



INFORMATION BRIEF

Working Toward Sustainable Futures:

Establishing a “Next Generation” of Family Support Services

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Over the past three decades, government authorities have made significant progress in establishing comprehensive service systems to support citizens with developmental disabilities. Presently, however, this trend is facing formidable economic and structural challenges and policy makers are increasingly being pressed to re-structure service systems to realize greater efficiencies.

Within this context rests the nation’s state family support systems. Most were developed in the 1980s and early 1990s with the intent of targeting children birth through 18 years old living at home. The programs varied greatly but generally they sought to do “whatever it takes” to assure that children could grow up with their families and that families could have a life like other families in their communities. These services, like others within state systems, are being closely examined and altered given changing circumstances.

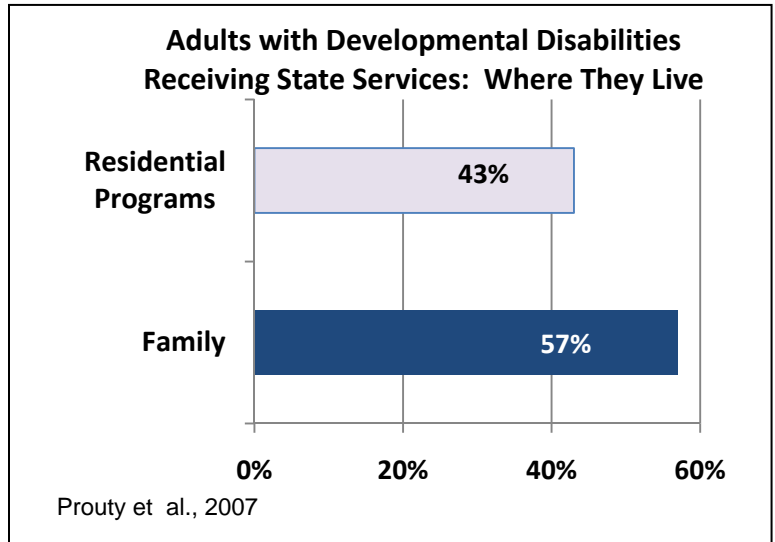
Yet change imposes choice. As we build the “next generation” of family support, partnerships and collaboration will be in the forefront. Families and self-advocates have their unique perspectives as users of services (or as those who are not being served at all). Policy makers have the perspective of those who design programs that are bound by the rules and parameters governing the funds that pay for the services. The next generation of family support systems requires that all perspectives be brought together to identify needs, examine barriers, educate one another about the realities of the “day-to-day,” and to come to reasonable consensus about how to move forward together. Perhaps, not everyone will get what they want, but each will have the opportunity to work together to carve out solutions within the realities that exist so that needed changes in policy and practice can be made at the local, state, and national level.

Within this context, we also understand that families and self-advocates, as the ultimate “end-users,” of the service system, must play a strong leadership role in shaping the policy choices and practices that define the next generation of family support. After all, these individuals are themselves the next generation of family support recipients.

What follows is a fuller explanation of these core themes, including: (a) descriptions of the challenges faced by a “next generation” of individuals with developmental disabilities and supporting family members, (b) challenges facing policy makers to support individual and family needs, and (c) concluding remarks.

A “Next Generation” of Children with Developmental Disabilities and Families

Depending on the definition of “developmental disability” used, prevalence studies suggest that approximately 5 million of 300 million Americans have a developmental disability. The great majority of these individuals live at home with family members. The younger the child, the more likely he or she is to be at home. Even among adults receiving developmental disability services, recent research shows that 57% live at home, and five states report that 70% or more of all people receiving support resided with their families (Prouty, Smith & Lakin, 2007). Given the growing demand for services, the limited availability of direct support staff to work in residential facilities and growing fiscal concerns, we will see growth in the percentage of people living with their families well into their adult years. This is important to note given that states are increasingly seeking to support individuals of all ages living in family households.



Providing support at home to an individual with developmental disabilities can be a challenging task. As with typical families, no two people with disabilities or their families are exactly alike. Moreover, the meaning and structure of what a “traditional” family is have evolved and must be addressed in a culturally competent manner. A person with a developmental disability may live in what we may conventionally think of as a family -- two biological parents and perhaps brothers and sisters. Or they may be living in a household headed by siblings, grandparents, or other extended family members. They may share a household with a spouse and perhaps their own children.

