



# An Exploratory Needs Assessment of Medically Fragile Adults with Intellectual and Developmental Disabilities (IDD) Receiving Homecare who Transitioned from Childhood: Results and Implications

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## Abstract

Medical technologies and care advances have begun extending the lives of medically fragile children with Intellectual and Developmental Disabilities (IDD) so they now can live far into adulthood. Consequently, medically fragile adults with IDD—with their unique characteristics, needs, and problems—are a growing special needs population about which little is known. Speculation about this population is based on data about medically fragile children with IDD, but this adult population is different. This article reports on an exploratory needs assessment study of demographics / characteristics, issues, needs, and cost of 50 (N=50) medically fragile adults with IDD receiving in-home care and 28 of their family members. Data were derived through a targeted sample from a public-sector IDD service provider located in the Greater Houston-Galveston metroplex. Need was identified for particularly vital care, services, and materials. Even with a high degree of integration into service / material systems, there were gaps and absences. Notably, there was no reported need for specialized nursing care, but there was need for Home Health Care Aides. There also was a need for Legal Aid and family support groups. Study findings suggested that medically fragile adults with IDD, when cared for at home, require less medical care and more medically informed supervision. Nevertheless, gaps in services / materials should be addressed for the sake of their families, which are critical for their support. Study limitations and future avenues for further study are discussed.

**Keywords:** Adult Medically Fragile; Intellectual and Developmental Disabilities; Special Populations; Needs Assessment; Service Receipt; Cost Analysis

## Introduction

Over the past decades, there has been a shift from institutional care to home care for medically fragile children with Intellectual and Developmental Disabilities (IDD) [1-5]. This shift has resulted from several factors: (1) improved survival rates of children with IDD who have serious pediatric medical conditions; (2) increased and substantial cost of institutional care; (3) reduced payments for institutional and inpatient care; and, (4) “normalization,” namely, attempts to reduce the developmental delays related to

long-term institutional care [6-12, cf. 13-15]. Additionally, there has been general support for providing care in the least restrictive setting; doing so is less expensive and at least as beneficial, as institutionalized care and families prefer it [16,17]. Consequently, along with medical advances, there has been an increase in the number of medically fragile children with IDD surviving into adulthood and being cared for outside of institutions and in homes with their families [14].

In a limited yet important seminal report on medically fragile adults suffering from severe epilepsy and who had IDD, Lintzinger, Duvall, and Little [18-20], found that improvements in anti-convulsant therapies and staff / family education allowed them to be transferred from state institutions back to the community with their families, which resulted in higher functioning with daily living activities. Unlike Litzinger, Duval, and Little[18], most peer-reviewed scientific studies that shed light on medically fragile adults with IDD who transition from childhood to adulthood are speculatively informed from studies of medically fragile children and adolescents—not studies of medically fragile adults with IDD themselves [4,18,19,21-23,24]. Nevertheless, medically fragile adults with IDD experience similar increased stress from financial hardships and service / material needs [2,4,5,7,8,16,17,22,25].

These reports raised grave public health and social service concerns [15]. Given the intimate parent-childhood bond, stress affecting medically fragile children with IDD transitioning to adulthood would be expected to negatively culminate in the dissolution of the family care unit [4,5, 7,8,10,14,16,17,21,22,24]. This substantially increased care burden for families arises because the children no longer have the school systems that traditionally have intervened to relieve stress by assisting families with healthcare and supervisory burdens—especially for those children whose medical conditions were compounded by IDD [11,26-28], Schools serve as major support mechanism for families coping with providing home care to medically fragile children, and thus preserving the family care unit [2, 11,17,26].

**Method**

Data for this study were derived from the Intellectual and Developmental Disabilities Division of a public-sector, community-based, Mental Health Center operating and located in the Greater Houston-Galveston Metroplex. This Division provides service coordination and care management for in-home support, medical and psychological evaluations, health and nutritional services, prescription medications, early childhood intervention, family support, and other means of respite to families who meet its means test.

