EMERGING POLICY CHALLENGES IN INTELLECTUAL DISABILITIES

Glenn T. Fujiura1* and Susan L. Parish2

1Department of Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois
2School of Social Work, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina

The forces shaping intellectual disability policy-making are diverse; while many of the policy issues reviewed in this issue are specific to intellectual disabilities, there are others that transcend disability-specific concerns. Our review is organized around six emerging demographic and socio-cultural trends that may directly and profoundly impact the intellectual disability field: aging, changing labor markets, immigration, families, federalism, and culture. Each of these trends is discussed in terms of their relevance and potential impact on disability policy. © 2007 Wiley-Liss, Inc.

Key Words: policy analysis; demography; federalism; families

The nation’s response to its citizens with intellectual disability has evolved in a dynamic policy environment. Major changes in economic conditions, legal precedent, political conditions, medical technology, and philosophies of governance have time and again altered the landscape of supports and services for persons with intellectual disabilities. Such external events and the policy challenges they present will most certainly play a significant role in shaping the future of the field as well. The intent of this analysis is not the prediction of future events, but rather to highlight forces not commonly considered in the disability field that may be crucial in policy development. Dror [1994] employed the phrase, “thinking-in-history” to refer to analysis of trends and processes as a means to understand the future without being bound by the past (p. 7). It is not simply a matter of linear extrapolations to the future, but rather anticipating the forces that may shape future circumstances. Our review is framed and organized around these forces or “drivers,” to borrow a term from the field of scenario building [Coates, 2000; Tangredi, 2000]. How does one identify these processes? There are no formalized methodologies for anticipating the future, but rather conceptual frameworks within which we attempt to tease out key themes. We employ here the conventions of scenario builders who begin their work with an “active scan” to detect early signals of themes in the macro-environment [Coates, 2000; Tangredi, 2000]. Though the labels may be unfamiliar, the task and objectives are not; social forecasting has a long history in the social sciences, particularly sociology [Henshel, 1982].

Discussing hypothetical futures is a delicate enterprise; future events are rarely predictable, omissions are likely, and erroneous extrapolations are almost certain. However, the act of forecasting can be an extremely useful device for clarifying the potential impact of emerging but low visibility trends. That said, we begin with the core theme of the paper—intellectual disability issues and policy are situated in the context of larger global forces, including demographic, political, and economic exigencies. It is not simply an intellectual disabilities agenda or a disability agenda, but rather a set of policy challenges inextricably linked to domestic and increasingly global policy concerns.

EMERGING POPULATION TRENDS

Population change is a natural starting point for our discussion of emerging policy challenges; anticipating the impact of population trends represents the oldest form of sociological forecasting [Henshel, 1982] and is a familiar topic in intellectual disability policy discussions. Aging was identified as an important intellectual disability policy issue in the 1980s [Janicki and Wisniewski, 1985; Seltzer and Seltzer, 1985] and the recent debates over autism incidence are examples of the nexus of policy and demographics. The connection between demography and policy is hardly surprising. Subtle changes in the underlying structure of populations can have profound effects on policy [Kraft, 1994] and the impact of demographic trends on policy making is a staple of the policy literature [Hoover, 2002]. To the extent that intellectual disability policy and practice serves a heterogeneous constituency with diverse needs, changes in the distribution of subgroups within the larger population with intellectual disabilities have important policy implications. Further, shifts in the general population are likely to have indirect but profound impacts on the intellectual disabilities service system.

The aging of populations in developed countries is singular with respect to its policy implications. This fact has been the subject of intense scrutiny (e.g., Freedman et al., 2002;
Lloyd-Sherlock, 2000]. Much has been written about how baby boomers will skew age distributions in the United States, impacting health care and every other age-sensitive system [Fujiura, 2000]. While the impact of aging on acquired disabilities is straightforward and predictable [Freedman et al., 2002], a number of issues specific to intellectual disabilities are linked directly to aging. The reviews in this issue by Hel ler et al. [2007] and Turnbull [2007] succinctly present the core challenges: developing appropriate service and care models, managing health, and securing and organizing public financing. Yet aging indirectly influences multiple other policy dynamics relevant to the intellectual disabilities field. We consider two issues that are the focus of considerable concern in the general aging literature but have yet to receive much attention in intellectual disability policy dialogue: changes in the labor market and immigration.

