

High Energy, High Hopes and HIGH-RISK!

Addressing the Ignored Mental Health Needs of Mothers with Special Needs Children

The Struggle Across a Mother's Lifespan

Imagine the excitement at the birth of your child... and then the devastation upon learning he or she has special needs. Then the care kicks in; you begin to recognize the special ways your child learns, communicates, understands, needs, reacts, behaves, processes, loves, shows affection. A child with special needs has a profound impact on you, the mother.

While there are a host of services and supports for a child with special needs—albeit not enough—there is virtually nothing in place to help the primary caregiver (typically the mother) who struggles to adapt and accommodate her child's every need.

Mothers of children with special needs experience:

- Depression (2-3 times higher) and anxiety
- Illness and fatigue
- Blame that she did something to compromise her child's health
- Guilt that she can not do enough to meet all of her and her child's needs
- A need to control her own expressions or emotions, and those of others
- Isolation (family, friends, school, dating relationships, faith community, etc.)
- Lack of understanding regarding a child's behavior resulting from special needs
- Loss and mourning at every life benchmark that her child doesn't reach (e.g. no graduation, no livable wage/job, no marriage, no grandchildren, unending responsibility to parent, etc.)
- Violence and uncontrollable behavior
- Higher divorce rates
- Fear and worry of aging and dying
- A lack of resources for herself and her family
- Job and career struggles
- Financial strain (from costs of specialists and impact on the job)





A Need for Action

Mothers of special needs children must have their own needs addressed. Initial steps to call attention to this important issue should include:

- A national education campaign to raise awareness of what special needs families go through. This will help to reduce stigma and isolation, while building a broader support network.
- Peer support programs where mothers can provide support and validation. Peer support should be a medically supported and reimbursable expense and is essential in the awareness of behavioral and other health concerns.
- Behavioral support benefits for the mother so that she can remain an active caregiver, avoiding the costly placement of the child/adult in an institutional setting.
- Attention to integrated family care, where services are coordinated across systems, not only to support the health of the special needs child and the entire family.
- Workplace accommodations so that mothers can provide the needed care for their special needs children without the risk of job and wage loss.

To learn more about this advocacy effort or to schedule a presentation or exhibition, please contact:

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About this Advocacy Effort

MOM2MOM is a peer support program based at the University of Medicine and Dentistry of New Jersey. The MOM2MOM program was designed as the missing link for mothers of special needs children, realizing that these primary caregivers experience loss, depression, violence, isolation and more. Support is provided via a hotline, support groups, live chats and referrals. To learn more about MOM2MOM visit www.mom2mom.us.com or call 877-914-6662.

This advocacy effort was done in partnership with the **GlassBook Project**, a collaborative effort of Artist Nick Kline and Witness Justice, a national nonprofit organization addressing the needs of survivors of trauma and violence. The GlassBook Project is an artwork that builds understanding of responses to trauma that often cause stigma or discrimination. Mothers involved in the MOM2MOM program created an advocacy glass book, with artist Sarah Stengle, that is to be exhibited in New Jersey and around the country to raise awareness and garner support.

This paper was authored by national trauma expert Helga Luest, President & CEO of Witness Justice and partner of the GlassBook Project.