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## A Wicked Problem: Can Governments be Fair to Families Living with Disabilities?

*Families provide priceless support to members with disabilities. Without the support of families the lives of most individuals with disabilities would be diminished in comfort, independence, opportunity, and caring relationships. Without the support provided to individuals with disabilities by family members, public expenditures for nonfamily assistance would be several times what is currently expended. In its responsibilities to the well-being of individual citizens and to the efficient and effective use of public resources, governments struggle to accommodate the great diversity among families in what they want and what they need. Governments are challenged in targeting limited resources to reach those who need them most, in the amounts that are most cost-effective, and in a manner that is most beneficial to the family and its member(s) with disabilities. The attention on support to families is further complicated by changes in families and their individual members as they pass through lifecycles of changing relationships, expectations, aspirations, and capabilities. This article offers a modest commentary on how in the midst of such complexities our society can develop fair, effective, and cost-beneficial approaches to*

*supporting families and their individual members.*

### HAPPY FAMILIES ARE ALL ALIKE

Tolstoy famously asserted that happy families are all alike and unhappy families are each unhappy in their own way. His families struggled for honor, love, and honest work in the face of luxury and social stratification. Dostoyevsky, while extolling the supremacy of Tolstoy's work, showed us miserable men, women, and children struggling for bare existence and every crumb of dignity and understanding in the face of crushing poverty, illness, avarice, drunkenness, madness, and disability. The reader may decide which author provides a better depiction of families and mankind.

Families with members with disabilities have one thing in common: one or more of their members has a disability. Yet they are more different than alike. They vary in the nature of the disability (e.g., sensory, physical, developmental, psychiatric) and in its cause. They vary in the severity and multiplicity of the disabilities. They vary on other dimensions as well. Some are poor, some are well-to-do. Some live in urban areas rife with difficulty but replete with public services including transportation. Some live in rural areas with no access to transportation or local necessities. Some families have one parent. Some have two. Some have more parents because they are blended families with more than one household involved in care. In some families none of the members is a

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parent. In some families the head of household is young. In others the head of household is old and experiencing diminished ability to support the family member with disability. Families vary in education, in primary language, and in religious orientation and intensity as well as community involvement. Some families have members with substance abuse problems. Some are home to physical, sexual, and/or psychological abuse. Some families are without a home or are in the process of losing their home. Some families are without a job. Some are hungry. Some are without hope. Some are overflowing with aspirations or watching their aspirations recede out of reach. In some families people rejoice in all that the disabled family member has contributed to the quality and meaning of being a family. Others feel that the weight of disability is tearing the family apart. Some barely think about the availability of public services or entitlements, some think of almost nothing else. Some cannot survive, quite literally, without the support of formal human services. Some sacrifice the advancement or human capital of everyone in the family, or of one key member, in support of the member who has a disability. And so it goes: these families have attributes in common and their variations are vast. Families with members with disabilities face the same variety of challenges as all other families, plus the additional challenges of supporting a member who needs a different kind or amount of assistance than most of his or her peers. The “additional challenges” associated with a family member with disability may be the dominant focus of a family. They may be hardly noticed. They may last a lifetime, or a few years or months.

The United States has made a national commitment to family life for persons with disabilities. National policies explicitly show preference for children and youth with disabilities to live in family homes under the policy of permanency planning (Pineles, 2005). The United States has greatly expanded assistance to families to maintain children and adult members with disabilities in the family through expanded personal care and other in-home services, cash payments, information, counseling, and respite care (Johnson & Kastner, 2005). The nation has made this commitment because it values families as generally the safest, most natural, and supportive place for people with disabilities. Other nations, too, have made this commitment to recognize the family

as the fundamental unit of society.<sup>1</sup> The nation has made this commitment because it must.

Caregiving by family members of individuals with disabilities is the single most important element to the sustainability of the system of long-term services and supports in the United States. Without the contributions of family members the costs and demand for personal assistance providers would increase dramatically and well beyond what is currently considered affordable. According to AARP estimates, on any given day in 2009, about 42 million family caregivers in the United States were providing assistance to an adult needing help with various physical activities of daily living such as bathing, or instrumental activities of daily living such as shopping, and that nearly 62 million family members were estimated to have provided such assistance at some point during that year (Feinberg, Reinhard, Houser, & Choula, 2011). Had those services been provided by paid personal attendants and other direct support providers, the costs were estimated to be about \$450 billion dollars. Another estimate by White-Means and Dong (2012), based on time diaries gathered as part of the 2009 American Time Use Survey and applying average wages for personal assistance services to the national estimate of family gathering hours, yielded an estimated value of \$335 billion for unpaid caregiving of adults with disabilities. Together these studies suggest that the direct value of uncompensated caregiving for adults with disabilities is in the range of 3 to 4 times the total state and federal Medicaid expenditures for compensated long-term services and supports (Eiken, Sredl, Burwell, & Gold, 2010). In addition, the American Community Survey estimated that in 2011 there were 3.02 million children with significant support needs related to disabilities living with family members (Houtenville et al., 2012). As a total, the economic value of the family and caregiver support to individuals with disabilities in the United States realistically falls in the range of \$400 to \$500 billion per year. As

