OUT OF THE SHADOWS: THE POSTWAR ERA

From the perspective of public policy, World War II provides a sensible, though somewhat arbitrary starting point in considering social insurance and categorical assistance policies to serve persons living with intellectual disabilities. The immediate postwar period also marks the emergence of family caregivers as an organized constituency making specific claims on public policy.

1945 provides a stark reminder of how far American public policies, law, and culture have moved. Before this point (and for a considerable period afterwards), families depended on a patchwork of over-crowded and under-funded large state institutions, forty of which housed more than 3,000 individuals [Braddock et al., 2005]. Forbidding realities of institutional care were far from public view [Rothman and Rothman, 1984]. The war engaged greater awareness of these conditions, partly because of Nazi crimes against people with disabilities, and also because of historical accident. Wartime legal authorities detailed conscientious objectors to institutions for the retarded. Some of these conscientious objectors went on to write scathing accounts of the poor conditions they had witnessed ([Richardson, 1946] cited in [Trent, 1994]).

This was certainly not the last time that inhumane institutional conditions caused a public outcry. In the early 1960s, Eunice Kennedy Shriver described equally forbidding institutional conditions in the pages of the Saturday Evening Post [Braddock, 2010]. In 1967, Look magazine published a series of graphic photos titled “Christmas in Purgatory” [Trent, 1994]. In 1972, young reporter Geraldo Rivera’s television exposure of conditions at Staten Island’s Willowbrook Institution produced even greater political and policy responses ([Rothman and Rothman, 1984]; Even in 2011, scandals regarding wrongful deaths and inhumane conditions continue...
to regularly surface [Hakim, 2011; Hopkins and Rose, 2011]). Without understating the impact of such later disclosures, revelations in the immediate aftermath of World War II initiated national debate about topics that had not previously been the subject of open discussion.

Shame and stigma regarding the etiology of intellectual disability—coupled with the lack of realistic alternatives or community-based services—led many parents to institutionalize a child, sometimes without even revealing that the child was born. In 1944, the psychologists Eric and Joan Erickson had a child diagnosed with Down Syndrome. The Ericksons concealed the child from their other children, saying that he had died at birth ([Jones, 2004]; As late as the 1960s, playwright Arthur Miller quietly institutionalized his son David, also born with Down Syndrome [Andrews, 2007]).

Even after the establishment of the New Deal, the federal government provided almost no specific assistance for disabled individuals or to their families. Aid to the aged, blind, and disabled was regarded as a state or local responsibility, which was sometimes concealed from federal policy. Federal expenditures specifically identified for intellectual disability services amounted to less than $1 million [Braddock, 2010].

1950 marked a watershed with the publication of Pearl Buck’s best-seller, The child who never grew [Buck, 1950]. The child who never grew broke taboos by recounting Buck’s gradual discovery of her daughter Carolyn’s intellectual disability (which was actually Phenylketonuria, or PKU). Buck describes her difficult decision to institutionalize Carolyn at 9 years of age: “I realized then that I must find another world for my child, one where she would not be despised and rejected, one where she could find her own level and have friends and affection.”

Buck’s account spurred public notices of parents caring for children. This vocabulary and rhetoric was suited to the times in which these books were written and read. It also matched the life expectancy of many intellectually disabled persons. In 1929, the mean lifespan for an infant born with Down’s Syndrome was 9 years [Strauss and Eyman, 1996]. As late as 1983, the median age of death among Americans diagnosed with Down’s syndrome was only 25 [Yang et al., 2002].

Mothers of intellectually disabled children began to find each other. Many found that they faced common challenges ranging from the provision of social and emotional support to finding appropriate summer camps, comparing notes regarding specific therapies and medical providers, sharing what would later be called respite care. Many parents discovered a need and a capacity for collective action to obtain services and resources for their children.

Katherine Jones profiles the local activism of New Jersey housewife Laura Blossfeld, who helped to found what would become the New Jersey Parents Group for Retarded Children [Jones, 2004]. In 1946, Blossfeld placed a local newspaper advertisement recruiting other parents to join the nascent organization. Her pitch might have been drawn from a political science textbook:

“...each parent can ultimately help his own child by doing something to help all children similarly affected... Therefore I suggest an organization for all parents of mentally retarded children, one that may well prove to be the first chapter in a nationwide organization.”

Similar appeals were undertaken in nearby states. In 1949, a New York City housewife placed a similar newspaper advertisement, writing “Surely there must be other children like [her son], other parents like myself. Are you? Let’s band together and do something for our children!” [Castles, 2004].

