Families of Individuals With Intellectual and Developmental Disabilities: Policy, Funding, Services, and Experiences

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Abstract

Families are critical in the provision of lifelong support to individuals with intellectual and developmental disabilities (IDD). Today, more people with IDD receive long-term services and supports while living with their families. Thus, it is important that researchers, practitioners, and policy makers understand how to best support families who provide at-home support to children and adults with IDD. This article summarizes (a) the status of research regarding the support of families who provide support at home to individuals with IDD, (b) present points of concern regarding supports for these families, and (c) associated future research priorities related to supporting families.

  Key Words: *employment; families; family support; siblings; intellectual and developmental disabilities*

In the United States, we are experiencing a watershed change in how intellectual and developmental disability (IDD) services are delivered nationally as ever-increasing numbers of individuals receive long-term services and supports while living at home with family (Larson, Salmi, Smith, Anderson, & Hewitt, 2013). Yet, even while states have, since the 1980s, sought to establish systems of support for these individuals and their families, no consensus has emerged to define what is meant by the term *family support*. As a result, it is not surprising that from the earliest initiatives until now, programs to support families vary greatly in their intent, design, and effect. Such variance, while useful for encouraging local autonomy and innovation, also embeds uncertainty within the field over what constitutes best practice and policy to establish cohesive state systems. In this context, what follows is a summary to illustrate (a) the status of research regarding the support of families who provide support at home to individuals with IDD, (b) present points of concern regarding supports for these families, and (c) associated implications for practice and research.

   There are different definitions of "intellectual" or "developmental" disability that make it difficult to identify the precise prevalence of IDD. Larson et al. (2000) suggest that approximately five million of 300 million Americans have a developmental disability. Regardless of the precise prevalence rate applied, however, the great majority of these individuals live at home with family members, making families the predominant providers of lifelong support (Heller, Caldwell, & Factor, 2007). Although many people with IDD live with their families, state IDD agencies support only 13% of the total number of families providing support at home (Braddock et al., 2013).

   Among people with IDD who receive state or federally funded supports, an increasing proportion live with a family member. In 2011, of the 1.06 million people with IDD receiving publicly funded support services in family homes or residential settings, an estimated 610,299 (57.6%) lived in the home of a family member (Larson, Ryan, Salmi, Smith, & Wuorio, 2012). In the past decade, the number of people with IDD receiving support while living with family members grew 3.3 times more rapidly than did persons receiving nonfamily-based support.

   In fact, focusing on Medicaid-funded Home and Community Based Services (HCBS) for people with IDD between 2000 and 2011, the percentage of people receiving Medicaid HCBS waiver-funded services while living with a family member grew by nearly fourfold from 74,939 to an estimated 312,058 (Larson et al., 2012). By 2011, five states reported that 65% or more of all people receiving support

resided with their families (Larson et al., 2012). In essence, during the decade, Medicaid-funded residential supports for people with IDD shifted from primarily supporting people to live in residential facilities to primarily supporting people to live with family members. Given protracted funding challenges in states and average costs of family care that are about 40% of out-of-family services (Lakin, Larson, Salmi, & Scott, 2008), these trends will likely continue.

Most adults with IDD live with their families, and over 25% of family caregivers are over the age of 60 years (Braddock et al., 2013); the role of siblings is taking on greater and greater importance (Heller & Kramer, 2009). This demographic imperative, combined with the long waiting lists for residential services, present an increasing need for sibling involvement. Although siblings have the longest relationship with their brothers and sisters, they are traditionally overlooked as both providers and as consumers of family support (Arnold, Heller, & Kramer, 2012).

Given the shift in emphasis in publicly funded services from people living in residential facilities to living with family members, it is reasonable to wonder what we know about how to best support families providing at-home support for their family member with IDD. Unfortunately, at present, we know a lot about the support needs of these families but not as much about how best to meet their needs. Newer models of service delivery through family support grants and self-directed options have enabled people with IDD and their families to hire family members and friends, thereby making selection and retention of workers easier, and these models provide some insight into how to meet family needs (Bogenshutz, Hewitt, Hall-Lande, & Laliberte, 2010; Walker, Bogenshutz, & Hall-Lande, 2009).