Changing Labor Markets

Adequate staffing of social and health systems is a universal concern across disability constituencies and systems of social care, and most prominently in elderly services care [Stone and Wiener, 2001; Wunderlich and Kohler, 2001; U.S. Department of Labor, 2002]. The impact of aging on labor market shortages is a matter of debate. A number of projections point to significant and widely reported labor shortages [Employment Policy Foundation, 2001; Hodge, 2004] while other analysts predict a market in approximate equilibrium and argue that shortfalls will be attenuated by increased multiple job holders, immigration, and industries managing human resources in response to labor shortages [Horrigan, 2004].

In their current configuration, labor market shortages are a matter of debate. A number of projections point to significant and widely reported labor shortages [Employment Policy Foundation, 2001; Hodge, 2004] while other analysts predict a market in approximate equilibrium and argue that shortfalls will be attenuated by increased multiple job holders, immigration, and industries managing human resources in response to labor shortages [Horrigan, 2004].

It is not simply a matter of linear extrapolations to the future, but rather anticipating the forces that may shape future circumstances.

The need for a decisive policy response to the growing demand for labor within the intellectual disabilities service system will also be exacerbated by the aging of adults with intellectual disabilities. Due to the technological and health care advances realized during the last century, the first generation of U.S. adults with intellectual disabilities is beginning to outlive their parent caregivers in large numbers. In their current configurations, service systems are ill equipped to handle the increased numbers of elderly people with intellectual disabilities who will require care from an increasingly strained service system, demanding greater levels of labor for their own service needs in direct competition with the elderly care service systems [Parish and Lutwick, 2005].

Immigration and Labor

The great unknown in these forecasts is how immigration will influence both the demography of aging and projected labor market shortages over the next few decades [Borjas, 2003; Hirschman, 2006]. While illegal immigration dominates the policy discourse, it is the sheer magnitude of legal immigration that has altered the U.S. landscape. During the 1990s the U.S. population increased by ~26 million; 70% of that population growth—18 million persons—was immigrants or their children [U.S. Census Bureau, 2004]. Rates have continued to increase through the current decade [Shrestha, 2006].

This influx directly influenced employment and looms large in forecasting shortages, particularly in the health and disability support professions. Immigrants accounted for nearly 50% of U.S. labor force growth between 1996 and 2000, and comprised ~15% of the total labor force in 2004 [Mosisa, 2006]. While the public face of immigration policy is most often framed in terms of excluding undocumented workers, the fact of immigration, legal and otherwise, is critical to the economies of high skill industries [Lowell, 2004], service industries dependent on entry level wages, such as the hotel and resort industry [Bergman, 2002] and the health care sector [Yamada, 2002]. Legal immigration is driven largely by economic considerations and we should expect enormous pressures to expand immigration from affected industries [Cornelius and Rosenblum, 2005]. International studies of population aging suggest access to a younger immigrant workforce represents a significant competitive advantage for the United States over the economies of Europe and Japan, whose populations are aging at an even faster rate [National Intelligence Council, 2000].

The link between the intellectual disabilities field and immigration is more nuanced than the balance of supply and demand for low wage workers. How will a system of disability services that is deeply influenced by social norms respond to immigration with its attendant mixing of cultures? An obvious example is Latinos’ displacement of African Americans as the largest U.S. minority group [U.S. Census Bureau, 2006b], a transformation Rodriguez [2003] has termed the “browning” of America. He has argued that while U.S. culture has always existed at the confluence of heterogeneous racial, ethnic, and cultural traditions, the browning of America is evident in the emerging centrality of Latin American cultural influences in the United States. Perhaps
the transcendent issue, and one inextricably linked to immigration policy and increasing racial diversity in the United States, is the need to develop a stable and committed workforce, a goal not likely to be facilitated by framing these issues exclusively in terms of low-income labor.

SOCIAL TRENDS

The distinction drawn between population and “social” trends is admittedly arbitrary, but their separation serves to shift the focus to issues more frequently represented in domestic policy evaluations. We selected three social trends based on the breadth of their potential impact on the intellectual disabilities field: families and poverty, governance, and the interface of technology and culture.

Families and Poverty

The family as a central policy concern has been addressed in detail elsewhere in this issue [Heller et al., 2007; Turnbull et al., in press]. The importance of the family to policy planning is related to the structure of caregiving in the United States; the majority of Americans with intellectual disabilities live at home with a family caregiver, most often a parent or parents [Fujiura, 1998]. The impact of aging caregivers is the most prominent of these concerns [Fujiura and Braddock, 1992], and briefly reviewed elsewhere in this issue [Braddock, 2007; Heller et al., 2007]. The size of the cohort suggests significant and as yet unrealized near-term demands on support systems as family caregivers age while significant demand for services remains unmet across the states.