The exploratory program evaluation study reported herein was conducted in two phases. Phase 1 focused on medically fragile adults with IDD who transitioned out of childhood; Phase 2 focused on their families. A consistent finding in the literature has been that expenses of dependence associated with medical fragility and IDD compels families to involve public-sector providers and payers [10,23,27,29,31]. Since populations with IDD often have concomitant medical fragile conditions [25], the first step of Phase 1 consisted of identifying medically fragile adults with IDD who had transitioned from childhood, using the IDD Division’s comprehensive electronic database.

Once identified, a review of medical records was conducted to verify their medical fragile status. Fifty (N=50) medically fragile adults with IDD who transitioned from childhood were identified. Demographic-Diagnostic, locator data, service / materials

receipts, and costs were collected. Service costs represent 2024 USD and cost per unit of service / materials with which to make relative comparisons. The intent of Phase 1 was to provide some idea regarding the characteristics of the group, their receipt of services / materials, and their costs while involved with the public-sector IDD Division. This was done to estimate the type, extent, and cost of meeting their needs.

The intent of Phase 2 was to identify and describe areas of met and unmet needs for the study group’s families. The locator data collected in Phase 1 was used to contact family members for the purpose of conducting a needs assessment interview. The interview was an open-ended protocol that followed precedents in the existing literature for surveying needs and problems of medically fragile children and adults with IDD [4,9,10,16,17,22,27,31]. Focus groups consisting of IDD Case Managers reviewed and revised the interview protocol instrument prior to vetting it in the field. Out of 50 medically fragile adults with IDD, 28 family members agreed to participate in interviews. The small number of study participants limited the data analysis to descriptive statistics; there is no attempt at inference here. Nevertheless, since this was an exploratory study, there was no way to gauge whether the participants’ experiences were so extraordinary as to warrant summary dismissal. Moreover, 25 years or so ago it would have been inconceivable that 50 study subjects would have even been available for this type of study. The import of this study is that it sheds initial light on a special and elusive yet growing population whose problems and associated costs are expected to expand substantially.

**Findings**

**Phase 1**

**Diagnostics**

**Table 1:** Demographic / IDD Diagnostic Profile

Demographic / IDD Diagnosis	Number	Percent
Gender		
Male	35	70%
Female	15	30%
Race/Ethnicity		
Caucasian	16	32%
African-American	17	34%
Hispanic/Latin	16	32%
Asian	1	2%
IDD Level		
Mild	7	14%
Moderate	15	30%
Severe	14	28%
Profound	14	28%

The study group appears diverse and widely representative of what might be expected from medically fragile adults with IDD,

especially the over-representation of males (Table 1) [23,32].

The medically fragile adults with IDD were diagnosed with 22 different medical conditions with some overlap (Table 2) listed in order of occurrence. Surprisingly, the average age was 25 years old (18-29). This clearly demonstrates that medically fragile children with IDD can survive well into adulthood; the longer they survive, the greater the expense, and the more numbers added to their population.

**Table 2:** List of Medical Conditions

Medical Condition	Order of Precedence
Cerebral Palsy	#1
Seizure Disorder	#2
Spastic Para/Quadriplegic	#3
Post Trauma Disorder	#4
Non-verbal	#5
Chronic Respiratory	#6
Scoliosis	#7
Visually Impaired (Blind)	#8
Hearing Impaired (Deaf)	#9
Kidney Problems / Failure	#10
Heart Problems / Defects	#11
Hydroencephalia	#12
Bone Disease	#13
Multiple Sclerosis	#14
Static Encephalia	#15
Stibialmus	#16
Non-ambulatory / Wheelchair bound)	#17
Dystonia	#18
Osteoporosis	#19
Bronchopulmonary Dysplasia	#20
Blood Disorder(s)	#21
Myopia	#22

The modal number of conditions was 1, but with overlapping, the number of conditions per study subject ranged from 1 to 5, with 34 having at least 2 or more medical conditions. The group had 4 medical dependencies listed in order of their severity along with the number having that dependency (Table 3).