Status of Present Research Regarding Family and Sibling Experiences, Support Needs, and Outcomes

Support Needs and Experiences of Families and Siblings

Families. Families of people with IDD often struggle to find formal services and supports because of gaps in service availability or barriers to access and utilization (Chou, Lee, Lin, Chang, & Huang, 2008). Samuel, Hobden, LeRoy, and Lacey (2011) reported that the largest barriers to services were

family lack of awareness of services, lack of knowledge about the process of obtaining the needed services, waiting lists, financial issues, and lack of transportation. Families have also reported that services did not help enough or that the quality of the service received was poor. Larson and Hewitt (2005) reported that finding and keeping direct support professionals have challenged families for decades.

Survey research underscores families' reported needs for support. In 2010, The Arc of the United States conducted a national online survey (the Family and Individual Needs for Disability Supports [FINDS] survey) to obtain information on the perceptions of family caregivers of individuals with IDD on a range of life-span issues (The Arc, 2011). This study was different from other survey efforts in that it specifically targeted families connected to people with IDD (instead of all types of disabilities). People responded from 38 states and Washington, DC, including 4,962 caregivers and 558 people with disabilities. The issues targeted included education, transition, employment, residential settings, status, and support needs of individuals and their families and technology needs as well as the effects of present budget shortfalls on services. Findings from the survey of family caregivers found among other things that

- The majority of people with IDD were not being fully included in their schools.
- Families had experienced a decrease in services from the schools, despite the schools being an important source of support.
- People with IDD and their families faced very real challenges to achieving their aspirations for the future.
- Many families were not prepared in terms of future planning, including residential options when family members are no longer viable caregivers due to age-related declines, illness, or death.
- Twenty percent of the people with IDD had no source of income.
- Sixty-two percent experienced decreases in services for their family member, and nearly a third were waiting for government-funded services (32%), most for more than five years.
- Eighty-eight percent of families experienced physical strain, and 81% experienced financial strain as a result of unrelenting caregiving responsibilities with diminishing or nonexistent respite or support options.

Families' experiences with employment indicate that employment practices for people with IDD are woefully inadequate as 4,217 out of 4,962 families in this study reported that their family member with IDD was unemployed (The Arc, 2011). Families' experiences with housing also represented a range of perspectives as some families thought that their family members should continue to live with them, and others believed that an apartment setting with roommates or a group home with several roommates is a preferred option (Anderson, Larson, & Wuorio, 2011). Families identified that technology was needed to assist them with support and caregiving, but many were unaware of what products were available to them or where to find this information.

More recently, in 2011, the PACER Center reported results of its 2010 FAST Family Support Survey involving a national survey of 2,416 parents or relatives of children with various disabilities (including IDD but also higher-incidence disabilities), age 11 to 39, from 50 states and four U.S. territories (Pacer Center, 2011). Survey respondents were asked to rate the importance of knowing how to gain support for their family in 20 areas. They were also asked whether the family needed help that they were not receiving, how good their current supports were, and where they turned to find information about disability supports. Overall, findings reveal that the services presently offered must be improved. The five top information areas listed by families included (a) helping their son or daughter improve social skills and build lifelong friendships, (b) advocating for their son's or daughter's rights, (c) helping their son or daughter develop skills for living on his or her own, (e) obtaining medical care and health insurance for their son or daughter, and (e) helping their son or daughter be prepared to work. Echoing many of the findings of the FINDS survey, the results of the FAST Survey also indicated unmet family needs in the areas of housing and support services, transportation, and employment (Pacer Center, 2011).