By 1950, Blossfeld’s New Jersey group had expanded to seven chapters. Two years later, parent groups in many states had mobilized to form the National Association for Retarded Children (NARC). NARC offered direct services, nursery school classes, recreational and social groups, counseling and guidance for parents, and referrals to social service agencies. NARC chapters also conducting need-assessment, established local lobbying groups, provided or subsidized training for service providers. By 1960, NARC had 681 local affiliates and 62,000 members. By 1964, membership exceeded 100,000 [Segel, 1974].

NARC materials emphasized that intellectual disability crosses racial, eco-
nomic, and class lines. This rhetoric underplayed actual socio-demographic disparities in the actual incidence of intellectual disability. NARCs inclusive rhetoric also did not reflect the composition of its own membership. A 1974 survey indicated that 96% of NARC parents were white. Most were married, had attended college, and reported middle-class incomes [Segel, 1974]. NARCs founding displayed many similarities to the founding of other successful voluntary organizations that found broad appeal. As the scholar of political movements Theda Skocpol describes this process:

[O]riginal Americans joined voluntary membership federations not only for political reasons but also in search of sociability, recreation, cultural expression, and social assistance. Recruitment occurred through peer networks, and people usually had a mix of reasons for joining. Men and women could be drawn in initially for nonpolitical reasons, yet later end up learning about public issues or picking up skills or contacts that could be relevant to legislative campaigns, electoral politics, or community projects [Skocpol, 2004].

In the case of NARC, this proved to be a potent combination. The organization provided members with mutual support, with local chapters facilitating such basic tasks as helping families plan beach vacations. Within the political realm, NARC advocated what would become special education, and it supported state bond issues to expand residential treatment.

EXPANDING SOCIAL INSURANCE

Partly as a consequence of such organizing, the 1950s marked a surprising turning-point, in which the federal government enacted major legislation to expand income support to persons with disability. Although the great increases in public expenditures would occur in later decades, the foundation was laid in several key items of legislation. In 1950, Congress authorized public benefits in the form of “Aid to the Permanently and Totally Disabled (APTD).” In 1954, President Eisenhower declared the first National Retarded Children’s Week, reflecting the increased visibility of this population [Segel, 1974; Trent, 1994].

By 1956, Social Security Amendments created the “Disabled Adult Child (DAC)” program, which authorized payments to the surviving child of a retired, disabled, or deceased worker past the age of 18 if that survivor was disabled [Braddock et al., 2005]. Under the provisions of the DAC program, the child of a retired or disabled worker can receive up to 50% of the amount available to the primary beneficiary. The child of a deceased worker can receive up to 75% of the amount available to the primary beneficiary.

The DAC program thus provided the first pillar of entitlement security for intellectually disabled Americans who might outlive their primary caregivers. By 1972, ~176,000 adults received benefits through the DAC program due to a diagnosis of mental retardation. In 1972, another 155,000 adults with the same diagnoses received assistance through the APTD program [Gettings, 2011]. By 2010, almost a half-million Americans receive such benefits due to qualifying diagnoses of autistic disorders (16,684), developmental disorders (3,998) and intellectual disability (441,956) [SSA, 2010].

In 1958, then-Representative George McGovern sponsored the Education for Mentally Retarded Children Act, which authorized modest federal training efforts for the teachers of intellectually disabled children [Braddock, 2010]. This also blossomed into expanded educational supports in a variety of settings. Such legislation provided a foundation for what eventually became PL 94-142, the Education for All Handicapped Children Act, enacted two decades later.

During the 1960s, NARC continued to serve as a key constituency, allying itself with other organizations in the “mind lobby” to advocate for the expansion of community-based mental health and mental retardation services. David Felicetti, in describing this history, notes that “The mind lobby hears many critics who will certainly help shape legislation... but they confront virtually no political enemies in Congress” [p. 124]” [Felicetti, 1975].

MEDICAID AND MEDICARE

The establishment of Medicare, Medicaid, Title I education funding, and more during the 1960s provided the largest components of federal funding for intellectual and developmental disability (I/DD) services.

Medicaid in particular has become the dominant payer—not only for medical and long-term care services, but also for a variety of school- and community-based services at the boundaries between personal medical services, case management, education, and other social services [Braddock et al., 2011; Gettings, 2011]. Medicaid’s Intermediate Care Facility for Persons with Mental Retardation (ICF/MR), and (after 1982) Medicaid’s Home and Community-Based Services (HCBS) waiver authority have provided the two principal mechanisms through which the federal government supports I/DD services.