**Table 3:** Medical Dependency

Medical Dependency	Number
#1 Ventilator	1
#2 Respirator	1
#3 G-Tube	1
#4 Medication Dependencies	50

Since the primary need appeared to be continuous medication prescription, a comprehensive list of 35 different medications was produced (Table 4).

**Table 4:** Medication List

Medication Listing
Depakote
Tegretol
Haldol
Luvox
Diazepam(s) (e.g., Valium, Ativan, etc...)
Transzene / Trazodone
Seizure Medication (generic unknown)
Phenobarbital
Kaolin
Maxzide
Neurontin
Benzotropine
Risperdal
Mellaril
Thorazine
Zantac
Albuterol
Lisinopril
Ventolin
Bactroban
Ditropan
Baclofen
Fiorinal
Carbamazepine
Prolixin
Hydrocortisone
Claritin
Nizoral
Floxuridine
Propulsid
Cogentin
Napheo Fero
Lactulose
Dulcolax
Griseofulvin

The number of medications prescribed to this group ranged from 1 to 7, with 22 using more than one. Of the top three prescribed medications, Tegretol was #1, followed closely by Diazepam(s) (e.g., Valium, Ativan), and Stool Medication (e.g., Kaolin and Dulcolax). Overlapping medications suggest this population is marked for higher incidence of compounded medical problems requiring strong prescription medications, especially for seizure disorders, muscular-skeletal dysfunctions,

bowel problems, and fungal infections.

**Service Receipt and Costs**

This group received a total of 45,790 IDD services during a 7-year period, or about 6,541 per year or about 131 services per person per year (Table 5).

**Table 5:** Services Received and Cost Table

Type of Service	Units Received	Total Cost	Unit / Cost
IHFS	24,633	\$5,070,464.00	\$206.00
Day Assistance Facilities	6,379	\$1,211,176.00	\$190.00
Case Management	5,153	\$407,921.00	\$79.00
Occupational Therapy	4,465	\$1,021,439.00	\$229.00
(Re-) Habilitation	2,373	\$507,577.00	\$214.00
Assessment & Evaluation	893	\$98,100.00	\$110.00
Other	781	\$23,757.00	\$30.00
In-Patient+	491	\$575,514.00	\$1,172.00
Respite	369	\$60,675.00	\$164.00
Skills Training	148	\$14,413.00	\$97.00
Psychological	72	\$14,141.00	\$196.00
Crisis	29	\$2,725.00	\$94.00
Nutrition	4	\$567.00	\$142.00
Total	45,790	\$9,008,470.00	\$197.00

+refers to admissions and number of bed days in the local psychiatric hospital.

The Types of Service are listed in descending order in terms of their receipt, with the top 5 as IHFS\*\* #1 (53%), Day Assisted Facilities (14%), Case Management (11%), Occupational Therapy (8%), and (Re-) Habilitation (5%). The top 5 most costly were #1 IHFS, 2 Day Assisted Facilities, #3 Occupational Therapy, #4 (Re-)Habilitation, and #5 Case Management. However, the most costly services in terms of price per unit were:#1 In-Patient Hospitalization; #2 Occupational Therapy, #3 (Re-) Habilitation, #4 IHFS, and #5 Psychological Services. In terms of expense over time, the most expensive year for the medically fragile adults with IDD was their 4th year, which was expected as that was their most service intensive year. Year 5 was their second-most costly and service-intensive year. After that, service usage and expenses declined (Table 6).

**Table 6:** Third Party Payer Support

Third Party Payer	Number Covered
Medicaid	46
HMO/PPO	2
Private Insurance	1

Waiver	1
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As a group, the medically fragile adults w/ IDD received a relatively substantial amount of expensive services that mostly seem aimed at maintaining them in community settings and their families' homes.