In addition to the 2010 FINDS survey and the 2010 FAST Family Support Survey, the National Core Indicators (NCI) includes family perspectives on disability services and supports received by their family member with an intellectual or developmental disability through the program. The goal of the NCI program was to encourage and support National Association of State Directors of Developmental Disabilities Services (NASDDDS) member agencies to develop a standard set of performance measures that could be used by states to manage quality and across states for making comparisons and setting benchmarks (Bradley & Moseley, 2007). In data collected by the Adult Family Survey (NCI, 2013b) and Child Family Survey (NCI, 2013c), findings show that families reported lower levels of satisfaction with overall supports and services. Less than half of families reported that their family member or family always receives all the services and supports needed, and less than half reported that services and supports always change when their family member's needs change (NCI, 2013b, 2013c). These findings indicate that the system of state-delivered disability services to people with disabilities across the life span is not optimally responsive to the changing needs of individuals with IDD and their families. Results also suggest that the lives of individuals with IDD and their families appear to be full of everyday experiences of challenges and unmet needs related to poor responses from service systems to individual needs (Bradley & Moseley, 2007).

Siblings. The research on siblings of adults with IDD has focused on the nature of the relationships, the outcomes for the nondisabled sibling, and to a lesser extent, the support needs of siblings. Generally, the relationships between the siblings with and without disabilities are characterized as positive with frequent contact (Heller & Arnold, 2010; Orsmond & Seltzer, 2000). Most of the recent studies indicate that siblings of adults with IDD have good health and low depression and report rewards of having a sibling with disabilities (Hodapp & Urbano, 2007).

However, the impact of having a sibling with IDD may also include negative aspects, such as greater pessimism, distress, and demands (Griffiths & Unger, 1994). In comparison with siblings of people with other forms of IDD (e.g., Down syndrome), siblings of brothers and sisters with autism have less contact and less positive outcomes (Orsmond & Seltzer, 2007).

As siblings age, future planning for the time when parents can no longer provide care becomes a central issue. Many families of adults with IDD are reluctant to make such future plans and to discuss future options with their other children (Heller & Kramer, 2009). In a national Internet-based study conducted by Easter Seals, 23% of siblings of adults with IDD were the primary caregiver for their sibling with a disability, and 14% of siblings were co-residing with their sibling (Easter Seals, 2013).

Key needs reported by siblings of adults with IDD include (a) obtaining disability-related information, (b) receiving support for their caregiving role, and (c) enhancing the formal support to address siblings needs (Arnold et al., 2012). Information needs include housing options, financial and legal planning, and future planning (Heller & Kramer, 2009). Other issues include how to navigate the system, how to assume caregiving responsibility, and educating the public about disability awareness.

Meeting Support Needs

Efforts to establish services to support families with members with IDD living at home have focused on supporting families so they can better support their family members with IDD, thus preventing the need for placement in more restrictive and costly service settings. By 1990, for example, 35 states had passed family support legislation, and as the century drew to a close, all states recognized the importance of supporting families (Braddock et al., 2013). Complementing these advances, in the 1990s, the U.S. Administration on Intellectual and Developmental Disabilities (AIDD) funded training and technical assistance grants to support the development of family support programs. Since 2004, AIDD has invested over $25 million to fund over 20 family "one stop" or "360" demonstration projects (Braddock et al., 2013).

Braddock et al. (2013) provide a summary of selected research regarding the impacts of supports to families. Among the many outcomes, families report reduced stress or financial worries, increased self-efficacy and satisfaction with services, increased maternal employments, lowered out-of-pocket costs for providing care at home, and reduced out-of-home placement. Receipt of respite care, in particular, has been found to provide caregivers with opportunities to work outside the home, positively affecting the family's financial well-being (Caldwell & Heller, 2003).

Still, a characteristic of efforts nationally to support individuals living at home and their families is the considerable variance in program design. Just as no two individuals or families are alike, no two programs are alike. Michigan families, for example, with an income of less than $60,000 may be eligible for a monthly cash benefit of $222, and 18 other states also report that they offer cash subsidies to families (Braddock et al., 2013). To contrast, Oregon offers supports to adults living at home via a Medicaid "supports waiver," but for children, provides for fixed sums of money to be distributed to local "family networks" that encourage family-to-family support giving. Meanwhile, other states may rely neither on cash subsidies nor family networks to offer supports.

