

## Children with Disabilities and Poverty: Breaking Free of Limiting Conditions

**M**ore than anything, the parents' Christmas wish was to move out of their relatives' basement and rent a home of their own where their three children with autism would no longer bother their relatives. The three kids went to a school for children with autism during the day. Their need for constant care forced their mother to stay home and do all the cooking, cleaning, and other household chores during school hours while her husband drove a truck for the water company. The children, a nine-year-old and seven-year-old twins, still needed diapers and a living environment that required extra attention, as well as home-based behavioral therapies that are usually recommended for children with autism.<sup>1</sup>

This New Jersey story illustrates many facets of the limiting cycle of poverty and disability in which loving families with disabled children and low incomes often find themselves mired. Disability does not cause poverty, nor does poverty cause disability, but each exacerbates the other. The following facts show this relationship:

- The U.S. Census Bureau reports that 29.2 percent of children with disabilities live in households with incomes below the poverty level, compared with only 17.3 percent of children without disabilities.
- Because the unemployment rate for adults with disabilities usually hovers at around 70 percent, if one of the parents or adult family members is disabled, there is a good chance that person is unemployed or underemployed.
- Researchers have estimated daily living expenses for families with a disabled child as 8 to 20 percent higher than their counterparts without a disabled child,<sup>2</sup> or annual out-of-pocket costs for an individual with a disability as an extra \$6,300 to \$16,000 per year.<sup>3</sup> Those expenses can include specialized equipment, therapies of one sort or another, and modifications to the home or apartment.



Children living in poorer parts of communities, particularly in some ethnic communities, are frequently labeled with disabilities at a higher rate than others in school systems. The dilemma presented to families is that their children cannot get some special services they may need without being diagnosed and labeled, yet doing so may impact expectations and opportunity. Being “disabled” does open a door to a variety of services and supports, but accessing those services often requires both time and skill: time to deal with all the systems, and the skills to understand and advocate for the services the child may need.

In poorer communities, those skills and time are hard to come by. Advocates for people with disabilities often fault community organizations, and sometimes churches, for not taking a more proactive role in supporting families with disabled members, but from the perspective of the families and communities, disability is only one issue in a long list: jobs, housing, crime, education and hunger.

So what can the church do? In the case of the family with the three autistic children, a mother assisting other mothers through the school contacted a support group



for mothers of children with special needs called And a Child Shall Lead Us, based at a Catholic church. That group hosted a holiday party to which 300 people came, raising \$20,000. Their example spurred offers of support from

businesses and corporations. A men's group at a nearby Presbyterian church told them, "You find the house; we will renovate it." The Catholic church did so, and the Presbyterian men's group came through, providing even the necessary extra modifications, such as safety gates and bars on the windows. The family moved in on Christmas Eve. This is a classic example of the power of faith communities to spark a community-wide response when presented with the needs of a specific family.

This story may inspire many, yet disempower others who think, "How could we do that?" or "Well, that's great, but what about the systemic issues and problems?" In any case, it does point to some key strategies:

- Start with those you know, the family who is already connected to your church or the one who comes through the door of your mission or outreach.
- Include a family and children in church activities. Doing so is a gift in itself, for both the spiritual nurture and inclusion can break the bonds of isolation and loneliness so many feel. Church-based programs for children and youth also provide a form of respite care for all families, a time when parents know their children are being cared for by others—and are even having fun!
- Begin with individual needs and advocacy. Are there members of the church with particular skills who could help a family deal with public services and systems? If the issue is in school, the pastor and others could offer to go with parents to the IEP (individual education plan) meeting to find out what the church can do and also help families advocate for the support for which they are eligible.
- Start a support group for families to help each other and to learn from speakers and community resources. Rev. Joe Gratzel, of the First Baptist Church of Manasquan, N.J. has done just that, particularly for families like his own whose faith led them to be foster parents and adoptive parents for children with special needs. It is a daunting task, especially when kids have multiple needs and fall between systems. In an e-mail he noted: "Some days we wonder, 'What will we do *if* we have to allow our children to be placed outside our home?' Other days we wonder, 'When will we be unable to care for them, and who will do it when we can't?' My family and I are *so* blessed to be part of a church family that welcomes all children and supports and encourages all parents in the difficult task we face."
- If the focus of a church mission is on other areas of poverty, such as employment and housing, pay special attention to the ways that families with disabled children may be impacted. Building an accessible Habitat House, for example, can help a family in multiple ways.

Years ago I heard Walter Brueggemann preach a sermon on blind Bartimaeus, in which he wondered if Bartimaeus was blind because he was a beggar (i.e., his poverty had led to an eye disease) or if he was a beggar because he was blind (i.e., there was no other job for him). Bartimaeus's strength was the power of his speech, leading Jesus to turn aside and pay attention to an individual, and the rest is history. We too must listen, turn aside, act, and add our voices to insistent advocacy.

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1. E. Moore, "Mothers of Disabled Kids Rally Around a Family," *Star Ledger*, Jersey City, N.J., Nov. 28, 2007.
  2. A. Hewitt, S. Larson and K. Lakin, *An Independent Evaluation of the Quality of Services and System Performance of Minnesota's Medicaid Home and Community Based Services for Persons with Mental Retardation and Related Conditions* (Minneapolis: University of Minnesota, Research and Training Center on Community Living, 2000).
  3. G. Fujiura, J. Roccoforte and D. Braddock, "Costs of Family Care for Adults With Mental Retardation and Related Developmental Disabilities," *American Journal of Mental Retardation* 99, no. 3 (1994): 250-61.