**Phase 2**

**Families and Their Living Situations**

Out of 28 families of medically fragile adults with IDD, their living situations were as follows (Table 7 and Table 8)

**Table 7:** Family Living Situations

Living Situation	Number
One Family Member	19
Two Family Members	8
Three Family Members	1

**Table 8:** Primary Provider

Primary Provider	Number
Mother	20
Father	4
Both Mother / Father	3
Sibling	1

This study found a large number of households where a single mom was the Primary Care Provider. Primary Care Providers reported that the percentage of time they devoted to care for their medically fragile adult offspring with IDD ranged between 50-100%, with 100% the mode, 67% the average, and 14% reporting devoting more than 80%. Twelve Primary Care Providers reported having an occupation and 16 reported having no occupation. Nineteen reported having support from friends and nine reported having none. Eighteen reported education levels of high school graduate or less, and 10 reported having some college education or a college degree. Thus, a substantial number of households caring for medically fragile adults with IDD had a Primary Provider who was also the Primary Caregiver with low levels of education, substantial amounts of time spent on caregiving, and little social support.

**Use of Emergency Services**

Seven families reported having visited an Emergency Room in the past year, with 4 admitting their medically fragile adult with IDD to the hospital once, 2 doing so twice, and 1 three times. Although some families accessed Emergency Rooms to obtain medical treatment for the person under their care, none called Ambulance Services. This was the case even among those for whom transportation was a problem. This consistent use of Emergency Room Services versus on-site Ambulance Services may reflect the fact that Ambulance Service requests are immediately and irrevocably billed, whereas Emergency Room service bills

may be deferred or even dismissed if a family cannot pay.

Types of Services Needed, Met and Unmet Need, and How Met.

The types of services that families reported they needed the most in their order of precedence are as follows (Table 9).

**Table 9:** Services Needed/Received

Services	Precedence
Medications	#1
Transportation	#2
Home Healthcare Aides	#3
Occupational Therapy	#4

Services that families did not acquire, or for which they received no 3rd-party payer coverage, include: Transportation, Home Healthcare Aides, and / or Occupational Therapy. The Third-Party Payer coverage that families received most often included Medicaid, followed by IHFS, Private Insurance, and Charitable (Non-Profit) Providers. Two additional services for which a need was anecdotally reported were Dental (1 family) and Optical (1 family).

The families reported that their medically fragile adults with IDD needed and received medications, for which Medicaid paid. Three also reported paying for medications with HMO/PPO or Private Insurance. Twenty-three families reported needing Transportation, of which 16 families claimed they were providing for it themselves (i.e., "out-of-pocket"). Medicaid, private taxi vouchers, and public bus services covered the remainder.

Eight families reported needing Home Healthcare Aides. Of those, two families claimed that they were unable to provide this service for the person in their care. Those families who were provided with Home Healthcare Aides were able to utilize Medicaid, followed by IHFS, and then Private Insurance.

Six families reported needing Occupational Therapy; two reported that the need was unmet. Others reported that Medicaid and IHFS met the need. Four reported needing Physical Therapy services. Two families reporting being unable to meet the need. Three reported that the person in their care needed surgery; one family said they could not provide it. Medicaid paid for the two people who received surgery.

Two reported needing Respiratory Therapy of which Medicaid met the need for one and IHSF met the need for the other. One family reported needing Psychological Services for the person in their care, which they paid for themselves. One family reported the person in their care needed Speech Therapy and another reported needing dental work for the person in their care and yet another reported needing optical care. For all three, the need went unmet.

Types of Materials Needed, Met and Unmet Need, and How Met

The three types of materials the families needed most for the medically fragile adult with IDD in their care in the order of their precedence were (Table 10).