Consistent with this observation, the AIDD family support 360 demonstration projects were not identical in their specific objectives and strategies. They did, however, share a number of common objectives or policy themes. Overall, these projects were charged with establishing a "one stop" site where families could apply for a range of services and/or receive a wide range of supports (AIDD, 2012). Given this intent, all projects set out to (a) provide a meaningful role for families to play in leading the project, (b) conduct effective outreach to families, (c) provide information and referral to targeted families so that they may access support offered by the state IDD agency and other governmental or nongovernmental resources, and (d) provide assistance to staff serving as "family navigators" to build support plans with families and access support from multiple sources.

Present Points of Concern and Debate

A number of issues cause concern among family support proponents. Chief among these, however, are these six points of contention: (a) the conflict between self-advocacy and family perspectives, (b) the absence of a consensus definition of family support, (c) the absence of a national database to track state investment in family support, (d) the growing demand for supporting individuals living at home with families, (e) the present and growing reliance on Medicaid funding for family support, and (f) the lack of support targeted to adult siblings.

Conflict Between Self-Advocacy and Family Perspectives

An important point of contention that undergirds this discussion is the degree to which family perspectives should be considered relative to self-advocate perspectives. Even as families hold the most responsibility as decision-makers or decision allies to their family member, especially in the childhood years if not through adulthood, some stakeholders in the disability self-advocacy community argue family perspectives should be dismissible altogether. This conflict is considered by

some to be a response to overprotective parents who will not advance self-determination goals. However, not all people with IDD take this stance. Many self-advocates acknowledge their need for family input on decisions affecting their lives while simultaneously upholding their right to be full participants in the decision-making process.

Absence of a Consensus Definition of Family Support

Any discussion of family support in the United States must begin with consideration of what is meant by the term. The term *family support* has been defined in various ways over time with no particular definition becoming the agreed upon standard through consensus-building processes (e.g., Tétreault et al., 2012; Turnbull et al., 2007). In effect, siblings have often been left out of the family support policies and practices. Presently, contrasting definitions of the term are provided within federal policy, such as Title 2 of the Developmental Disabilities Act of 2000 (P.L. 402) and the Children with Families of Disabilities Support Act of 2000. States that offer family support services base them on their own state statutes or administrative rules, and family support advocates or researchers fashion their own standards for the field. Given the autonomy of states, the challenge of reaching a consensus definition of family support remains ever-present.

Two difficulties embedded within current definitions of family support concern the mix of supports offered individuals and their families at home and differences in how services are viewed based on the age of the person with IDD. Regarding the mix, some suppose that any supports offered to the individual living at home may be counted as family support, including those directed primarily at the individual and others more directed at family caregivers. For instance, such services may be day programs (e.g., day habilitation, supported employment), prosthetics for the individual, professional services (e.g., therapies directed at the individual), or respite support. In essence, any service received by the individual or family member while he or she lives at home can be considered family support.

Others argue that services directed at the individual with IDD are more accurately viewed as "in-home" support. These services, after all, are meant to support the individual and would be provided regardless of where he or she is living and so are not family support. Here, a defining emphasis is placed on the supports offered directly to caregiving family members, such as training, family-to-family support groups, and homemaker chore services. Consistent with this approach, the National Agenda on Family Support defined the elements of family support as including (a) instrumental supports for day-to-day needs (e.g., respite, financial assistance, cash subsidies), (b) emotional support for mental health and self-efficacy (e.g., parent-to-parent, self-advocacy groups, support groups), and (c) information and training supports to develop knowledge and skills (e.g., information about disability, training on advocating for services and policy change) (Reynolds, 2011).

In 2011, AIDD supported a group to meet at the Wingspread Conference Center in Wisconsin. This group deliberated over family support policy and practice. Its working definition of family support that evolved was "strategies designed to ensure that families have access to person-centered and family-centered resources, supports, services, and other assistance. These strategies are directed to the family unit but ultimately benefit the individual" (Hecht & Reynolds, 2012). Examples of supports included service coordination, cash assistance, assistive technology, and home modifications.