Likewise, families may include individuals of varying ethnic origins, pressing service systems to accommodate varying languages and customs. Some, too, may be very difficult to reach, given residence in rural areas or even in urban areas that are hard to penetrate.

Moreover, because states are increasingly targeting individuals “from birth to any age,” families will include support-givers of varying ages, some young and others past retirement age. Their needs, as well as those of their family member will likely be affected by their place in the family’s lifespan. Finally, families may have unique circumstances that must also be addressed, such as families where a parent is serving in the military, or where the support-givers themselves have disabilities.

Each family has unique needs, strengths, capabilities, and preferences. Yet many families find that the “ordinary” challenges faced by others can become “extraordinary” when providing support to an individual with disabilities at home.

Contemporary family life already poses significant day-to-day obstacles. Having a family member with a disability, however, often complicates matters. The difficulties experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of challenging behavior, family characteristics, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community supports. As a result, though not all families who provide support at home have extraordinary problems, all are more "at risk" for having more

difficulties than families without members with disabilities. For instance, research shows that families may experience one or more of the following challenges:

- *Natural reactions* to the discovery that a family member has a disability, including a sense of shock or numbness, denial, grief, shame, guilt or depression. These natural feelings are also sometimes accompanied by social isolation brought on by negative or stigmatizing reactions of neighbors, extended family or other community members.
- *Chronic stress* that can affect family interactions and functioning. Such stress may be felt within the parental marital relationship, given a need for both parents to adjust to their child’s disability and to take on new roles. Likewise, siblings of children with disabilities may also experience a variety of stressors.
- *Changes in lifestyle* often affecting established social relationships within the family or with others, which may result in isolation from their personal or larger communities.
- *Difficulty in undertaking family routines* such as shopping and house cleaning, or in finding ample time for recreation.
- *Difficulty managing relationships between brothers and sisters and the individual with disabilities.* Certainly, brothers and sisters can be a great source of support within a family. Sometimes, however, families have difficulty reconciling between disability related support demands and the needs of other family members.
- *Financial costs, or lost opportunities for employment or education.* Families frequently report that there are numerous out-of-pocket expenses associated with providing care at home for a child with disabilities. The costs can be relatively low, yet persistent and ultimately significant (e.g., for diapers), or quite high (e.g., home barrier removal).

Added to the out-of-pocket expenses are the various *opportunity costs*, most often tied to lost chances for a job or advancement. Very often, someone must stay at home to provide support. Inevitably, the lost opportunities translate into reduced family income.