In the present analysis, we expand on the family theme by focusing on transformations, still unfolding, in the structure of American families. The idealized notion of the nuclear family has been widely critiqued as a myth of the postwar era; families have never been a “fixed form” and are always evolving in response to cultural, economic, and other forces [Hernandez, 2003]. Nonetheless, there is little question that the structure of the American family has undergone radical transformations during the past generation. The centrality of marriage to family formation has been profoundly affected by rising divorce [Gruber, 2004], cohabitation [Bumpass, 1990], and nonmarital childbirth [Smeeding et al., 2004], which has occurred as intergenerational family households have declined [Silverstein and Bengtson, 1997].

The increased labor force participation of American women directly affected their traditional caregiving roles and influenced the declining size of families [Hooymann and Gonyma, 1995], with indirect albeit important implications for the intellectual disabilities service system. Most caregivers of people with disabilities—both adults and children—are women, but women’s caregiving roles often conflict with their responsibilities as workers [Parish et al., 2004; Parish, 2006]. Women’s employment reduces their availability to serve as caregivers, and will likely increase pressure on the formal service system to support greater numbers of people with intellectual disabilities. Furthermore, family size has declined as women’s employment rates have increased. These smaller families subsequently have fewer children who ultimately have less capacity to care for their siblings with disabilities when their parents are unable to continue caring. This dynamic will increase pressure on the formal service system in the future [Parish and Lutwick, 2005].

The connection between poverty and family structure and recent poverty trends in the United States are of special interest to our projections. Although the connection between disability and poverty is an old story, there are two features of special relevance to family policy. The number of children living in poverty has been increasing in the United States since 2000 [National Center for Children in Poverty, 2006], and the absolute numbers are large (20.6 million low income children 18 years or younger in 2005; U.S. Census Bureau, 2006b). Furthermore, income inequality has sharply increased [Palloni and Morenoff, 2001]. Income earners have become more concentrated into a smaller number of households since the late 1960s [DeNavas-Walt et al., 2006]. This rise in income inequality is in part linked to the growth of one-parent families, particularly among minorities [Lerman, 1996; Landrigan, 1997].

Similar patterns are found among families with disabilities [Fujiura et al., 1998] with extraordinary rates of poverty among single parent, primarily female-headed households (an average of 64% across all groups; 79% for single parent Latino families). These exorbitant poverty rates among households headed by women and increased income poverty trends are of particular concern. Poverty-exposed children with intellectual disabilities appear to be at elevated risk for adverse outcomes as contrasted with their typically developing peers [Park et al., 2002]. Welfare policies that once exempted single mothers of children with disabilities from work requirements were repealed with the enactment of TANF in 1996, and the recently passed Deficit Reduction Act further increased the amount of work required by welfare recipients [Parrott et al., 2006]. Yet the limited existing evidence suggests the quality of child care available to poor and low-income children with disabilities is likely inadequate when compared with that used by nondisabled children [Parish and Lutwick, 2005]. Despite continued work requirements for low-income mothers, states have cut child care funding for the last 2 years [Matthews and Ewen, 2006]. The child care support necessary for mothers’ labor force participation appear insufficient, particularly for mothers raising children with disabilities.

We know very little about the scope and status of immigration and people with disabilities [Mautino, 2002a,b] and how it may affect the disability-poverty relationship. Research on the health of immigrant communities suggests “healthy immigrant paradox” trends, although perhaps as an artifact of the population they and their children are relatively healthy [Morales et al., 2002]. A number of hypotheses have been put forward: (1) cultural mediators protect against the risks of poverty [Beiser et al., 2002]; (2) regulatory biases of the immigration process limit the influx of individuals with impairments [Mautino, 2002b]; (3) selection biases are imposed by the difficulty of the immigration process [Franzini et al., 2001]; and (4) the more prosaic effect of undersampling [Palloni and Morenoff, 2001]. The limited existing data suggest the healthy immigrant paradox trends hold for disability in the United States: rates for activity limitations are substantially lower for immigrants across all age cohorts [Benjamin et al., 2000]. Yet, exposure to poverty among children of immigrants is significantly higher than for the native born population—36% versus 11% in 2000 [Douglas-Hall and Koball, 2006]. Though relative risk rates remain favorable for first generation families, the paradox effect has consistently been found to diminish as acculturation increases [Flores and Brotek, 2005]. Given the strong covariation of poverty status and risk for intellectual disabilities in the epidemiological literature [Emerson, 2007], crossgenerational exposure to poverty and its collateral
risks suggest external pressures of unknown long-term impact.