**Table 10:** Materials Needed

Materials	Precedence
Clothing	#1
Equipment (e.g., wheelchairs, mobile beds)	#2
Toilet items (e.g., Diapers)	#3

The Third-Party Payer that most often addressed the Materials need was Medicaid, followed by IHFS. Thirteen families reported needing clothing for the medically fragile adults with IDD in their care; 12 claimed that Medicaid met the need. For one, the need was unmet. Nine reported needing equipment (e.g., lifts, wheelchairs, moving and turning equipment, mobile beds). Of those, 4 reported the need was unmet, though they added that IHFS promised to meet the need in the future. Out of the other 5, Medicaid paid for the equipment for 3 and IHFS paid for the other 2. Five families reported needing toiletry items, specifically diapers. Of the 5, 4 reported that Medicaid paid for the toiletries and one family paid for them with a combination of IHFS and out of pocket. One family anecdotally reported that the medically fragile adult with IDD in their care needed medical devices and eating utensils. Medicaid paid for the medical devices, but the caregiver had to pay for the eating utensils out of pocket. The type of Met (with Gaps) and Unmet Needs and official resources are summarized as follows (Table 11).

**Table 11:** Met [with Gaps] and Unmet Need

Met (w/ Gaps) Needs	Service /Materials
	Medication
	Respiratory Therapy
	Physical Therapy
	Occupational Therapy
	Medical Devices
	Toilet Items
	Surgery
	Clothing
Unmet Needs	
	Transportation
	Mobility Equipment
	Eating Utensils
	Psychological Services
	Speech Therapy
	Respite
	Home Healthcare Aides
	Long-term Planning
	Dental care
	Optical care

Third Party Payers	Medicaid
	IHFS
	HMO/PPO and Private Insurance
	Non-Profit / Charitable Organizations

**Need for Home Healthcare Aids**

Of those families reporting a need for Home Healthcare Aides, 4 specifically reported needing aides for hygiene (i.e., bathing) for the person in their care, one for dispensing medication, and the other for Respite (e.g., additional supervision).

**Adequate Support**

Twenty-five families felt they were receiving adequate support to care for their medically fragile adult with IDD. Of those needing additional support, 3 reported a need for Respite, and 2 for extra financial aid. Ten families reported currently being on some type of program waiting list for services or materials.

**Third Party Payer Coverage for Care**

According to the families, the top Third-Party Payers were: (1) Medicaid, and (2) IHFS.

**Support**

Seven families reported they did not have an adequate social support network.

**Caregiver Stressors Experienced**

The foremost stress families experienced was “hardships” with eight reporting. The second most cited stress was a tie between “scheduling conflicts” and “not enough resources” with seven reporting. Third was a tie between “feelings of incompetency about being a caregiver,” and “inability to afford care” with three reporting. Fourth was a tie between “not trusting care workers” and “lack of respect for service providers” with 2 reporting. One family member cited each of the following stressors: “an uncaring attitude among service providers,” “lack of trained service providers,” and “a high turnover rate among service providers.” The number of stressors families reported ranged between 1 -7, with seven families reporting more than one.

**Long-term Plans**

Only six families reported having long-term plans regarding legal disposition of the medically fragile adult relatives with IDD in their care, in the event the families suffered misfortune or death. Three reported provisions in their Wills. Two had specific instructions to transfer the person in their care to a trusted relative and another had drafted a Living Will. Three out of the 6 were single moms. Overall, there were a substantial number (22) who did not have any long-term plans. Particularly disturbing was the case of the single moms (16) who had no legal instruments

to transfer or provide a disposition plan for the medically fragile adults in their care. Notably, those family members with some legal disposition plan were on average older than those without one.

**Conclusion**

Advances in medical technologies and care have extended the lives of medically fragile children with IDD. Thus, whereas they might previously have died in childhood, many continue to thrive and live on, and this population continues to grow. Some may even outlive their parents. Findings regarding the medical conditions of this study’s group of medically fragile adults with IDD suggest that those with very serious and catastrophic medical conditions tend to die early on. As this “screening effect” happens, medically fragile children with IDD who transition into adulthood require less intensive medical care as opposed to medically informed supervision and medications. However, such required care can be expensive (Table 5).

The families in this study seemed capable of assuming the burden of this care in their own homes, as they understand the needs of medically fragile adults with IDD and were addressing them as best they could. Like medically fragile children in the nursing care literature [cf. 2,10,11,13,22], the medically fragile adults with IDD in this study were probably better off at home, with trusted relatives who know and understand them. Nevertheless, such home care poses substantial financial burdens for the families. Even those families where the Primary Provider earned an income were still compelled to seek help from outside sources (e.g., Medicaid, IHFS). Of course, the fewer assets a family has, the greater the impact of negative service gaps. Such an impact may push some families to their limit both emotionally and financially, resulting in deterioration of the family unit and of care for the medically fragile adult with IDD.