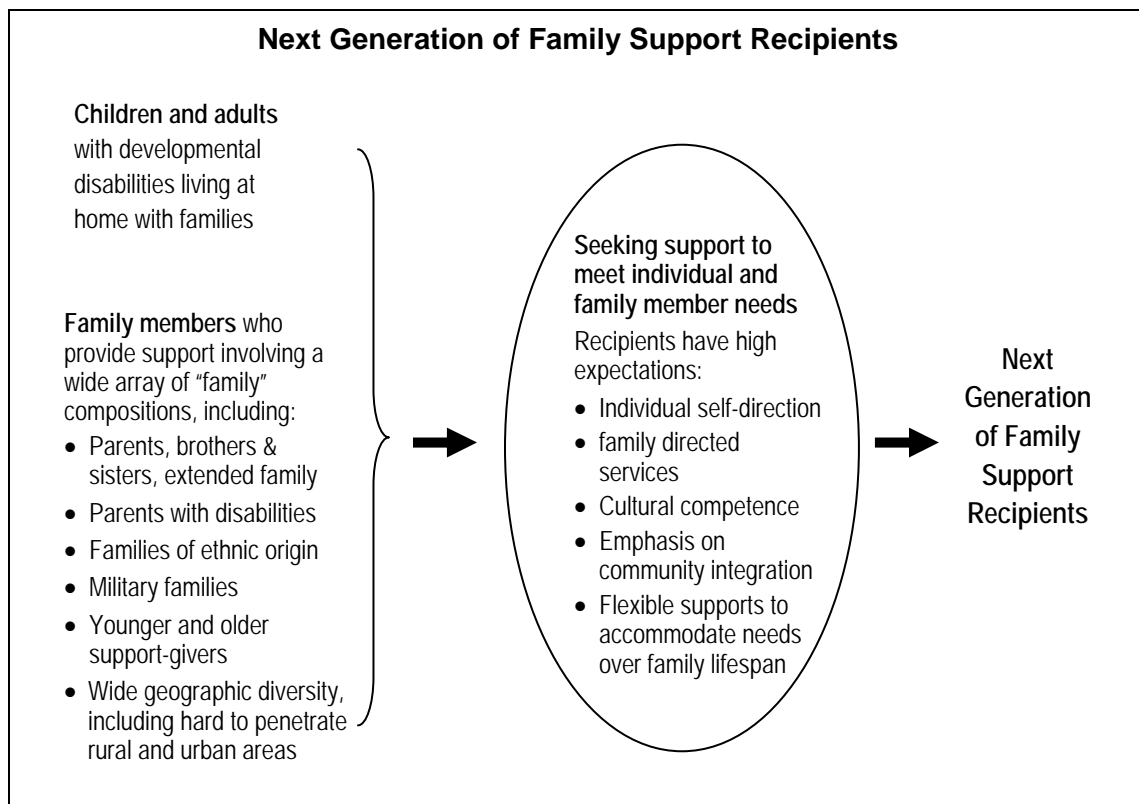
- *Extraordinary time demands* involved with providing personal support to the family member with disabilities, finding needed specialized professionals, or negotiating bureaucratic systems.
- *Difficulty with physical management* (e.g., lifting, carrying). As the child ages, so do parents. The combination can result in increasing difficulty with providing needed care.
- *Lack of skills needed to cope* with potential medical emergencies and/or to teach necessary adaptive skills.

Within this context is the individual with developmental disabilities. Typically, these individuals want a full and rewarding life just like any other person. Young children attend school, seek playmates and enjoy participating in their communities. Teens seek separation from their parents, look forward to the transition to adulthood, and along the way, also create anxieties for their parents. Adults want to go to school or find a good job and make decisions for themselves. Many eventually want to live away from parents and even build their own families. All want to live their life in the community with the support they need. Still, these individuals often have needs in one or more of the domains listed below.

- *Assistance with life threatening health impairments:* Several types of disabilities require frequent monitoring of medical conditions and require that caretakers be knowledgeable and adept in coping with chronic medical needs.

- *Help with learning adaptive skills:* Individuals with intellectual disabilities may have trouble learning new skills, while others with physical disabilities and no intellectual disabilities may acquire skills at a slower pace due to their physical condition.
- *Help with undertaking various activities of daily living:* Individuals with disabilities may have difficulty with completing a variety of everyday activities such as toileting, eating, bathing or communicating.
- *Help with developing a life outside the family,* such as making friends with others his/her age or getting to participate in typical community activities. This issue may intensify as the child grows into an adult, brothers and sisters leave home, and parents age.
- *A need for specialized support:* Individuals with disabilities may require specialized therapies (e.g., communication training or physical therapy, prosthetics).
- *Support and treatment for behavioral health problems:* The inability to grasp concepts quickly, diminished capacity to communicate or the frustrations of having a disability can result in challenging behavior. An individual may disrupt household routines, inflict harm on others or self, destroy objects or surroundings, or otherwise pose a behavioral threat.

As illustrated by the graphic below, the next generation of family support service recipients will look a lot like past generations, but with important differences. After all, families are families and people with developmental disabilities will have fundamental core needs that know no generational differences. This next generation, however, is more diverse in terms of its composition and ethnicity. Further, this generation of adults is more likely to have been included in school, and have high expectations for living a life in the community like any others with the support they need. Support-givers and individuals with disabilities will vary considerably in age. Families additionally will not be so easily reached given residence in rural or hard to penetrate urban areas. Finally, some families will pose unique circumstances (e.g., military families).

