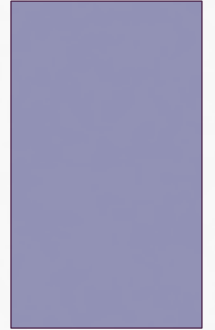


DSCC/MFTD WAIVER FAMILIES
FACEBOOK GROUP

SUSAN AGRAWAL



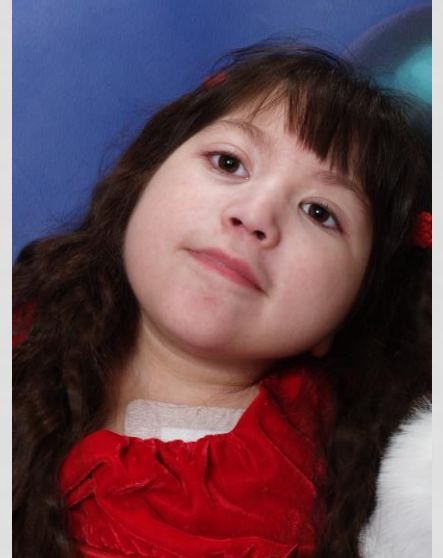
ABOUT ME

Founder, MFTD Waiver Families

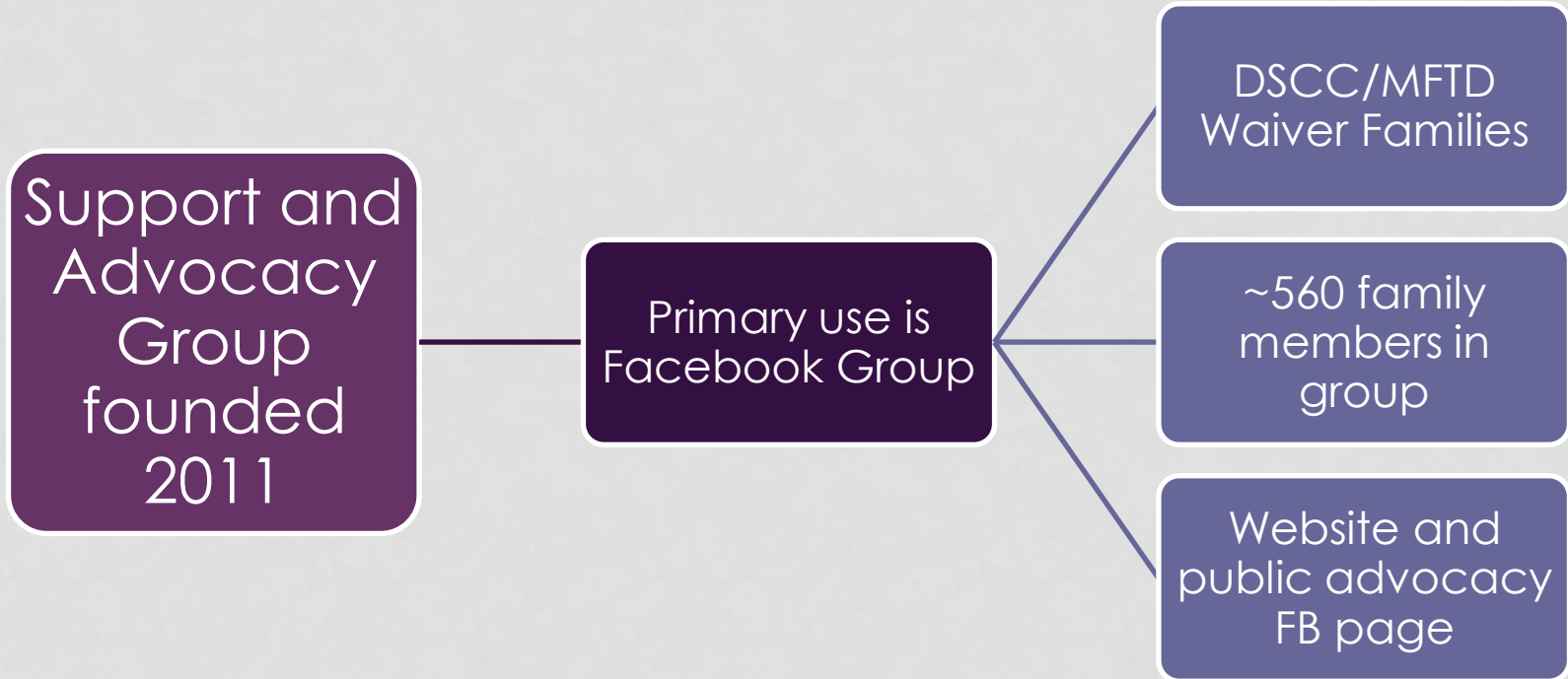
- For families in the Medically Fragile, Technology Dependent Waiver in IL

Parent

- Karuna (2003-2014) with complex medical conditions
- Sameer and Neena



ABOUT MFTD WAIVER FAMILIES



HOW IT ALL BEGAN...

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



Family members formed a Facebook Group to determine how to save the program

FROM ADVOCACY TO SUPPORT

Original focus: Advocacy

A light blue downward-pointing arrow indicating the flow from the first step to the second.

We found a surprising need to support each other

A light blue downward-pointing arrow indicating the flow from the second step to the third.

Gradually morphed into more of a Support Group

PRIMARY FUNCTION

Answer questions about MFTD Waiver and other services

Answer questions about common medical issues

Exchange medical supplies and equipment

Exchange information on doctors, clinics, hospitals, and nurses

Coordinate advocacy efforts as needed

Older families mentor younger ones

GROUP ACCOMPLISHMENTS

Support

- Some families meet in person socially
- Families help each other out in emergencies
- Helped several kids get adopted or placed in safe foster homes
- Support for dealing with difficult times, including child death
- Lots of new virtual friends!

Advocacy

- Passed a law reversing changes to program in 2012 Smart Act
- Passed a law keeping kids out of managed care
- Lawsuit to improve nurse staffing, raising reimbursement rates
- Lawsuit to reverse hours reductions
- Small advocacy, such as adding generator coverage to program



VIRTUAL FORMAT

Ideal for this population

Some children may not be able to be exposed to others

Some children cannot travel

Families often cannot leave home due to lack of nursing

Often the only way these families can connect

No cost other than website

MEMBERSHIP OF FACEBOOK GROUP

Restricting membership is critical
Stay hyperfocused!

Members must be:

- From Illinois
- Parent, guardian, family member, or individual on MFTD waiver
- Those who receive home nursing care from another program, such as Home-Based Waiver, Home Services Program, non-waiver nursing (NPCS)

Private group

- Must be approved to join
- Membership questions
- All members verified

Families only!

- No nurses, doctors, caseworkers, state officials, or DSCC officials unless they have a child in the program

MAKE RULES!

Primary rule: don't share anything outside the group

No hate speech or bullying

No medical misinformation

Use moderators to monitor group

OTHER HELPFUL TIPS

Website as a repository
for frequently asked
questions

Public Facebook Page
for when we need to
engage with wider
community on
advocacy issues

Make sure group name
has important keywords

- Added “DSCC” to Facebook Group name to help people find group

INFORMATION

Facebook Group:

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

Website: <http://www.mftdwaiver.org/>