

Constructing the New Service Paradigm: Responding to Today's Challenges

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In the 1970s, the only service available for people with intellectual and developmental disabilities (I/DD) and their families was placement in a large institution. Today, services are predominantly community-based. In just one generation our thinking about people with I/DD has been transformed. Today, nine states and the District of Columbia have no publicly-operated institutions dedicated to people with I/DD. In 2006, states spent over \$43.83 billion on services to people with I/DD. Of that amount, \$35.5 billion was targeted to community services.¹

Even when institutions were the only service option available, they were an undesirable alternative. Reluctant to send their children far from home, many families simply struggled on without public support. However, with the introduction of community group homes in the 1970s, families were provided a new and more attractive alternative. As the demand for community group homes began to grow, states felt increasing pressure to expand services. In 1981, Congress passed Section 1915(c) of the Social Security Act which created the Home and Community-Based Services Waiver program, also known as the Medicaid Waiver program. This program allowed Medicaid funding, which previously had been available only for institutional services, to be used for community services as well. Thus, the Medicaid Waiver program fuelled service expansion.

The Paradigm Change of Tomorrow

By the late 1990s, states were discovering a limit to their capacity to expand group homes. The aging of the nation's baby boomers was increasing both the demand for services and the competition for caregivers, while the number of people in the workforce available to work as caregivers was not growing commensurately. Frustrated by long waiting lists for services, in some states people began to file lawsuits.

The then current paradigm had been built on a residential model in which a service provider had 24-hour responsibility for all aspects of the person's life. But the high demand for services and the legal pressures compelled states to look for a solution—and that solution was to expand supports provided to people living at home with their families.

States had been providing family support services for many years, but those programs were often minimal and were generally limited to respite care and, in some cases, a small financial stipend. Now states realized that the federal Home and Community-Based Waiver program could also be used to provide services in a person's home. This meant

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that states could expand family support programs to cover a full range of services in addition to respite care, including day programs, therapies, family training, environmental modifications, and in-home support.

As a result of this expansion in home-based services, we are now witnessing another transformation in our state service systems. By 2007, the majority—a full 56%—of people receiving services from state developmental disability service systems were not living in residential programs but with their families.² Given the demographic and economic realities of our time, we will likely see this shift toward home-based services continue to grow.

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New Challenges

The shift in the service paradigm, to one in which adults with disabilities will live with their families well into their adult years, presents new challenges to states. What is the role of the state and service providers when family members are the primary caregivers? Where does the role of the family end and that of the service system begin?

Adults with developmental disabilities generally cannot declare their independence or strike out on their own; their everyday dependency on family members makes it difficult for them to rebel in the same way that other children do. A family that is caring for an adult child with a disability at home faces the challenge of helping that son or daughter become as self-sufficient as possible, while at the same time providing care and support to them—they are liberating their child even as they continue to be the primary support for that child. Families with children without disabilities do not face such a challenge; a family that is caring for an adult child with a disability may need help not only in meeting this challenge but also in recognizing it.

The National Core Indicators Project

What do we know about people living with and getting support from their families? The National Core Indicators (NCI), a project of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Resource Institute (HSRI) has been collecting data on the performance of service delivery systems for people with I/DD since 1997. An annual survey of individuals and families receiving services in each participating state provides reliable data on a wide array of topics, including individual and family demographics, personal outcomes, and system performance.

The 2007 National Core Indicators Adult Family Survey Final Report – April 2008 reveals a great deal about people with I/DD living with families.³ The 25 states that participated in the NCI project in 2007 reported that the annual income of 50% of families was under \$25,000, 62% of family caregivers were over the age of 55, and some families who had a family member with a disability living with them felt isolated and cut off from their communities. People with a disability living with their families reported being less lonely, happier, and liking where they were living more than people living in residential settings. However, the report also tells us that people living with their families are not as likely to recount having a best friend, not as likely to be able to see friends when they want to, and more likely to say they don't have any friends. Compared to adults in other residential settings, people living with families are also less likely to have had a physical exam in the past year, less likely to have had a gynecological exam in the past year (if female), and less likely to have been to the dentist in the past six months.

The Importance of Family

The family is the core unit of our society. Within the nurturing environment of family life, we develop our identity and our self-confidence, we perfect the ability to get along with others, we discover our capacity to love. Home is the safe harbor within which we can grow. Unfortunately, sometimes families cannot meet the need of every family member. Extended family, friends, and community services, such as schools and medical facilities, make up a larger support system which stands a greater chance of meeting these needs.

It is also true that home can be a place where family members can be at risk of harm. Protective service statutes and reporting systems have evolved in response to this unfortunate reality. People with developmental disabilities are often ill-equipped to protect themselves, to seek safety, or to report abuse.

What is the role of the state and individual providers when family members are the primary caregivers? Can we ensure that people living with their families have a say in decisions that affect them, that they get routine medical attention, that they have opportunities to make friends outside the family, and that they have a good diet and get exercise? Can we facilitate a life outside the family home—one that includes a job and friends? Can we assist in resolving conflicts as the family struggles to meet everyone's needs? Can we protect individuals with developmental disabilities from harm? The answer to these questions is of course—"we must." State agency personnel and service providers must learn about the complexity of family life for parents and other family members and for the individual with disabilities, and must be prepared to serve them appropriately.