Medicare receives less attention in connection with the same services. Yet it has also proved important, since many Americans with intellectual and developmental disabilities receive benefits through the Social Security system.

The 1960s also saw the creation of an infrastructure for I/DD services and research sparked by the 1961-62 President’s Panel on Mental Retardation. The Panel issued 97 recommendations, many of which were eventually enacted into federal law. Other legislation, notably the 1970 Developmental Disabilities Act and its subsequent reauthorization, also proved important in broadening the populations eligible for assistance based on intellectual and developmental disabilities, and in furthering efforts to move individuals from large public institutions to community-based settings [Gettings, 2011].

Supplemental Security Income

The 1972 establishment of Supplemental Security Income (SSI) provided what may be the final pillar of entitlement security for persons living with intellectual disabilities [Daly and Burkhauser, 2003; NRC, 2002] SSI established a federal assistance program to the aged, blind, and disabled, supplanting the patchwork of state disability programs and the 1950 APTD amendments. SSI emerged as an outgrowth of political debate over the proposed negative income tax of the late 1960s and early 1970s. By December 2010, 1.5 million Americans receive SSI benefits due to qualifying diagnoses of autistic disorders (151,260), developmental disorders (271,506), or intellectual disabilities (1,077,484). Within these recipient groups, average SSI monthly benefits are ~$549 [SSA, 2011]. Even when combined with Food Stamps and other in-kind aid, SSI provides only modest economic support. Low income remains a key challenge facing many individuals with intellectual disabilities. Even at this modest level, SSI allows hundreds of thousands of men, women, and children to live within their family homes, or to otherwise reside in community settings. Throughout the 1970s and beyond, the “mind lobby” continued to
benefit from support that crossed economic and political boundaries. For example, in the early 1980s some officials in the Reagan administration sought to curtail the scope of benefits provided under PL 94-142. They were opposed by a diverse network of influential family caregivers that included Republican Senator Lowell Weicker and conservative columnist George Will (Melnick, 1994).

In large part as a consequence of this political change, public expenditures on I/DD services have steadily increased over the past four decades. Published tallies indicated expenditures of $52.9 billion spent on I/DD services by 2009; an inflation-adjusted increase by a factor of four in such spending since 1977 ([Braddock et al., 2011]; By comparison, federal expenditures on traditional welfare—cash assistance for low-income families with dependent children through the TANF program—was $33.5 billion in FY2009 [Schott, 2011]). This $52.9 billion figure itself likely understates public and private expenditures on education, income maintenance, health, and social services.

The role of litigation

The same political dynamic played a complementary role in litigation pursued on behalf of intellectually disabled persons. Full accounting of the intricate legal history is beyond the scope of this paper. However, several aspects of this history are especially noteworthy [Bazelon, 1973; Melnick, 1994; Gettings, 2011].

Some political scientists and legal scholars presented litigation as a substitute for other forms of organizing and advocacy—even at times a harmful substitute—such as the long-term proved politically counterproductive [Silverstein, 1994]. This critique may have merit in some policy domains; it does not appear to describe the history of I/DD services. Within this domain, litigation has proved complementary to other forms of advocacy and to other efforts to improve the quality and reach of I/DD services. Such litigation resulted in a substantial expansion of special education services, [Melnick, 1994] and the right to humane and decent treatment [Bazelon, 1973].

In accounting, for example, the history of litigation surrounding the Willowbrook scandal, Rothman and Rothman [p. 353] note that litigation resulted in the transfer of most patients to appropriate settings. Unlike the case of severely mentally ill persons, this deinstitutionalization resulted in the transfer of substantial resources across care settings to promote improved outcomes.

Political advocacy complemented litigation, as disability rights groups were able to convince legislators to provide the required resources to comply with court rulings. At the same time, litigation proved politically generative, as the discovery process brought to light substandard or inhumane conditions at public care facilities.

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More recent litigation has also strengthened the legal and programmatic foundation of community-based services. In the 1999 case, Olmstead v. L.C and E.W., the state of Georgia appealed a lower-court ruling which concluded that the Americans with Disabilities Act (ADA) required Georgia to provide services in the most integrated setting appropriate to the needs of individuals with disability. Georgia argued that the lower court’s ruling would lead to the closing of state hospitals and to the disruption of important state services. Originally, 26 states had signed an Amicus Brief in support of Georgia. Many of these states, however, withdrew their support in response to the disability rights community [Anonymous, 1999]. Writing for a 6-3 Supreme Court majority, Justice Ruth Bader Ginsberg affirmed the lower court’s decision:

States are required to place persons with mental disabilities in community settings rather than in institutions when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities [Anonymous, 1999].