Essential to the Wingspread definition was the observation that family support "strategies are directed to the family unit but ultimately benefit the individual." Indeed, this facet of the definition has been a point of contention for years. This definition asserts, finally, that simply because a person with IDD lives at home, all the supports offered to the individual and his or her family cannot be summed and labeled as *family support*. Still, some of the examples offered for family support (e.g., assistive technology, home modifications) seem more directed at individuals and so illustrate again the difficulty with defining family support.

While there is a tendency to want to develop a unified definition of *family support*, there is also a reality that given the autonomy of states even with a single specific definition, family support and services will likely look different from state to state and locality to locality. One advantage to this autonomous approach is the ability to see varied services and support emerge and to learn from the difference across service models.

Absence of a National Database on Family Support

Presently, there is no single, unified, and comprehensive database available to provide accurate and reliable state-by-state information about the characteristics of the individuals who are receiving supports while living at home with their families or their service use patterns and related expenditures. The federal AIDD funds several Projects of National Significance that provide data and show trends in the field of IDD. These projects gather information related to expenditure data through the State of the States Project at the University of Colorado, Boulder (Braddock et al., 2013); service provision data through Access to Integrated Employment National Data Collection at the University of Massachusetts, Boston (Butterworth et al., 2013) and the Residential Information Systems Project and Family and Individual Information Systems Project at the University of Minnesota (Larson et al., 2013); and individual outcome data for service recipients through the NCI project at the Human Services Research Institute and NASDDDS (NCI, 2013a). However, these national data sets only provide information on people who are receiving formal supports. As a result, policy makers, even while increasing the number of people receiving services at home with families, are doing so without benefit of informative data to guide the way.

Between 1977 and 2011, AIDD had funded two of the Projects of National Significance (State of the States and Residential Information Systems Project) to collect information relevant to family support efforts state by state and nationally. Each of these projects has unique utility and responsibilities albeit in some cases overlapping. Neither had been able to collect all of the needed information regarding supports to families. For example, to date, it is unknown on a national level the age of individuals who receive services in their family home. Additionally, while the NCI program includes family outcome indicators (choice and control, family outcomes, satisfaction, family involvement, community connections, access and support delivery, and information and planning), only 14 of 36 participating states actually gather data using the adult family survey.

Recognizing the problems associated with existing national data sets, in 2006, the State of the States in Developmental Disabilities Project teamed with state IDD state agency directors to consider the type of family support data that are needed, evaluate the difficulties associated with data collection, forge a solution, and test a revised way for collecting information on family support. Eventually, a new Family Support Services Taxonomy was developed and tested (Braddock et al., 2011). The field test reaffirmed that states vary in their capacity to report service use and expenditures by the categories that researchers request. Sometimes the data simply are not available or too time-consuming to retrieve and recategorize to fit a common standard.

More recently, AIDD has asked researchers at the University of Minnesota to build on this work to operationally define the concept of family support and collect data across states. This work is in its early stages, and as the State of the States in Developmental Disabilities Project found, it is challenging to find agreement on what family support is and is not. Still, it is essential to proceed in ways to build consensus around its operational parameters and steadily gather data from states regarding the number of people served, the services received, and the amount spent.

Growing Demand for Supporting Individuals Living at Home With Families

Demand for publicly funded developmental disabilities services is growing nationwide. This increase in service demand is the product of several factors. One of the most important is the increased longevity of people with IDD (Katz, 2003). This circumstance has two ramifications for IDD service systems. First, turnover among individuals receiving services is reduced (and, thereby, there is less capacity to absorb new demand). Second, there is a growing cohort of individuals who live in households with primary caregivers who are themselves aging (Braddock et al., 2013). Increased service demand may also be due to the significant numbers of youth with developmental disabilities exiting special education systems each year and needing ongoing services and supports as young adults as well as people seeking services because their families cannot continue to support them or need extra assistance.

