

Equipping Churches To Serve Families Affected By Disability

Children Who are Medically Fragile

When it comes to churches supporting families who are raising children who are medically fragile, we often ask what they need. But how often do we ask how they feel?

Before we can truly provide what a family needs from the church, we first have to understand how they feel.

What Does Medically Fragile Mean?

Children who are medically fragile have a chronic condition (or conditions) that require ongoing medical attention that limits their daily activities. They often rely on special equipment, such as feeding tubes or ventilators. They are more likely to need frequent hospital stays or surgeries, and even when they are home they may require a caretaker or skilled nursing.

What Families Might Be Feeling At Church (And How Churches Can Help)

1. Scared of Germs -

Germs are scary for families. Common viruses that may be inconvenient for most, may be very dangerous for kids who already have breathing, digestive issues, or are immunocompromised. **Churches can help by:**

- Encouraging people to stay home if they are sick.
- Enforcing guidelines that say visibly ill children are not accepted into classrooms.
- Sanitizing rooms in between services.
- Checking on families who are not coming to church regularly due to germs and seeing if there is another way for them to stay connected.

2. Grateful When Policies Are Adapted -

Most church policies were not designed for people with special needs. Which means that some policies will not be helpful for children who have complex medical needs. This can lead to frustration for families. **Churches can help by:**

- Looking at policies and asking how each would apply to a child who is medically fragile.
- Working with church leadership and families to adapt policies BEFORE they are needed.
- Common policies to consider include: Restroom policy, Special Event policies, and how to handle private caregivers or nurses in the classroom.

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3. Emotional -

Medical trauma is common. This type of trauma can come from hearing a life-altering diagnosis, watching a child struggle, or being part of repeated medical procedures. Medical trauma can cause big emotions to be triggered unexpectedly. This may look like an emotional outburst that seems out of proportion to the circumstance, like tears or anger over something you may think is no big deal. Or it may look like a family withdrawing from the church for what appears to be no apparent reason. The good news is that people in the church can help. **Churches can help by:**

- Responding with grace and without judgment.
- Creating an environment where people feel safe sharing messy emotions.
- Listening to understand.
- Letting families know that it is OK to not be OK sometimes.

4. Uncomfortable Asking For Help Again -

Many families with children who are medically fragile spend a lot of time at the doctor's office or the hospital. Which means they often need help at home. However, many feel that the more they need help, the harder it is to keep asking the church for it. Some even worry that their family will become a burden to the church. **Churches can help by:**

- Offering help instead.
- Watching Wonderful Works Tangible Support video and learning new ways to help.