The shift to community-based services

Olmstead proved to be one of the most important decisions in the history of American disability policy. In affirming the right to community services, it spurred both state and federal provision of home- and community-based services for children and adults living with diverse disabilities.

In part because of these changes, there has been an enormous increase in the proportion of persons with intellectual disabilities who are able to live in the family home or in other community care settings. Indeed, the number of people with intellectual and developmental disabilities living in large state institutions declined by almost 85 percent between 1965 and 2009, from 223,590 to 34,447.

Healthy People 2010 sought to "reduce to zero the number of children age 17 and younger living in congregate care facilities" [Larson et al., 2011]. The number of children and youth in public institutions declined by 98 percent, from 92,000 to about 1,500. Between 1977 and 2009, the number of Americans under age 21 reported to live in congregate settings sharply declined. Meanwhile, the proportion of those over the age of 21 living in such settings more than doubled, from 156,854 to 384,011—a trend which often reflected greater community care opportunities for autonomy and personal development among intellectually disabled adults.

That same period witnessed dramatic declines in unit size of residential settings that housed individuals living with intellectual or developmental disabilities living in large state institutions declined by almost 85 percent between 1965 and 2009, from 223,590 to 34,447.

Challenges looking ahead

Given these broad accomplishments and the steady expansion of I/
DD services, several challenges remain central:

Public policies have yet to match the increased life-span and physical well-being of intellectually disabled persons.

The majority of individuals with mild or moderate intellectual disabilities will outlive their parents, who are often their primary caregivers. Indeed 731,000 individuals with intellectual disabilities now live with caregivers over the age of 60. Many of these older caregivers will themselves experience physical and cognitive challenges.

This is an ironic but inevitable consequence of the great progress in medical and social services to the disabled themselves [Glasson et al., 2002, 2003]. As noted, the median age of death was 25 among Americans diagnosed with Down’s syndrome. By 1997, median age at-death had nearly doubled to 49 years of age within this same population [Yang et al., 2002].

Survival is strongly associated with the severity of individuals’ intellectual disability. In one Australian study, median life expectancy was 74.0 years among people with mild disability, 67.6 years among those with moderate disabilities, and 58.6 years among those with severe disabilities [Bittles et al., 2002]. Thus individuals most likely to thrive in the family home or another community-environment are most likely to outlive the men and women who are their direct caregivers.

Current public policies do not provide families with the options and assistance required for proper transition planning. The widely-cited 2010 FINDS national survey documents some of these gaps, as well as family and individual needs for social support. FINDS data indicate that most family caregivers do not have a plan for where their loved one would go if they themselves could no longer able to provide care (62%). Nearly two-thirds of all family caregivers worry that the person they care for might have to go somewhere they do not want to live [Anderson et al., 2011].

FINDS web-based dataset may also understate service difficulties and material hardship among intellectually disabled Americans. Ninety percent of FINDS respondents reported that they were non-Hispanic white. Fifty-six percent reported before-tax income of at least $60,000 [Anderson et al., 2011].

The transition to a decentralized network of home- and community-based care places significant burdens on families to select and monitor services.

The quality of such services is often low. Services are often provided through a low-wage, high-turnover direct care workforces that requires improved training and work conditions to provide effective care [Stancliffe and Lakin, 2005]. In 2009, the median hourly wage for all direct-care workers was $10.58. One in four nursing home workers and more than a third of aides working in agency-based home care lacked health coverage [PHI, 2011].

The shift to decentralized home- and community-based services may also heighten economic, race/ethnic, and educational disparities in access and utilization of key services. Communities vary in their provision of such services. Higher-income families may also have greater resources and skills for self-advocacy in successfully obtaining and monitoring community-based care. At the same time, low-income communities bear disproportionate burdens of intellectual disability, even as these same communities often provide more limited access to disability services [Emerson, 2012]. Although existing data are unclear, research on California.
services indicate that nonwhites were less likely to obtain intellectual disability services [Harrington and Kang, 2008].

The sheer size, complexity, and expense of I/DD services poses inherent challenges to state and local government, particularly during the current recession.

