Hygiene-UH-Manoa
Ota, Ruth	Chief, PHN, DOH
Parlin, Leolinda	Family Voices of Hawaii
Powers, Gerald	CCOH
*Rosen, Dr. Linda	Family Health Services Div. DOH
Shacter, Joe	Planner, DD Council
Smith, Frank	Med-QUEST DHS

**HUMAN RESOURCES WORK
GROUP**

Name	Agency
Bojorquez, Melissa	HMSA
Carey-Goo, Pam	KMCWC PICU Dept.
Gallagher, Dr. Thomas	Chief, Exceptional Family Member Program
Hayashi, Miki	Nursing Dept. KCC
Iwaishi, Dr. Louise	KMCWC
Kabel, Joya RN	Nursefinders
LaFontaine, Susan, Mgr.	KMCWC Rehab Services
Lee, Cory	Dtr. Of Professionals Kokua Nurses
Mitsunaga, Dr. Richard	
*Morton, Willow	Vice President KMCWC
Ota, Ruth	Chief, PHN, DOH
Poyzer, Rose Ann	VP-Homecare & Hospice Div. Healthcare Assn of HI
Taketa, Sachi	DOE
Vanderford, Dr. Paula	Director, Pediatric Intensive Care Unit @ KMCWC
Wehrman, Steve	
Yamamoto, Dr. Kara	KMCWC-Pediatric Unit

**FAMILY SUPPORT WORK
GROUP**

Name	Agency
Hill, Judy S.	Nursefinders
Iwaishi, Dr. Louise	KMCWC
Kusunoki, Laurie	Parent
Miki, Lynette	KMCWC
*Ota, Ruth	Chief, PHN, DOH
Paeste, Gina	Parent
Parlin, Leolinda	Family Voices of Hawaii
Ratliffe, Clark	UH School of Nursing
Shacter, Joe	Planner, DD Council
Smalley-Bower, Helen	Parent