

Invited Commentary

A Parent and Policy Perspective on the Quest for Ordinary Lives

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Cradling a newborn infant who has just been diagnosed with a significant developmental disability is an experience that inspires in mothers conflicting emotions, ranging from profound love to an oppressive sense of fear about the future. This was certainly true 34 years ago when Jonathan Will was born with Down syndrome at a time when institutionalization was still a primary option for families.

Although the past 34 years have seen major changes in public education and human service policy, it was still a valid cause of trepidation 5 years ago when Miriam Talis was born with Down syndrome in Madison, Wisconsin, the community that was the focus for Lou Brown, Betsy Shiraga, and Kim Kessler in their paper *The Quest for Ordinary Lives: The Integrated Post-School Vocational Functioning of Fifty Workers With Significant Disabilities*.

In equal proportion to the swelling hopes and dreams of any new mother, the fears of mothers with children with disabilities centers on prospects and possibilities: What does the future hold for my child? The outlook of a mother for her disabled child is dimmed by what she knows and can easily observe about American society: People with disabilities live very different lives, often in the margins of communities.

Lifelong Impoverishment

Being born with a disability, specifically an intellectual disability, is still a one-way ticket to impoverishment as an adult in America. As Brown, Shiraga, and Kessler (2006) point out, 70% of people with disabilities ages 18–64 are “unemployed or grossly underemployed.” Meanwhile, approximately “90 percent of people with intellectual disabilities are unemployed.” With data so skewed in one direction, it is impossible to overstate the effect this has on families facing the reality of a disability—their aspirations, their optimism, their ambi-

tion, their expectations, and their personal resolve to alter their own circumstance.

The result is lifelong impoverishment for people with disabilities in the obvious financial sense and, perhaps more significant from the perspective of a mother, an impoverishment of human experience for the child or adult with a disability. They lack choices about where they live, with whom they associate, and options for meaningful participation in society.

Being born an American is an asset for most children in this country, yet the American Dream remains largely inaccessible to people with significant physical and intellectual disabilities, even though the United States now offers many public programs to serve these individuals and expends a significant amount of taxpayer resources on them over the course of their lifetimes through public education, community-based programs, Social Security, and Medicaid. In large measure, a family’s acceptance of this assistance locks into place a life of mandated poverty, segregation, and a loss of freedom to make basic choices. These limitations affect the entire family, including parents, siblings, and extended family.

The President’s Committee for People with Intellectual Disabilities (2004), on which we have served, offered this analysis of the present public policy environment:

We have concluded that, historically, public assistance in exchange for enforced poverty and the absence of freedom is a bad deal—one that fails all parties to the arrangement.... A great challenge before our government and society is to *will* a public safety net that not only permits persons with intellectual disabilities to pursue economic and personal freedom, but also leads them to achieve it in a systematic way. This can only be accomplished in a culture that goes beyond mere toleration to one that warmly welcomes and appreciates persons with intellectual disabilities (p. 53).

The Quest for Ordinary Lives is a moving testimony that shows us the present reality need not reflect the future for people with disabilities—for our children or

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those yet to be born. Appropriate allocation of funds toward individualized supports achieves results. The profiles of these 50 workers offer evidence to support a vision for American society in which people with disabilities can have a place in the work force, which is the main avenue toward personal and economic freedom in this country.

Caught Between Ignorance and Arrogance

Brown, Shiraga, and Kessler's study depicted *attitudes* in the 1970s as one of the primary barriers to integrated employment opportunities. According to the paper, vocational instruction for students with disabilities in integrated, real-world settings was widely considered "extreme, dangerous, impractical, too costly, developmentally absurd and generative of false hopes," reflecting ignorance about the capacity of people with disabilities, including intellectual disabilities, to function in society at any level approximating normal.