Some of the gaps may appear trivial. However, if the stressors the families experience accumulate, combined with unpredictable and precarious circumstances, even a minor need left unmet could prove extremely consequential. Since family homecare represents the least restrictive and expensive way to maintain this special population, it is imperative to permanently close gaps in service / materials to relieve undue stress and hardship. Every service / material gap and need should be taken seriously to determine how they can be best addressed.

The group in this study appeared to be fairly well-integrated into the available services and care delivery systems and seemed to be more or less meeting their needs. This only leads to wonder about those less fortunate, the struggles they face, and the degree to which they manage. Despite sufficient service system integration, there were still gaps in services / materials. These gaps were particularly acute for Transportation, Occupational Therapy, Clothing, Toilet Items, Mobility Equipment, and ancillary

services like dental and optical care, and especially provision of Home Healthcare Aides. Families consistently reported need for Home Healthcare Aides to help with their medically fragile adult relative with IDD regarding hygiene, feeding, dispensing medications, and watching the person in their care so they can catch a break. (Calls for using Home Healthcare Aides in lieu of Respite care suggest the families had few alternatives for Respite care.)

The findings in this exploratory study support other literature on medically fragile children that found that the burdens on the family caregivers may be greater without access to healthcare personnel [10,22]. One finding different from previous studies was no reported need for Nursing Care [2,10,13]. Nonetheless, there was a need for outside professionally trained healthcare workers. Participant families in the study stated having concern that healthcare workers lacked the appropriate skills and were unreliable. Trust issues pertaining to healthcare workers were plainly evident. The lack of reported need for Nursing Care as opposed to Home Healthcare Aides also may be the result of inordinate expenses associated with Nursing Care; families may have been hoping to obtain useful and sufficient alternatives at a lower cost. Expense also may be why the families sought Emergency Room care as opposed to Ambulance Services. Ambulances are expensive and must be paid for, regardless of income, whereas cost of Emergency Room services might be written off for those in financial hardship.

Of particular concern was the amount of time that primary caregivers had to devote to the medically fragile adults with IDD under their care. Especially worrisome are the primary caregivers, particularly those single and living alone, who have little education and few marketable skills. These caregivers appeared to be providing care for their medically fragile adult relatives with IDD while solely supported by Social Security Income (SSI). Without access to in-home Respite care, such caregivers have scant opportunities to pursue job skills and marketability. They are locked in a situation where they must focus all their attention and energies on the adults under their care, until and if the adult no longer requires it. At that point, the caregivers are out of their "job," and have nothing to fall back on.

Since many of the medically fragile adults with IDD in this study may outlive their parents, it was alarming that few families—in particular the single moms living alone—had long-term plans should something unfortunate happen to them. Wills and other legal instruments are additional expenses (i.e., luxuries) that these often cash-strapped families could ill afford. Also, this is an uncomfortable and disagreeable subject that some simply wished to avoid. This is clearly an area of undefined and unmet need, especially when considering the advancing age of the caregivers.

Another area of unaddressed need was an absence of social

support networks, in particular for married couples. Ironically, more single moms who lived alone and reported no social network support system did not feel a sense of being abandoned by friends, as opposed to the married couples. Evidently, the married couples felt they had few friends they could call on and were left to their own devices.

### Limitations and Future Studies

This is an exploratory and descriptive program evaluation study; caution is advised regarding inference from the findings. Second, the group in this study represents a geographically isolated, targeted sample from one public-sector service agency. They were a heterogeneous byproduct of a filtering process as they wound their way through the system. They appear to be diverse and fairly representative of this special population at large [4,8,14,17,18,21,23,24,27,29,31]. However, further similar studies of other groups in different geographical settings and from more agencies are required to confirm this. This should be recognized and considered when generalizing findings.