<sup>1</sup>UN Convention on the Rights of People with Disabilities, Preface, X.: “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.”

the population of the United States ages (e.g., more than doubling the number of 85-year-olds in the next 25 years; U.S. Census Bureau, 2012), the dependence on families and their value to society for providing care will only increase.

In addition to estimating the value of family caregiving, studies have shown that families providing care for family members with disabilities often incur significant direct and indirect economic costs. A 1994 study of nonreimbursed expenditures directly related to the care of adults with developmental disabilities in the Chicago area estimated those costs to average \$6,348, or \$10,140 in 2012 dollars (Fujiura, Roccoforte, & Braddock, 1994). Parish, Seltzer, Greenberg, and Floyd (2004), using data from the Wisconsin Longitudinal Study, found that 165 families with children with disabilities by mother's age 53 had fallen considerably behind a comparison group of 165 peers with whom they were matched at age 18 by family income (76.2% of the comparison group) and savings (73.3% of the comparison group). Responses of family members with children with disabilities in the 1994–1995 Disability Supplement to the National Health Interview Survey (Anderson, Larson, Lakin, & Kwak, 2002) indicated that nearly one half of respondents with a child with a developmental disability indicated significant career-related decisions by one or more parents related to the demands of caring for that child (e.g., not accepting a transfer, turning down a promotion, working only part-time). But not all families were affected by such costs.

The core policy question is: How do we create fair, effective, and cost-beneficial approaches to supporting families given the variety of disabilities and of families, and given the need to appreciate and leverage the efforts families make to fulfill societal promises of family lives for children and noninstitutional lives for all citizens (Olmstead *et al.* v. *L.C. et al.*, 1999)?

#### WHAT DO FAMILIES NEED?

Although families may not need the same things provided to them from outside the family, there are commonalities among most families. These needs might be characterized in a manner similar to the famous Maslow's hierarchy. From society's point of view, families cannot be effective in support of members with disabilities unless they can do so from a foundation of

basic safety and control, yet the nation's housing and transportation policies do not offer universal access to either accessible, affordable distributed housing or transportation services; and even more basic needs such as food are more and more out of reach as income distributions become more extreme and food security programs are threatened by political wrangling. Even though "belonging" is a common level of attainment on Maslow's hierarchy, it is almost certainly less prevalent among families with disability. Having a family member with a disability can, depending on the disability and the community, severely threaten a family's ability to "belong" in a community (Hall, 2010). It is not rare for a person with a disability or their family to feel unwelcome at school, at a community event or public place, or even in a church.

Meeting other families can bring a feeling of community and belonging and may create the beginning of advocacy as well. Advocacy, likewise, can be a gateway to aspiration though often a family of a child with a disability will aspire to different goals than they did before disability came into their life. Achievement can be defined quite differently, not so much in terms of income or the trappings of wealth, but in terms of learning to survive and thrive with disability, or learning to achieve social goals like offering counsel or support to other families, participating in the political life of a community, being on a board, volunteering, or taking on leadership roles in a school, or running for office. Having a child or another family member with a disability can activate one's social consciousness in ways that are entirely unexpected, given the previous track that a family was on. This is not to imply that the lack of income often experienced by families is somehow made up for by social consciousness. Studies have identified out-of-pocket costs, but few studies have identified the effect of childhood disability on families' income mobility, and political action and volunteering are activities that require resources.