Providers and support coordinators need training to understand the experience of people with disabilities and their families, and they must develop the skills needed to negotiate the complex and ambiguous territory of family dynamics. In situations of conflict, they must learn to stay focused on the point-of-view of the person with a disability, even as they work to meet the needs of the whole family. Caregivers and supporters must learn to collaborate with families—as well as to respectfully challenge them on behalf of the person with a disability. They must learn to recognize stress in the family and to anticipate a family's need for assistance.

And what happens when the parents of adults with disabilities can no longer provide supports? In the first half of the 20th century, when parents began to consider their own mortality and sought to plan for their child with a disability, they placed the responsibility on the siblings if they were present. But as the service system changed in the latter half of the 20th century, parents shifted their expectations to the public system and often spoke of not wanting to burden their other children with the care of the disabled sibling. But in this area, too, the paradigm is changing. As more

and more children with and without disabilities grow up together at home and in schools, siblings or close relatives are increasingly taking an interest in the sister, brother, or cousin with a disability and want to be involved. If, once the parents have passed away, the same supports can continue for other family members willing to open their homes and provide support, we may find far more siblings willing to be the primary caregiver for their brother or sister with a disability.

Individual and Family Control Over Services

In addition to the demand for expanded services, people with disabilities and their families also expect to have more control over the services they receive. The authority to hire and fire caregivers and to control a budget are the essential elements of “self-directed services.” As of January 2009, 13 states offered individual budgets and consumer control for at least some individuals and 11 states had a consumer-directed option available to a small number of people in a limited geographic area as a pilot project.⁴ Studies conducted of self-directed services demonstrate both high levels of satisfaction and significant cost savings as people take more responsibility for how their resources are utilized.⁵

In the developmental disability field, consumer-directed services is a necessary component of what is referred to as the “right of self-determination”—the right of people to control where and how they live their lives. People and families who rely on publicly funded services have often found their capacity to control their lives hampered by inflexible service provider rules and state service systems.

Giving people the ability to hire and fire support staff opens the possibility of hiring people who might otherwise not work in the human service system—neighbors, friends, and even family members. This option expands the pool of people available to provide supports, in addition to also opening up many possibilities for people with disabilities and their families. Self-directed services are also a partial solution to the shortage of available workers to provide services. In addition, having control over a budget has enabled people with disabilities and their families to use services when they need them, to “save for a rainy day”—i.e., a time when family situations demand a higher intensity of services.

Self-directed services require that states have necessary infrastructures in place to determine appropriate levels of funding, to assure that IRS rules are adhered to, to make certain that caregivers are appropriately trained, and to guarantee accountability for funding. Above all, state developmental disability agencies are responsible for overseeing the quality of services that are being provided and ensuring that individuals with I/DD are living the lives that they want to be living.

Guidelines for Creating the Service Paradigm to Support People and Their Families

Our state service systems will continue to maintain out-of-home residential service options. But, recognizing that families are the primary support system for people with disabilities, we must design the service system with this fact as a core concept. This will likely require instituting new practices, developing new training, establishing new standards for services, and thinking differently about the provision of services. To achieve the goal of providing supports for individuals with I/DD living at home, we will need to:

- Start planning early with the person and their family. Connection to the service system and the benefit of some basic services early on will give families confidence that the system will be there for them throughout the future. Early contact can facilitate the transition from school to adult life and a job.
- Think of family in broad terms and build relationships with the entire family network: include parents, siblings, grandparents, other relatives, and friends.
- Focus both on the desired outcomes of the person with a disability and on the needs of all the family members. Remember that a person with a disability lives in the context of their family. Be prepared to negotiate and facilitate during service planning sessions in order to identify and reconcile the needs of the person with the disability with those of the whole family.
- Remember that adults need relationships and activities outside the home, including:
 - Employment—a competitive job at a competitive wage is the pathway to independence and community participation.
 - Friends—making friends and spending time with them provides both fun and support.
 - Organizations—participation in self-advocacy organizations offers an opportunity to meet others with similar interests and concerns and to solve problems together.
 - Community—participating in community life by joining community organizations, attending events, and volunteering expands a person’s network of support.
- Use innovation. Be prepared to offer individuals and their families the opportunity to direct their own services, control an individual budget, hire friends and relatives, and explore home ownership.
- Develop and maintain strong support/coordination services to assure responsiveness to families. Limit the size of the support coordinator’s caseload. Offer training in family systems and provide meaningful supervision. The support coordinator’s role is a high-stress position but it is the one most critical to preventing crises or breakdown in the family support structure.

The New Question

Service systems in the 20th century evolved in response to events, pressures, and opportunities. But rapid development prevented leaders from paying adequate attention to determining the service paradigm and to building the infrastructure necessary to support it. In 2009, we can see that another change is upon us. We know that for the next generation the role of families will be essential in providing

support for people with I/DD. Ultimately, the question is not whether people with I/DD will be living with and relying on their families for support—they most certainly will. Rather, the real question is whether the person with a disability and their family will continue to struggle, and sometimes fail, alone, or will that adult son or daughter with a disability have a good and successful life because of the supports we have planned for and made available to them and to their families? **NCMJ**

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