

“Invisible Disability” Kids are Being Left Out

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We are the parents of two children with what are often termed “invisible disabilities.” Invisible disabilities can include learning disabilities, autism spectrum disorders and Asperger’s syndrome, Tourette’s syndrome and other tic disorders, obsessive-compulsive disorder and other anxiety disorders, mood disorders and behavioral disorders.

Why are these disabilities “invisible?” When you see our children and others similarly diagnosed, you think they are “typical” children. These kids are often verbal and sometimes highly articulate; they are of average intelligence and even extremely bright, and their ability to maneuver physically, socially and emotionally in the real world seems unimpaired.

In reality, these kids are dealing with a lot of complex issues. Many of these children find our loud, smelly, busy world overwhelming and may take refuge by shutting the rest of us out. Some seek out even more sensation and have difficulty modulating their voices, sitting still or remaining quiet. Many of them have trouble making and keeping friends despite an often passionate desire to do so. A need for order and control may make the regular, chaotic play of many children unappealing or scary. More profoundly, these disabilities are invisible because these children have become invisible in our community. Synagogues do not provide Shabbat programming for children who cannot handle the standard Shabbat groups or junior congregation.

Day schools do not educate many of these children, and prayer services in synagogue are not welcoming places for these families. While there have been a number of stories in the Jewish media recently about the rare programs that do exist, more often, families like ours hear that such programs are too expensive and serve too few children to make them viable. We in turn have pulled away from the community in our search to have our children’s needs met. We send our children to secular schools and camps that serve the special needs population, we consult with psychologists, psychiatrists and neurologists rather than our rabbis, and we create community with each other, the folks who “get it.” And we convince ourselves that we are doing just fine all by ourselves.

The truth is that we and our children need the support and acceptance of our community. We have asked for help in the past, but we have been told “no” so many times that by now we feel it is futile to ask. And we are angry — angry because our children survive by our advocating for them, and advocacy is not always pretty.

Our synagogues and our Jewish communal institutions need to become safe spaces where we can bring our children, confident that their behavior will be tolerated or, better yet, understood. Our children are entitled to learn and live their Jewish heritage, and they cannot fully do so if they continue to exist at the margins of the Jewish community.

We can't do it alone. We are overextended emotionally and financially. We worry every day about our children's future. Will they be able to make a living? Will they marry? How will they manage when we are gone? And we have current worries, too. Will we be able to continue to afford the education, the therapies, and the medications that our children need?

We have been forced to accept that we will not find a place for our children in the Jewish day schools, but we can no longer tolerate that this extends to our synagogues as well. For our children, inclusion in the prayer services and programming at synagogue is a last chance to be part of the Jewish community, and they are being pushed out with both hands.

We want to be a part of the community, desperately. But to do so our children must be made welcome. What does that mean? Rabbis and community leaders need to become educated about these populations and they need to share this knowledge with the community.

Address our issues from the pulpit. Teach that Jewish values of inclusion, of justice, of caring, extend to our children as well. Help parents instill in their "typical" children the value of befriending children that are not exactly like them and their peers. Teach all of us that the true worth of the individual goes beyond academic achievement, athletic ability, and earning power.

Develop community programming. Talk to us; we have developed, of necessity, a great deal of expertise on what works and what does not work for our children. Ask us if something can be done to modify existing programs so that they can meet the needs of our children. Seek our input when creating new programs. Our families are hungry for Jewish programming and you will find us willing partners if you just open the door to us.

Most importantly, speak to our children and recognize them for the beautiful souls they are. Our children are poets, artists, philosophers and psychologists; their emotional and spiritual lives are deep and intense ones. Our children are valued by their peers, special educators, and therapists; show them that they are valued by the Jewish community as well.

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