Social capital is a measure of connection within communities and has been identified as a goal for persons with developmental disabilities (Gotto, Calkins, Jackson, Walker, & Beckmann, 2010). Fewer forays have been made to understand the role of human capital in resilience and self-determination. *Human capital* is defined in economics as "[a]bilities and skills that enhance an individual's potential income earning, especially those acquired

through investment in education and training.” Clearly it is in the nation’s interest that the investment in human capital of family caregivers not be lost due to their caregiving responsibilities, whether the family member’s human capital is the product of intense educational investment in a neurosurgeon or an astronaut, or whether it is the product of a high school diploma and long job experience as a waitress. Often, public supports including respite care and information seem to be more available to families with children living in poverty and eligible for Medicaid than they are to middle- or upper-income families. Often it seems that the reverse may be true for adults, and that poor families do not have equal access to Medicaid waivers. It is accepted in U.S. society to allocate services to resource-constricted families first, but it does not seem right to make the same argument for access to information and other low- or no-cost supports. In addition, markets for supports may be accessible only within public systems; that is, families who wish to pay privately for supports might find that the best or most complete supports are not available to them. If there is a legitimate public health agenda in the support of caregiving families, then surely that support should not be limited to those families who live near the poverty line.

#### AS GENERAL MOTORS GOES, SO GOES THE NATION

Henry Ford famously said his customers could have any color car they wanted, as long as it was black. Alfred Sloan, the president of General Motors, introduced the revolutionary idea that different groups or segments of people would want different kinds of cars. Likewise it should be clear that different segments of caregiving families have different needs and wants, and achieving public health outcomes may well depend on finding new ways to understand those needs.

Segmentation studies offer a potential strategy to support planning for serving the diversity of family needs and to develop strategies for reaching families with the right support at the right time. Segmentation studies use U.S. Census and other data including commercial data that describe decisions and behaviors to create categories that are meaningful to commercial, civic, and other interests. The main categories of segmentation strategies are:

- Behavioral segmentation: What benefits do caregiving families seek from supports? Do they need day supports to be free to work? Are they seeking information about managing troubling behaviors in their home? Do they need respite care to save their marriage, or support groups to combat loneliness?
- Demographic segmentation: How do the ages, races, and ethnic backgrounds of caregiving families affect what they need and ask for? How are the goals of young adult sibling caregivers similar to the goals of young parents of children with disabilities?
- Geographic segmentation: Where are caregiving families located, and how can we reach them? If they live in a rural county, where can they find support? Do they travel farther than a suburban family travels to find support?
- Psychographic segmentation: How do factors such as education, income, urbanicity, cultural beliefs, and the age of caregivers or disabled family members affect their needs for family support?

Psychographic segmentation is the most comprehensive of these strategies. It is generally agreed that 66 key segments make up the American population. Market research firms can identify segments at the household, Zip+4, and Zip code level and can compare by city, county, school district, state, or other political boundary. They often present these segments on maps. The segments can be explored at the Web sites of industry leaders Nielsen/Claritas PRIZM and ESRI, and other sites such as SRA International explore the process of segmentation. The generic segments have meaning for people with disabilities and their families, and they may be further enriched to meet particular purposes (Swenson, 2008). The key point for planners is that segmentation allows systems to address a manageable number of variables: five or six or even 66 segments of families can be comprehended and even put into visual formats, whereas the individual needs of millions of families resist comprehension.

A generic psychographic segmentation study might describe how family segments differ in their employment or access to the Internet, how many cars or computers they own, how much time they spend in various activities, what publications or news sources they read regularly, whether they have a primary care doctor, whether they save for college, or any

number of other behaviors and beliefs that might be useful to social scientists who are trying to figure out better ways to support families. Many of the same data would be useful to social scientists or human services professionals involved in promoting healthy behaviors or desired outcomes among all families, not just families with a disabled member. Key segments may have characteristics that are especially important for a particular service. For example, implementers of the Affordable Care Act found that “the unbanked” (people without bank accounts) will be limited in their ability to pay for health insurance through exchanges that only accept checks. The implementers have also identified “young invincibles” as a key segment to target for enrollment in the health care exchanges. These are young and healthy people who may decide they do not need health insurance if it costs too much but who will be able to afford it and would enroll at exchange prices. This is also a critically important group to enroll for an insurance plan based on pooled risk.

Segmentation is useful beyond the design of promotional strategies. Segmentation is used to design products and services that are responsive to the needs and wants of particular groups of consumers, enabling manufacturers and marketers to manage product and service development and sales to maximize profit. In contrast, differentiated service design may seem problematic to agencies that manage government programs and entitlements where customer service is dictated more by Congressional authorization than it is by customer needs. In these large public systems, regulated processes guarantee that every citizen has equal access to exactly the same services and supports. In an era of “nudges” and libertarian paternalism (Sunstein & Thaler, 2008), it might be productive of public health and of cost savings, and therefore useful for government supports, to be flexible enough to provide different supports to different people. For example, it might be possible to reach middle- or upper-income families with an extremely low-cost but highly flexible informational, motivational, or investment program targeted specifically to encourage them to preserve their human capital, launch a child with disabilities to a productive or less-dependent life, or maximize their whole family’s health.