Family looms large in American poverty policy: debates over the proper role of government in encouraging family stability and structure have been a recent and controversial approach with both proponents and critics [Fein and Ooms, 2006]. Promoting marriage and reducing nonmarital childbearing was an explicit focus of the 1996 welfare legislation, and represents a watershed of sorts. It was the first time federal policy explicitly sought to influence family formation, albeit with limited effect—states did not emphasize these programs in their welfare programs [Fein and Ooms, 2006]. While federal revenues are still earmarked for these efforts, the evidence suggests their impact (like the level of allocated resources) will continue to be limited over the near term.

What does the future hold for family policy as it relates to poverty? As Turnbull [2007] notes, “There is no single family policy in the field of developmental disabilities”. Rather, a set of core concepts are addressed via diverse disability-specific or generic policies [Turnbull, 2007; Turnbull et al., in press] that are not complementary [Turnbull et al., 2001]. The trends suggest a bifurcation of families into two groups: the conventional target of family supports and those of extreme poverty and vulnerability not traditionally served by the intellectual disabilities service system. Our analysis converges on Folbre’s [2001] characterization of family policy as economic policy—she argues and we concur that families must be approached in a comprehensive fashion with the goal of allowing members to care for each other. Family policy may differ in minimum-wage policy, child care supports, health policy, and taxation policy. Family policy is family and poverty policy.

Goverance

In April of 2001 the National Disabled Students Union (NDSU) organized marches across the nation to protest the Supreme Court’s Board of Trustees of the University of Alabama v Garrett [2001] decision. The core of the Court’s decision rested on the Eleventh Amendment’s prohibition against equal protection suits brought against states by private citizens [Cahill and Malloy, 2004]. A lapel button distributed by the NDSU proclaimed, “civil rights before states rights.” The Garrett ruling is part of a larger Court trend restricting federal authority over interstate commerce, states’ implementation of federal programs, and enforcement of the equal protection clause of the Fourteenth Amendment [Parmet, 2002]. The NDSU lapel button expressed the underlying anxiety about the impact of the new federalism: Garrett was viewed as an ominous extension of the precedence of state sovereignty over federally defined “rights” [Cahill and Malloy, 2004].

Federalism accentuates the development of differences across states while the thrust of disability advocacy and policy has been to secure uniform, national protections. Publicly-funded support of persons with intellectual disabilities has historically been the province of state government [Braddock, 2007]. The structure of intellectual disability services reflects this fact of federalism: the most notable feature of service systems is how variable states are in their fiscal commitments and the character and quality of services. Will the new federalism lead to a retrenchment by some states in their commitment to their citizens with intellectual disabilities? Recent examples are instructive. Florida is modifying its health care system for the poor and people with disabilities through a waiver eliminating its traditional “defined benefit” Medicaid program, replaced with a “defined contribution” Medicaid program. Florida is venturing into uncharted Medicaid territory, offering services based largely on cost, not type or need. This is particularly alarming for people with intellectual disabilities because troubling disparities currently exist in the health care of people with intellectual disabilities [e.g., Parish and Saville, 2006; Krahm and Drum, 2007]; cost sharing for result in rationed services and further exacerbate such disparities. A more positive development is illustrated in Massachusetts’ enactment of universal health insurance in 2006. The coverage will be achieved by a combination of expanding Medicaid, subsidizing private insurers for coverage of high risk individuals, compelling people who can afford coverage to purchase it, and other measures [Executive Department, 2006]. Given the long-standing barriers to employment that health insurance poses for many people with disabilities and parents of children with disabilities, Massachusetts’ new approach may signal improved well-being for families affected by disability. These and other experiments underway across the states suggest that the evolution of the “new” federalism must be seen in gradations of gray rather than dichotomies.