Moreover, when county funds were shifted from segregated work environments to supports for integrated employment, opponents "...manifested vehement opposition to this departure from traditional funding practices. They predicted the workers would lose the integrated jobs they had when they exited school and would not be able to get others. They told parents their children would be unsafe, abused, isolated, lonely and ridiculed in integrated settings." This reflects both age-old ignorance and a paternalistic *arrogance* of the human services system toward families that together create a push-back against the allocation of human services funding toward integration of the American work force.

The kinds of statements made by those who opposed shifting funds to integrated employment are reminiscent of statements made decades ago by opponents of de-institutionalization. It is important to remember also that just as in the struggle to move persons with intellectual disabilities into the community, many of the opponents of integrated employment are parents, siblings, and friends who are thoroughly frightened by the idea. Many have been taught to fear the idea. As we seek to "unlock" funds that now flow at a three to one ratio in the direction of nonemployment programs, we can anticipate fierce opposition. But surely, the lessons of the struggle for de-institutionalization, which continues to this day, have taught us the importance of not judging families who are fearful of change.

As mothers who have attempted to navigate the present labyrinth of state and federal programs and as individuals who have worked actively at the state and national levels to reform public policy for people with disabilities, we have found that this dichotomy of public perception plays out politically in the governance, administration, and practice of adult services for people with disabilities. A failure to reconcile or deal with these polar viewpoints about segregation and integration has led to programs that lack clarity of purpose; hence, the

substantial expenditure of public funds at the local, state, and federal levels has netted the dismal employment statistics cited previously.

Local, state, and federal funds continue to be expended in fragmented, often discordant ways, focusing on bureaucratic counting and sorting goals that ignore individual or family goals because looking at these goals would evoke the thorny dichotomy. Where one agency might focus on opening doors to employment, barriers will exist in another agency. These programs are not held accountable for specific outcomes with respect to employment and economic success for people with disabilities.

Nor is there any effort way under to provide incentives and sanctions across federal and particularly state agencies that do not coordinate and *share* the financial cost and risk of investing in the support of individuals with disabilities in employment, one person at a time.

The Government Accountability Office (GAO) has found that there are over 200 programs that provide supports to persons with disabilities across over 20 departments of government. Yet this much is certain—as long as government fails to create a new culture of measurement to evaluate the effectiveness of these programs across the lifespan of persons with disabilities, the adult service system will improve slowly, if at all. As long as government fails to develop program indicators and benchmarks that measure gains in personal and economic freedom across the lifespan of the individual with a disability, progress is painfully limited. As long as public policies regarding programs for persons with disabilities do not derive from a common understanding and acceptance of the premise that persons with disability are capable and competent, the mistakes of fragmentation and incoherence continue to plague us.

The lack of knowledge of the capacity of these persons continues to underpin a rigid and incoherent system of lifelong supports. It also impacts broader public perception. The 2003 *Multinational Study of Attitudes Toward People With Intellectual Disabilities*, commissioned by Special Olympics (2003) and conducted by Gary N. Siperstein of the University of Massachusetts in Boston, showed that slightly more than 40% of the American public believes that people with intellectual disabilities should work in a segregated "special workshop," whereas a similar, but slightly smaller, percentage of the American public believes that people with intellectual disabilities should work in integrated unskilled jobs. Equally disturbing was the view expressed by large majority of respondents that their own employer would not consider hiring a person with an intellectual disability.

Asset Development

One of the most exciting developments on the horizon offering hope to families and individuals with disabilities is the movement in our country toward asset-based policies. Considered radical 15 years ago, the notion of asset development for the poor is rapidly gaining