I/DD services comprise one of the largest line items in most state budgets. Compared with K-12 education, general Medicaid expenses, and public employee retiree benefit obligations, I/DD services may also be particularly susceptible to retrenchment in times of fiscal stress.


The impact of these state and local fiscal challenges is revealed in the 2011 edition of State of the States in Developmental Disabilities, a periodic compendium of state policies, service patterns, and spending across the United States. The 2011 edition extends previously-available data from 2006 to fiscal year 2009, and thus into the current recession ([Braddock et al., 2011]; this section expands [Pollack, 2011b]).

I/DD services serve a politically appealing, vulnerable population. Yet these services impose fiscal burdens on states and localities experiencing sharp declines in tax revenue and sharp increases in the demand for a variety of public assistance and social services. States’ different approaches to preserving or to cutting these services in hard fiscal times thus provide a signal of states’ larger values and vision of government.

Reliable time-series data regarding state I/DD expenditures are available since the late 1970s. As shown in Figure 1 [Braddock et al., 2011], inflation-adjusted growth in I/DD expenditures far outpaced inflation between 1977 and 2002. Growth then precipitously dropped as states began to experience the most serious fiscal stress. By numerous metrics, state budgetary retrenchment is the deepest on record.

Between 2008 and 2009, 23 states actually reduced real spending on I/DD services. (See Fig. 2 below, reprinted by permission from David Braddock.)

If one excludes federal dollars, 47 states reduced I/DD service spending between fiscal years 2008 and 2009. Nationally, the average spending reduction was 12%, with Alabama, South Carolina, Idaho, and Rhode Island reducing state expenditures by more than one-quarter [Braddock et al., 2011; Pollack, 2011b].

These changes in federal and state expenditure are associated with tangible changes in service delivery. An estimated 123,000 persons with intellectual disabilities are now on waiting lists for publicly-funded residential services [Lakin et al., 2010]. Many states have also curtailed Medicaid-funded ancillary services such as dental care, home health care, and even hospice services provided under the ambit of Medicaid [Pollack, 2011a].

FINDS data reflects these patterns. Sixty-two percent of family caregivers, seventy percent of those caring for individuals with severe intellectual or developmental disabilities, reported that services in their communities were decreasing [Anderson et al., 2011]. As Anderson and colleagues report:

Decreasing supports were reported to result in the person with ID/DD losing services such as PT, OT and Speech provided by schools (43%), not being able to go outside the home as much (29%), not seeing friends as frequently (37%), and losing other services such as social security (23%).

Fig. 3. State fiscal effort 2009. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

Fig. 4. Changes in state I/DD spending 2008–2009. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]
much (24%), not making as many choices (23%), and not talking to as many people (18%) as they had in the past.

Changes and levels in I/DD expenditures reflect state specific circumstances. Yet these expenditure changes also reflect partisan political alignment and ideological concerns. Figures 2 and 3 below illustrate these patterns.

In Figure 3, the vertical axis represents states 2009 “fiscal effort” on intellectual and developmental disability services. Here fiscal effort is operationalized as dollars spent on I/DD services per $1,000 of state personal income. The horizontal axis provides an even simpler measure of states’ political alignment, simply operationalized as the proportion of state’s voters who cast their vote for Barack Obama rather than for John McCain in the 2008 presidential election. The red line corresponds to predicted values, computed on the basis of linear regression weighted by state population size.

As shown, traditionally Republican states such as Oklahoma, Utah, Alabama, and Texas are clustered in the lower left quadrant of the graph. In contrast, traditional Democratic states such as New York, Connecticut, and Maine are clustered in the upper right quadrant.

In fact, a one standard-deviation (8.44 percentage points in the popular vote) rise in Candidate Obama’s 2008 voting share was associated with an accompanying 0.54 standard deviation rise (about $1.15 per $1,000 in state personal income) in fiscal effort in supporting I/DD services. This is a large observed association—corresponding to ~27% of state mean expenditures. This illustration of the change in state spending yields similar results. Figure 4 below shows the percentage change in states’ spending on I/DD services between 2008 and 2009, again graphed against Barack Obama’s share of the two-party presidential vote. As above, the red line represents predicted values based on weighted linear regression.

The same general pattern held. In this analysis, a one standard-deviation rise in Barack Obama’s voting share was associated with an accompanying 0.47 standard deviation rise in states’ fiscal effort. Especially striking are the number of states with the lowest fiscal effort going into the great recession—South Carolina, Oklahoma, Texas, and others—that also implemented the deepest cuts between 2008 and 2009.

