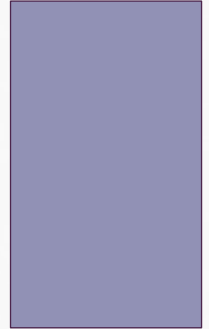


SUPPORT AND ADVOCACY FOR MFTD WAIVER FAMILIES

SUSAN AGRAWAL



ABOUT ME - PARENT

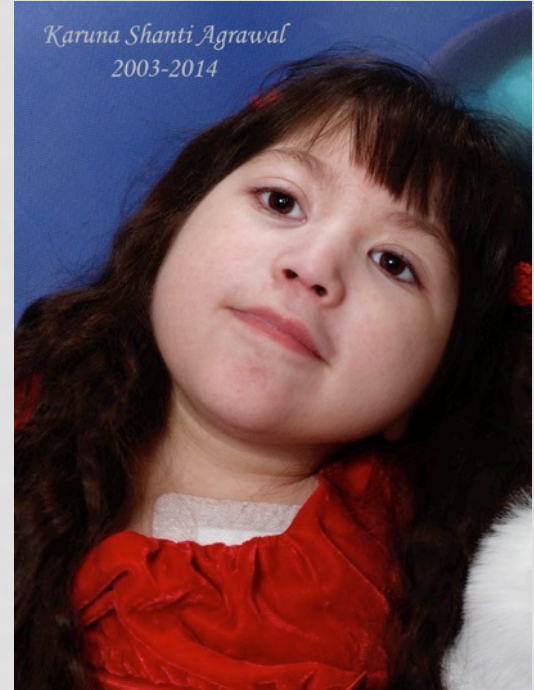
Parent of a child who was medically complex

Main Diagnoses

- Cerebral Palsy
- Autoimmune Disease

Technology

- Vent
- Central Line
- IV Nutrition
- Feeding Tube
- Oxygen
- Foley Catheter



KARUNA AND THE MFTD WAIVER

Karuna was on the MFTD waiver from 2006-2014

Services Received through Waiver

- Home/Vehicle Modifications
- Extermination
- Respite
- Care Coordination



MEDICAID SERVICES

Services Received Through Medicaid Once on Waiver

- Home Nursing 140 hours/week
- Non-covered equipment
- Non-covered supplies
- Non-covered therapies
- Prescription copays
- Doctor/hospital copays and coinsurance
- Deductibles



ABOUT ME - ADVOCATE

Writer and Editor

- Complex Child Magazine
- Feeding Tube Awareness Foundation
- Freelance Projects

Advocacy

- MFTD Waiver Families, Founder
- Kids' Waivers Website
- Partnerships with Advocacy Organizations

HOW MFTD WAIVER FAMILIES BEGAN

In 2011, Healthcare and Family Services (HFS) began discussing eliminating or restructuring the MFTD Waiver

Children with Complex Medical Needs (CCMN) Workgroup Meeting Notes

Director Hamos reported that HFS has been directed to cut \$2.7B from its budget (approximately 25% of the entire budget). The budget is very bleak and in the next few weeks programs will be reviewed and legislators will make decisions on what cuts will be made. Unfortunately, everything is on the table for cuts, even small cost programs. Subsequently, the waiver and waivers that disregard family income are under scrutiny. The current 300 percent Federal Poverty Level (FPL) is also under review and could be reduced.

There was significant discussion from the group on the risks of discontinuing this program such as forcing parents to give up jobs, drop insurance or give up custody of children. There was an appeal for the Department to carefully analyze the cost of dropping the program and choosing more flexible options such as providing services based on actual needs and making the program more flexible. One participant

OUR FIRST FIGHT

2012 Changes to MFTD Waiver

- Restrict program to lower income families
- Add premiums and copays
- Replace nurses with unskilled aides
- Reduce program level of care leading to less hours of home care
- Cut reimbursement rates

"Section 1. Short title. This Act may be referred to as the Save Medicaid Access and Resources Together (SMART) Act.

Sec. 5-2b. Medically fragile and technology dependent children eligibility and program. On and after September 1, 2012, subject to federal approval, medical assistance under this Article shall be available to children who qualify as persons with a disability, as defined under the federal Supplemental Security Income program and who are medically fragile and technology dependent. The program shall allow eligible children to receive the medical assistance provided under this Article in the community, shall be limited to families with income up to 500% of the federal poverty level, and must maximize, to the fullest extent permissible under federal law, federal reimbursement and family cost-sharing, including co-pays, premiums, or any other family contributions, except that the Department shall be permitted to incentivize the utilization of selected services through the use of cost-sharing adjustments. The Department shall establish the policies, procedures, standards, services, and criteria for this program by rule.

FAMILIES CAME TOGETHER

Created a family group using Facebook

Created a website

Created a petition

Obtained extensive media coverage

Filed a civil rights class action lawsuit

Worked with legislature to rewrite law



Murray Goldberg plays with his son, Quincy, who was born premature with chronic lung disease and uses a ventilator.



After undergoing a grueling course of treatment, Lenny, who has a muscle disorder,



After Thomas' diagnosis, Michael's parents, the 30-year-old Michael's parents, are struggling to cope.