Complex problems will require nuanced solutions; neither blunt application of centrist principles or rapid devolution of powers to localities will likely emerge as a realistic option [Parmet, 2001]. The essential message of the discussion of federalism and federal mandates is that the push and pull of sovereignty is a natural tension of the U.S. system of governance. What is most likely is a continuation of governance trends that extend nearly back to the country’s founding: state experimentation with policy initiatives, working within broad federal guidelines. Federalism has expressed itself cyclically throughout U.S. history [Nathan, 2005]. Medicaid funding appears to be following this pattern and as federal deficits and states’ fiscal health vary over time we should expect an ongoing tension in the federal profile in supporting disability services, which will likely be challenged under the banner of federalism. Indeed, the new federalism was stimulated in part by the escalating costs of Medicaid mandates for the poor; Medicaid, including the disability Waiver program, was caught in the backlash and nearly converted to a block grant in the mid-1990s [Braddock et al., 2002]. In turn, states have resisted efforts to severely restrict growth in the Medicaid program [Holahan et al., 2002; Nathan, 2005]. However, states’ capability to greatly expand their existing services is unlikely to manifest itself in the near future and the fundamental importance of federal resources to the intellectual disability policy agenda will continue. Critical unknowns are whether federal leaders have the will to expand this role, whether alternative models for states’ role will emerge from states’ current Medicaid Waiver experimentation, and perhaps most critically, and the adequacy of federal resources. The federal debt was at a record high in 2006, driven largely by recent tax cuts and increased defense spending [Congressional Budget Office, 2006]. Current federal outlays to finance the debt totaled $184 billion in 2005, and exceeded federal spending for a host of domestic priorities, including Medicaid ($181 billion) Supplemental Security Income ($37 billion) and the Children’s Health Insurance Program ($5 billion) [Congressional Budget Office, 2006]. While there is no consensus about the potential impact of the federal debt on domestic spending, Medicaid spending was reduced in the February 2006 Deficit Reduction Act, signaling the strong
possibility of future federal budget cuts if tax reductions and increased defense spending are maintained.

Culture

Our discussion of cultural trends is approached from the perspective of technology; a pairing that may initially seem odd. The juxtaposition is crucial however; the synergy in our cultural understandings of humanity shape both the direction and goals of technology just as technology can fundamentally shape our notions of what it means to be human.

A concise discussion of technology trends at any level of specificity is beyond the scope of this review because the area is vast, dynamic, and inherently complex. Discerning underlying themes is a more manageable challenge. The National Science Foundation (NSF) explored this general idea of technological themes in their analysis of the emergence of nanotechnologies from the confluence of advances in biology, information sciences, and cognition [Roco and Bainbridge, 2003]. Our cultural analysis emerges from the core themes of the NSF analysis, which focused on how converging technolo-gies can be applied to “improvements” in human cognition, health and physical capabilities, and social interactions. Most of the anticipated impacts are familiar to the disability field and come in the form of environmental modifications, personal assistive technologies, new medicines and foods. These are obvious extensions of our history with technological innovations—to expand our control over our environment. It was the NSF’s fifth category of applications—those that were permanent and internal—that require additional reflection by both the disability and “human performance” communities. We have until now thought of technology in terms of its potential to assist, but technology convergence suggests assistance is only one, perhaps minor, implication of today’s technology. Extending technological applications into permanent and internal modifications of humans is unequivocally a movement towards “supplantive” rather than assistive technolo-gies [Roco, 2004]. What is the signif-

There are no answers yet but rather a series of moral dilemmas. How these are resolved will tell us much about the future of intellectual disability in society. What is not normal? What needs to be fixed? What needs to be prevented?

There are no answers yet but rather a series of moral dilemmas. How these are resolved will tell us much about the future of intellectual disability in society. What is not normal? What needs to be fixed? What needs to be prevented?

in stark contrast to emerging concep-
tions of disability that frame limitations primarily as socially or environmentally created [Altman, 2001]. The distinction is critically important. Wolbring and Golledge [2003] note that while these new conceptions of disablement do not deny the “biological reality of impair-
ment, they demand a reconsideration of conceptions of normality. The shift in emphasis away from individual attributes force attention on our cultural and po-

tical responses to them.

We return then to conundrums raised in the Manger et al. [2007] review of the Human Genome Project. Technology is a fundamental force in modern life, but the truly dramatic changes have yet to occur. How the world of intellectual disabilities navigates these changes is profoundly important. The cautionary notes from emerging
disability paradigms is not an antitech-

SUMMARY

What the future holds for intel-

ducity policy is of course unknown. Our projections have been drawn in only the broadest of strokes; there are most certainly omissions of emerging trends that will be equally critical to the evolution of disability policy. Our caveat is to treat this summary as a cautionary note rather than as portent of the future. The act of fore-

casting is useful not for the predictions, but rather in forcing awareness of futures not necessarily bound by what is familiar. The central theme of our analysis is that intellectual disability policy occurs in the context of larger forces; for the intellectual disability field the message is that we must challenge our-

REFERENCES


Benjamin AE, Wallace SP, Villa V, McCarthy K. 2000. California immigrants have mostly lower rates of disability and use of disability services than state’s U.S.-born residents. Los Angeles, CA: UCLA Center for Health Pol-

ic Research. Policy Brief PB00-2.


Board of Trustees of the University of Alabama v. Garrett (99-1240) 193 F.3d 1214.