Third, a large proportion (44%) of the families chose not to participate in the Phase 2 interview portion of the study. There may have been important differences between responders and non-responders. Such potential differences should be explored in further and more definitive studies. However, other research seems to support the findings from the results of this study's responders [1-5,7-11,14,16,17,20,22,23,27,29,30,31].

Finally, the study may not have completely exhausted the range of needs, problems, issues, and resources required for medically fragile adults with IDD and their caregivers. Simply put, there may be something yet to be discovered. Given increasing numbers of medically fragile adults with IDD in home care settings, there should be further attempts to improve the general knowledge and understanding about this special population and their caregivers' experiences. Further studies with larger samples are needed to validate this exploratory study's findings.

**\*Note:** Medical dependencies that would qualify an adult as medically fragile were: Ventilation (Assistance for Air), Respiratory Support, Intravenous Support, Tube Feeding, Prolonged Dependence on Medical Technology (Dialysis, Ostomy Care, Catheterization), and Dependence of Medication to Sustain Life. Under this study's rubric of medical fragility were such medical disabilities as: Cerebral Palsy, Muscular Dystrophy, Spina Bifida, Post Head Trauma, Cystic Fibrosis, Life Threatening Respiratory Conditions, Bronchopulmonary Dysplasia, Multiple Birth Defects (other than IDD), Severe Heart Defects, Leukemia, Blood Circulatory Problems, Life Threatening Seizure Disorder and Diabetes Mellitus and Immunodeficiency, and Cancer.

**\*\* Note:** IHFS refers to In-Home Family Support, which was a IDD program and other related service packages. The IDD IHFS

program provided direct funds for approved services and material items as a contract between care and service providers and IDD. The funding for IHFS came directly from the State Legislature and was earmarked for disability and material items designed to maintain the integrity of the family and that would not be funded through other sources.

## Declarations

Ethical approval and consent to participate: Study was reviewed and approved by HC-IDD's Institutional Review Board.

## Consent for Publication: Yes.

## Availability of Data and Materials

Yes, publications and sources are available on-line or provided by author upon request.

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## Author's Contribution

All authors contributed to the study and production of the manuscript.