At present, the challenge these circumstances place on policy makers is compounded by a national weak economy, resulting in state revenue shortfalls (Braddock et al., 2013; Johnson, Oliff, & Williams, 2011). States generally operate their

developmental disabilities service systems under fixed capacity limits with only a few (e.g., Arizona and California) providing for automatic annual caseload increases to accommodate additional eligible individuals. System capacity is managed by capping dollars or "slots" (service openings) or a combination of both. Likewise, capacity is regulated by changes in funding from year to year.

Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto wait lists. The number of people on a wait list measures the gap between current system capacity and expressed service demand. This gap grows when the expansion of system capacity does not keep pace with growth in service demand. Given the budget shortfalls faced by states, policy makers will be harder pressed to address rising service demand. As a result, the trend to support increasing numbers at home with families, a less expensive option than out-of-home alternatives, will likely continue.

Over-Reliance on Federal Medicaid Funding for Family Support

Medicaid serves as a primary funding engine for IDD services in the United States (Braddock et al., 2013). The program works as a state-federal partnership whereby states are reimbursed a percentage of their eligible expenditures by the federal government. States may be reimbursed for 50% or more for their expenses, and so this option is very attractive to state leaders strapped for resources. Increasingly, states are applying Medicaid to help finance services for individuals living at home. To do so more efficiently, states are fashioning "supports waivers" that offer a restricted set of services to people living at home (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013; Smith, Agosta, & Fortune, 2007). Most significantly, these waivers do not offer residential services all day and each day (i.e., "24-7"), and the number of people served is capped as is the amount of money that may be allocated to the individual.

This strategy allows policy makers to stretch the resources they have and reach more people, most notably people living at home with an array of "in-home supports." Going forward, future family support systems will need to be reconciled with the pressing demand in states to utilize Medicaid. It will not be easy, and it will be important to consider that Medicaid can only serve the eligible "beneficiary,"

which is to say "the individual with IDD" and not the "family," a circumstance that narrows the array of services for which Medicaid will pay. It will also be important for states to remember that not every individual with IDD is eligible for Medicaid-funded services, and therefore, relying solely on Medicaid-funded supports will not meet the needs of some individuals with IDD. Lastly, Medicaid does not have an all-inclusive menu of services to meet the holistic needs of a person or family; this can result in a tendency to recast human needs by what is "Medicaid reimbursable."

Still, Medicaid is an essential component to any state's support system. A major challenge for states is determining how to incorporate Medicaid to support people with IDD and their families and also to make available other needed supports that Medicaid will not fund. It seems prudent then that future systems must take into account that building a service system based in Medicaid carries significant potential for establishing an exclusive reliance on this type of government funding. The result may be an inevitable redefining of family support in terms of what this resource will fund and an undercutting of efforts to establish systems that consider multiple facets of an individual's life and encourage use of natural supports in the community that are not funded directly through Medicaid.

Absence of a Focus on Adult Siblings

Siblings have often been left out of the family support policies and practices. There is some tension between the needs and desires of parents, siblings, and adults with IDD in regard to having a voice in setting goals and future plans. The role of nondisabled siblings as a distinct group can be somewhere in between that of a peer and a parent. Also, the roles of siblings can vary widely from primary caregiver within the same household to distant sibling living many miles away. Siblings may also be involved in caring for their parents and their own children as well as their brothers and sisters (Orsmond & Seltzer, 2000).

Service providers are accustomed to engaging parents in decision-making and in providing support but not so much to involving the siblings (Arnold et al., 2012; Heller & Kramer, 2009). Research suggests siblings are generally not involved in formal future planning tasks, such as establishing a special needs trust, establishing power of attorney, or writing a letter of intent for their

sibling with a disability (Heller & Kramer, 2009). They are an untapped resource. Many siblings want to be actively involved in the lives of their brothers and sisters but need more information and support in order to do so. Siblings' involvement in future planning discussions is critical as they are likely to assume primary caregiving responsibilities for their brothers and sisters when their parents are no longer able to do so (Heller & Arnold, 2010; Heller & Kramer, 2009). The way to involve siblings may vary from the way that parents are involved given that they are more likely to be employed, to live further away, and to have other ideas about the best options for their brothers and sisters (Orsmond & Seltzer, 2000).