Assistive, communications, and management technologies are often thought of as the three

keys to a better future for people with disabilities and their families. We imagine a robot that assists with functional or instrumental tasks, or communications technologies that allow a person with a disability to be always in touch with her family. Technological innovations in particular are less likely to be available equally to all segments of the American family population, so knowledge of segments and prediction of behaviors might be a necessary precursor to government investment in technology. For example, a cloud-based disability record would not be an unexpected development in the wake of electronic health records. If families that have Web access could benefit by having all of their important disability information stored under their own private password (or fingerprint) in the “cloud” for access anywhere from a public benefits office to a school Individual Education Plan (IEP) meeting to a prospective employer, it would save time and frustration, not to mention space, over the current paper-based records management system most families and public systems must manage. Cloud-based records might also improve services and reduce costs by ensuring that records are accurate, complete, and timely. For example, foster families could be given access in real time to any parts of a child’s records that they are entitled to see; families that support an adult with dementia could have accurate daily health records downloaded to the doctor’s office before a scheduled visit. A cloud-based record might also support middleware that could deliver targeted suggestions to stressed-out families along the lines of Amazon, Facebook, or Netflix: “We noticed you liked X support, you might also like Y,” or “We see you asked about discipline for a child with autism, here is a video about positive behavior support.” Of course, there are privacy and security concerns, but the cloud was specifically constructed to be secure, unlike paper or server-based files, which are highly accessible and highly destructible. To date, the field has little to no understanding of how much privacy a caregiving family would risk in order to gain more responsive services, and it is likely that there will be different privacy concerns in different family segments. This area is ripe for investigation.

If cloud tools can really make a difference in the management of services and supports, should families with Internet access be the only ones to benefit? What if a service proved to be highly beneficial to a particular segment

such as low-income young families fostering a disabled child? Should governments invest in Internet access for those families? What if the service achieved public health or public administration goods such as reductions in repetitive injuries or fraud and abuse? It is possible to see that principles of universal design could be used to create a system of supports that is informed by an understanding of the needs of the various segments of families, just as architectural universal design is informed by an understanding of the variations of people's functional limitations. In a time of resource limitation, it is unclear whether disability or family leaders would advocate for new funding to support innovation in management or communications technology instead of more funding for existing direct supports. Henry Ford is rumored to have uttered the phrase, "If I had asked people what they wanted, they would have said faster horses." The intention here is not to diminish the importance of family voices in the discussion about needed innovations but to remind us that the commitment of visionary individuals to solving problems has vast potential to improve lives through divergent means. If the concerns of the disability community were more meaningfully included in the national dialogue and embedded in the mainstream of professional education, perhaps disability issues would receive more attention and effort across a range of fields and disciplines.

The intersection of human services and management disciplines brings other questions to the fore. What is the role of government in the improvement of services, and what are the proper roles of each branch and level of government in the innovation of such services? Good government requires good management of government services, and for how long will it be possible to define good management as stewardship of existing systems rather than as innovation to meet future challenges? Current systems were constructed for the management of state-based institutional plans. They are unlikely to be agile or responsive enough to add value to systems that provide individualized, family-based, and self-determined supports. At the same time, the expectations of the families who are "customers" of public services and supports are indexed to what is available in their private world. If FedEx can deliver a package overnight, why can't an agency respond to a request for information in less than a month? If Starbucks

or McDonald's can figure out just the right place to open a new store, why can't a government service be available in the right place at the right time? If a customer can get a tall no-foam nonfat extra hot decaf cappuccino at any time, why are options so limited for the supports that might allow for continuous care for an aging mother or disabled teenager at home? Surely the family is more important than the coffee.

Equity, efficiency, and effectiveness—never mind elegance—are all at risk. New expectations and new social and cultural challenges have been layered on top of systems of supports that have been constructed in a piecemeal fashion across decades by succeeding Congresses and defined interest groups, and managed by multiple layers of agencies with many different missions, used well or badly by many different kinds of families in many different circumstances with many different challenges and goals. It is unlikely that any part of the current delivery system is cost effective. Even so, it is the system we know, and might even be demonstrably good compared to many other national systems. Where would we get the courage to build a new system that responds, over time and distance, to meet the various and changing needs of all of the families who use it, as well as all who should be able to use it? Perhaps the prior question is simpler and more courageous: If the family is indeed fundamental to America, then what is the role of the government in supporting families?

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