Thomas' father holds son 'L', while he takes a break during physical therapy.

Our most fragile

Parents fear cutoff of children's home nursing services

TECHNOLOGY REPORT BY HEATHER CHAMBERLAIN

Hundreds of Illinois parents whose medically fragile and technology-dependent children receive skilled nursing services at home through a state-run program are anxiously waiting to find out if their sons and daughters will continue to qualify. The parents say proposed changes to the program would make their children ineligible, forcing the youngsters out of their homes and into hospitals or other facilities. Some of them have vowed to fight and filed a lawsuit in July. The changes have been pushed back twice, putting the families in an agonizing limbo. "I can't put into words how stressed and worried we are," one mother said. "Anyone who has children and loves them can understand the heartbreak of this."

—By Deborah L. Shellen, Tribune reporter

Meet the caregivers: Tribune photographer Heather Chamberlain spent several months with four Chicago-area families, documenting their daily lives and challenges as they lived under a cloud of uncertainty.

Please turn to Page 2A

THE RESULT

MFTD Waiver
was saved
relatively intact!

Families were
connected for
future
advocacy

Parents were also able to provide
support to each other

MFTD WAIVER FAMILIES TODAY

Primary focus is Facebook support group

- 500 family members in group
- Most kids in MFTD Waiver but also accept:
 - Kids receiving non-waiver nursing (former NPCCS group)
 - Individuals receiving nursing through other waivers (HSP, DD)
 - Kids in the process of getting nursing
 - Families from other states with nursing who are moving to IL

PURPOSE OF SUPPORT GROUP

Safe space restricted to family members only

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graph TD; A[Safe space restricted to family members only] --> B[Information]; B --> C[Support]; C --> D[Supply and equipment exchange]; D --> E[Advocacy];
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Information

Support

Supply and equipment exchange

Advocacy

OTHER CHANNELS

Public Facebook/Twitter
pages for advocacy
needs

Website: mftdwaiver.org

- Information about program
- How to apply
- Ancillary programs
- Appeals information
- Advocacy updates

Questions answered by
email

ADVOCACY – MY ROLE

Identify systemic problems families are facing

Collect data to support position (FOIA, database, surveying families)

Research and identify solutions

Reach out to DSCC and HFS

Work with legislators (state and federal)

Organize action

Work with the media

Work with lawyers on class action lawsuits and settlements

ADVOCACY: BIG AND SMALL

Big

- Change laws
- Civil rights lawsuits

Small

- Support or oppose a bill
- Submit comments on legislation/program
- Seek changes to program
- Work with other groups for federal change

BIG EXAMPLE: MANAGED CARE

We used information from Texas to convince Illinois legislators managed care was a bad idea

- Testified in multiple hearings
- News coverage
- Partnered with other organizations who had lobbyists
- Social media campaign
- Organized advocacy

When a giant health care company wanted to save money, a foster baby paid the price

By J. David McWane and Andrew Chavez | Staff Writers
Photos and video by Tom Flea | Senior Staff Photographer
Published June 3, 2018



He was born three months too early, unable to breathe or eat on his own. But after a year of intense care in a foster home in Mesquite,

PAIN & PROFIT

Part 1 of a Dallas Morning News investigation

**The preventable
tragedy of
D'ashon Morris**

EXAMPLE LEGAL SUCCESSES

Boyce vs. Hamos

Filed to prevent the state from making changes to the MFTD waiver that would have eliminated/reduced home nursing services

Withdrawn once the legislature and HFS reversed course

Hampe vs. Hamos

Allowed adults over age 21 in MFTD waiver to receive the same number of home nursing hours

Settled and now codified in program

MA vs. Bellock

Addressed cuts in nursing care hours for primarily non-waiver children

Settled in 2019

OB vs. Eagleson

Addressed the state's failure to provide approved home nursing services

Settled in 2019

CHANGES TO PROGRAM WISH LIST

Additional services for 21+ group

Palliative care coverage

Parents who are nurses can continue to care for their own minor children

Parent CNA or PCA program that allows parents to be paid to care for children

Coverage for generators

Additional resources for staffing issues

PARENT TO PARENT SUPPORT

Help get a
letter of
medical
necessity

Refer to other
programs

Connect
families
regionally or by
diagnosis

Help families
with appeals

Help families
find doctors,
therapies

Help families
deal with
nursing and
nurses



REFERRING FAMILIES

Facebook Group:

<https://www.facebook.com/groups/mftdwaiver>

Website:

<http://mftdwaiver.org>

Email:

mftdwaiver@gmail.com

MY OTHER WORK: COMPLEX CHILD

Complex Child is a free online magazine with primarily parent-written articles about all aspects of caring for a child who is medically complex or has a disability

Hundreds of
articles since 2008

New editions
currently on hiatus
due to pandemic



MY OTHER WORK: KIDS' WAIVERS



MY OTHER WORK: FEEDING TUBE AWARENESS FOUNDATION

Content Specialist

Write and update both written and website content

Assist with activities such as Facebook page and Feeding Tube Awareness Week

Give presentations about feeding tubes

Ask me your feeding tube questions!



QUESTIONS?

Contact me at
susanagrawal@gmail.com