Moving Forward

Establishing Best Practice in Family Support

The variation in family support programs makes it difficult to establish a definitive evidence base to identify best practices for supporting families. The programmatic trends revealed by the collective work of programs such as the AIDD family support 360 demonstration projects, however, show that, going forward, the most effective efforts will emphasize important concepts such as the multiple facets of life, family-centeredness, effective collaboration, systems efficiency, and effective use of community assets.

Until recently, the needs of people with disabilities and their families were often measured and accommodated as though the facets of one's life (e.g., self, family, home, school, leisure) could be separated and treated in isolation. An alternative view places the individual within the full context of his or her life (Turnbull, 2004). Within a life-span framework, individuals with disabilities and their families are seen as continually developing entities that must juggle any number of variables to meet the challenges of life (e.g., job, health, family, personal, social). The challenge to policy makers is to view the needs of individuals with disabilities and their families in ways that stretch beyond a single, narrow life domain to involve services or supports that target multiple life functions.

Moreover, service systems must be purposeful in their provision of family-centered care. Service providers are urged to reconsider the common conceptualization of service delivery and consider the "client" as the family unit (Reinke, 2013).

Intentional partnerships among professionals, individuals, and their families will serve to promote the recognition and prioritization of families' unique needs, wishes, and cultural beliefs.

Because current service systems are terribly fragmented, people and families must negotiate across several service "silos," cobbling together what they can to meet their needs. Future service systems must seek new opportunities to weave together resources and offer cohesive responses to families' needs. Future systems must also pursue every opportunity to seek real value for the dollar. We must systematically disinvest from high-cost and/or low-value service options, investing instead in options that cost less, like in-home or family support, and bring the highest value.

Finally, future systems must seek to discover and utilize every capacity within our community. People volunteer daily to do any number of tasks for others, formally through structured groups or spontaneously through individual initiative. Beyond individual efforts, any community also has an array of other potential community-serving entities, such as churches, schools, colleges, businesses, libraries, neighborhood associations, clubs, recreational entities, and other community-serving organizations. Future systems must seek to forge reciprocal alliances with individuals and the vast array of community assets available to find additional means for supporting people and families.

Future Research Priorities

It is essential that we come to a consensus on the operational parameters that define the term *family support*. This will guide data collection on the very basics of state and federal investments in family support. To start, knowing the number of those living at home receiving services by age would provide a good platform on which to build. Next, learning more about the services these individuals and their families receive and the amounts spent to do so would add significantly to the database. Finally, targeted research is needed on specific practices used to support individuals and their families, consistent with a consensus understanding of the definition of family support to identify those practices carrying the greatest promise for success in meeting the needs of individuals and their families and also with regard to the most efficient and effective use of public resources.

In this context, the perspectives of people with IDD and their families who negotiate service delivery routines daily may be most helpful. Increasingly, individuals with IDD—the primary "end users" of service systems—are articulating their opinions about the lives they prefer and the supports they need. Likewise, for those families who provide daily care to people with IDD or who are deeply involved in the life of their family member, outcomes of services and supports are shared in the family unit, and their views carry great value as well. A key emerging question needing exploration is to tap into the expertise of individuals and their families as experts in that they use the system and are most familiar with the working parts of the process and are also familiar with where the process breaks down. Together, they may be considered field experts in services and supports, and the field will benefit tremendously from involving them in solution-generation activities as essential informative stakeholders.

Finally, while there are some national Internet-based studies of siblings, there is no national data on the demography of siblings of adults with IDD. Data on the extent that siblings are actually co-residing with their brothers and sisters with IDD would be useful. Additionally, nearly all of the studies are cross-sectional; more longitudinal studies across the life span would provide a better picture of long-term impacts on siblings and on transitions at various periods across the life course. Sorely lacking is the perspective of people with disabilities. We need information on their views of the relationships with their siblings and the supports they receive and provide for them.

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