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## References

1. Toly V-B, Blanchette JE, Al-Shammari T, Musil CM (2019) Caring for Technology-Dependent Children at home: Problems and solutions identified by mothers. *Appl Nurs Res* 50: 151195.
2. Breneol S; Goldberg Lisa, Watson J (2019) Caring for children who are Technology-Dependent and their families: The application of Watson's Caring Science to Guide Nursing Practice. *Advances in Nursing Science* 42(2): p E13-E23.
3. Mesman GR, Kuo DZ, Carroll JL, Ward W (2013) The impact of technology dependence on children and their families. *J Pediatr Health Care* 27(6): 451-459.
4. Palfrey JS, Walker DK, Hayne M, Singer JD, Porter S, Bushey B. (1991) Technology's dependent children: report of a statewide adjustment and adaptation response model. *Family Systems Medicine* 6: 202-239.
5. OTA (Office of Technology Assistance). Technology-dependent children: Hospital vs. home-care—A Technical memorandum: 1987 (OTA-TM-H\_38). U.S. Congress: Washington, D.C.: GPO.
6. Frampton KK (2006) Medically fragile children challenge medical home concept: Experts question whether in-home care is the only right choice. *PALTMED* 7(1).
7. Mentro AM and Steward DK (2002) Caring for medically fragile children in the home: an alternative theoretical approach. *Res Theory Nurs Pract* Fall;16(3): 161-77.
8. Harrigan RC, Ratliffe R, Patrinos ME, Tse A (2002) Medically fragile children: an integrative review of the literature and recommendations for future research. *Issues Compr Pediatr Nurs* 25(1):1-20.
9. Curran JA, Breneol S, Vine J (2020) Improving transitions in care for children with complex and medically fragile needs: a mixed methods study. *BMC Pediatr* 20(1):219.
10. Patterson JM, Jernell J, Leonard BJ, Titus JC (1994) Caring for medically fragile children at home: The parent-professional relationship. *Journal of Pediatric Nursing* 9(2): 98-106.
11. Krier JJ (1993) Involvement of educational staff in the health care of medically fragile children. *Pediatr Nurs*19(3): 251-254.
12. Toder DS and McBride JT (1997) Home care of children dependent on respiratory technology. *Pediatr Rev* 18(8): 273-80; quiz 281.
13. Sobotka SA, Lynch E, Agrawal R (2022) The Role of Care Coordinators for Children with Respiratory Technologies and Home Nursing. *Pediatr Allergy Immunol Pulmonol* 35(2): 49-57.
14. Joly E (2017) Access to services for young adults with medical complexity. *Nurs Ethics* 24(3):329-336.
15. Goldberg AI (1996) Outcomes of home care for life-supported persons: Long-term oxygen and prolonged mechanical ventilation. *Chest* 109(3): 595-596.
16. Hoover CG, Collier RJ, Houtrow A, Harris D, Agrawal R, Turchi R (2022) Understanding caregiving and caregivers: supporting children and youth with special health care needs at home. *Acad Pediatr* 22(2S): S14-S21.
17. Caicedo C (2014) Families With Special Needs Children: Family Health, Functioning, and Care Burden. *Journal of the American Psychiatric Nurses Association* 20(6): 398-407.
18. Litzinger MJ, Duvall B, and Little P (1993) Movement of individuals with complex epilepsy from an institution into the community: seizure control and functional outcomes. *Am J Ment Retard* 98: 52-7.
19. Young L (2006) Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian-matched sample. *Comparative Study. J Intellect Disabil Res* 50(Pt 6):419-31.
20. Luckenbill J and Zide A (2017) Supporting medically fragile children and their families. *NAEYC* 72(4).
21. Kuster PA and Merkle CJ (2004) Caregiving stress, immune function, and health: implications for research with parents of medically fragile children. *Issues Compr Pediatr Nurs* 27(4):257-76.
22. Patterson JM, Leonard BJ, Titus JC (1992) Home care for medically fragile children: impact on family health and well-being. *J Dev Behav Pediatr* 13(4):248-55.
23. Youngblut JM, Brennan PF, Swegart LA (1994) Families with medically fragile children: an exploratory study. *Pediatr Nurs* 20(5):463-8.
24. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, et al. (2011) Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics* 127, 3, March, 529-538.
25. Durkin MS, Schlupf N, Stein ZA, Susser MW, (2007) Childhood Cognitive Disorders: In *Public Health and Preventive Medicine*, 15<sup>th</sup> Ed., RB Wallace and Kohatsu N. (Eds.), New York, NY: McGraw Hill, inc.: 1173-1185.
26. Raymond JA (2009) The integration of children dependent on medical technology into public schools. *J Sch Nurs* 25(3):186-94.



27. Prieto V (2020) Caregivers of Medically Fragile Children With Technology Needs. Doctoral Dissertation. UTHSC-Houston SON.
28. Strauss D, Shavelle R, Reynolds R, Rosenbloom L, Day S (2007) Survival in cerebral palsy in the last 20 years: signs of improvement? *Dev Med Child Neurol* 49(2):86-92.
29. Scott R. Transitioning Teenagers who are Medically Fragile Severely Intellectually Delayed Into Adulthood: Perceptions of Parents, School Staff, and Medical Community Members. Doctoral Dissertation, ISU.
30. Eyman RK, Grossman HJ, Chaney RH, Call TL (1990) The Life Expectancy of Profoundly Handicapped People with Mental Retardation. *N Engl J Med* 323(9): 584-589.
31. D'Ooge JB. Needs and Availability of Resources for Seniors and Medically Fragile Adults: An Assessment of Administrators' Perceptions. Doctoral Dissertation. SHRP-UM.
32. Kraemer S (2000) The fragile male. *BMJ* 321(7276):1609-1612.



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