Data are not yet available for fiscal years 2010 and 2011. Subsequent budgetary retrenchment may prove more pronounced. The 2009 federal stimulus package—more formally, the American Recovery and Reinvestment Act of 2009—provided key federal assistance that has now ended. ARRA provided an enhanced federal matching rate for Medicaid services. This provided strong financial inducement for states to maintain Medicaid services. ARRA also imposed maintenance of effort requirements that constrained states’ ability to cut Medicaid or K-12 educational services. These requirements are no longer operative, which may facilitate further budget cuts.

CONCLUSION

By chance, this article was submitted on the same day that the Obama administration announced that the CLASS (Community Living and Social Supports) Act cannot be implemented as originally defined within the 2009 Patient Protection and Affordable Care Act (ACA).

A complex long-term disability services program, CLASS’s abortive trajectory exemplifies the continuing challenge to American social insurance posed by the cost and the complexity of care required to assist a diverse disability population. This is a particular disappointment, especially given the particular value of CLASS [Caldwell, 2010] for persons with intellectual disabilities living in community settings.

ACA still provides many important benefits for citizens with intellectual disabilities. The new law establishes expanded Medicaid benefits for low-income individuals who do not otherwise qualify for public aid, as well as subsidies to moderate-income families who obtain health coverage through health insurance exchanges.

The new law institutes insurance regulations of particular importance to intellectual disability. These include the removal of lifetime expenditure caps and prohibitions against discrimination in coverage or premiums on the basis of preexisting conditions. Adults younger than age 26 can now receive coverage under their parents’ employer-based policies. ACA also supports demonstration projects and initiatives to improve services to dual-eligible Medicare-Medicaid recipients. All of these provisions are of particular value for children and adults with intellectual disabilities. ACA also offers states valuable options in addressing some challenges of long-term care [Reinhard et al., 2011].

ACA does not address services that are provided outside the ambit of health care, many of which are financed at the local level. Policymakers face serious challenges in every area of service delivery, income maintenance, and clinical care. At one level, services for intellectual disability are often insulated from efforts to promote management innovation, evidence-based practice, and pay-for-performance that have improved medical care systems such as the Veterans Administration [Gettings, 2011]. Service agencies are provided funds sufficient to provide custodial care. They often accomplish this mission through low labor costs in a low-skill workforce, with accompanying questions of employee morale and turnover.

Policymakers also struggle to provide families with the information needed to make wise choices within a decentralized network of community services. Few caregivers can scrutinize whether their daughter or brother is receiving the right mix of services. Recent scandals exemplify families’ deepest fears of custodial care [Hakim, 2011; Hopkins and Rose, 2011]. Many persons with intellectual disability also experience complex physical or psychiatric comorbidities. Many are treated by physicians and social service professionals who have limited experience in addressing these concerns.

Notwithstanding these challenges, the arena of intellectual disabilities should be recognized as a genuine, readily-overlooked triumph of American social policy. Prodigious expenditures reveal the latent generosity of a welfare state which draws stark distinctions among public help recipients. The same society that can stigmatize millions of people deemed unworthy of help behaves quite differently towards those it deems genuinely needy. A paradigmatic example of the worthy poor, persons with intellectual disability now receive substantial support from federal, state, and local government.

Sixty years ago, the birth of a child living with intellectual disabilities was regarded as a private tragedy. To the extent attention was paid, it was focused on family caregivers and sometimes on children. The lifecourse possibilities and challenges facing the individual himself (or herself) was rarely considered. Persons with intellectual disabilities were excluded from public education and the labor market, enjoyed no legal protections within the
labor market, had little access to basic income support and health services required to enhance their well-being. All of these burdens have been lifted. Yet intellectual disability services are now recognized as a proper task of American social insurance. Legal protections have greatly expanded. The embrace of persons with intellectual disabilities within new media and popular culture has, if anything, been more dramatic (e.g., [Dick Jones, 2010; Matthews, 2011]). Foremost credit for these changes belongs to persons with intellectual disabilities and their caregivers, who mobilized as a social and political force to bring about needed policy changes.

These historic developments are noteworthy; they do not merit complacency. America’s fragmented and contested welfare state often undermines our best efforts to help. IDD services are delivered by state and local governments that increasingly lack the fiscal and administrative capacity to implement these programs well. As the current recession indicates, this brings a real price.

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