credibility. There are many, many ideas being advanced that are designed to lift the nation's poorest minority, persons with disabilities, out of poverty. Current policy deliberations center on asset development vehicles such as individual development accounts, accounts where earned income is deposited and matched at a rate of up to one dollar to eight dollars, tax-exempt qualified disability savings accounts, children's savings accounts, health and education accounts, and other savings instruments to which the individuals and families could contribute. It is critical that as asset-based policies develop, the lifelong needs of persons with disabilities for health, education, employment, independent living—including home ownership—and long-term care be fully addressed. This will mean confronting the two most implacable barriers to employment and asset development in the adult maze of statute and regulations: income limitations and the \$2,000 asset limitation created in the Social Security Act. Another hugely important policy discussion looming on the horizon is whether persons with disabilities will be able to use their benefits to develop assets. Failure to grapple with these barriers in the policy arena is likely to result in the development of strategies such as tax-exempt savings accounts for other populations of Americans in the decade ahead leaving behind millions of Americans with disabilities. Then, the tedious, lengthy, frustrating and all-too-familiar process of retrofitting existing savings instruments to give families and individuals with disabilities access to them will have to begin. The federal statute that created individual development accounts, for example, provided access to low-income workers but not persons with disabilities. These citizens cannot be an afterthought; the newly emerging "ownership" society cannot ignore the needs of its citizens with disabilities.

Education

In our view, achieving the vision depicted in *The Quest for Ordinary Lives* starts, as Brown, Shiraga, and Kessler attested, in public education. School staff from the 1970s, as described by the authors, seemed quite sure of what disabled students could not do, and that translated into an unwillingness to provide instruction that would lead to integrated employment. In contrast, *The Quest for Ordinary Lives* suggests that all children in America must be viewed as emerging and flexible, as young people who have not yet reached their limits. Schools cannot focus on managing the status quo but rather must be dedicated, as these Madison area educators were, to changing and improving it.

The case studies cited by Brown, Shiraga, and Kessler demonstrated that high expectations combined with effective, individualized curriculum in integrated settings can significantly affect the functioning of students with disabilities and their ability to perform meaningful work and contribute to the society of the work place.

The report further reveals a basic truth that bears repeating in this new era of standards, accountability, and assessment: To enter the work force, students with intellectual disabilities need a *marketable* set of *relevant* skills. How do those lessons apply to public education today? The No Child Left Behind Act (NCLB) represents a significant departure from the past in that it establishes a new framework of accountability, for all students, including students in special education. Parents and policymakers alike must make sure that while concept of accountability in NCLB is preserved that NCLB does not derail the development of effective, rigorous curriculum for students with disabilities, a particular concern for students with intellectual disabilities. Schools must provide learners with intellectual disabilities a solid foundation of academic knowledge, functional skills, technological competency, and appropriate behaviors that apply to community life, work, and postsecondary education. Knowledge of universal design concepts and strategies such as scaffolding must be embedded in every program preparing regular or special educators. This will require a shift in the mindset both at the academy, where teachers are trained, and at the schoolhouse where standards, curriculum, instructional strategies, and assessments must be universally designed.

But schools cannot do this job alone and will need public and private partners to support high school students with intellectual disabilities as they transition into employment or further education. Public education, human services, and economic support must be converted into a seamless pre-K-16 continuum that focuses on the goal of integrated employment and postsecondary opportunities for lifelong learning—with strategies for providing financial aid for that learning, such as through access to loans, grants, and work-study funds, developed and implemented.

All programs that support students with intellectual disabilities must be systematically evaluated to ensure that their success is measured by increasing the numbers of students who enter the work force or postsecondary education. Data points focused on income generation and savings and ownership should be systematically and routinely incorporated into evaluation systems. But there should also be careful and equal attention paid to whether individuals with intellectual disabilities are able to escape loneliness as well as poverty.

Conclusion

After the birth of a child with a disability, friends, neighbors, and colleagues start to assume that we mothers have magical powers of reasoning that can transcend all barriers. And, somewhere along the way, we begin to feel as though we do.

Then real life gets in the way. We get out of the family centered world and fall into the world of reality full of bureaucracies and processes, full of ignorance and

arrogance. We are confronted by the statistics. And fear and dread sets in.

The *Quest for Ordinary Lives* suggests that there is no need for magic—what we need is unity purpose in America to give people with disabilities a chance to participate in the economy of the 21st century.

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