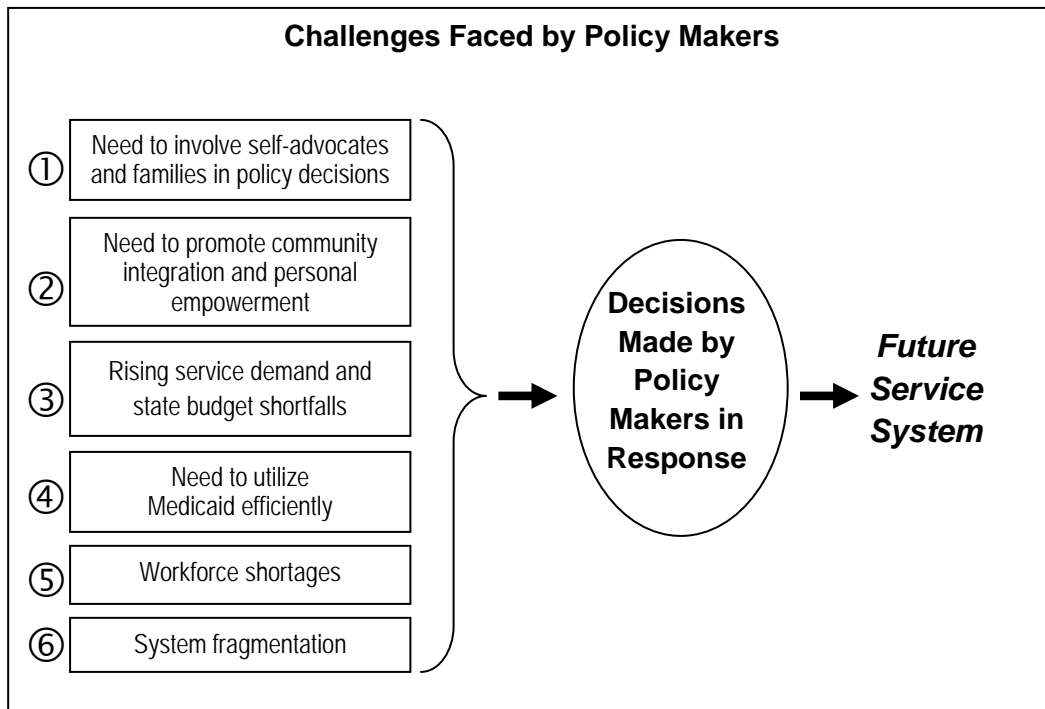


Challenges Faced by Policy Makers Seeking to Address Service Needs

Over the past three decades significant progress has been made at the federal and state levels to establish comprehensive systems supporting children and adults living at home. State government’s interest in supporting families began in the early 1970s. Pennsylvania developed one of the earliest family support initiatives for children with mental retardation in 1972 and over the next two decades all other states including the District of Columbia fielded some type of family support for children. At least 35 states now have legislative mandates on family support targeted at children. Likewise, states have increasingly shown interest in supporting adults with individuals living at home, as well as their families

Further, the use of Medicaid waiver funding to finance family support is increasing as well as the identification of a range of generic and informal community supports that can be mobilized on behalf of families. While family support is not yet the "law of the land," the idea continues to gain momentum, as well as needed political and financial backing.

While much has been accomplished, there is still much to do. The current policy environment presents formidable challenges to policy makers committed to supporting families of children and adults with developmental disabilities living at home. It is important to realize that policy makers in each state are everyday working to address the challenges before them. In essence, they are already designing and implementing a next generation of family support.



To move forward, as illustrated by the graphic above, six related issues must be taken into account.

1. Need to involve people with disabilities and family members in shaping policy and practice. The cornerstone to the family support movement has been the family itself. Family members have worked hard to educate policy makers across the country on family support issues, and enjoyed great early success. Working with families, states developed a variety of innovative policy responses to address support needs. Several states, for example, established family support councils to help

guide the way and established practices to enable families to lead the service planning and delivery. Touchstone phrases like “family-driven” and “family-directed” came to characterize the most progressive efforts.

Regarding specific practices, some developed “cash assistance” programs to offset care-giving expenses (e.g. IL, OK, MI, IA, KA), utilizing cash stipends, vouchers or other reimbursement means. Others typically defined “family centered” supports planning processes that resulted in family members, not just the individual with disability, having access to an array of flexible supports. In addition, the best programs sought flexibility to accommodate a wide range of needs, including rather unique ones.

Within this context, emerging best practice centered on “self-determination” principles suggests that individuals with disabilities must also have a strong say in shaping disability policy and practice. After all, these individuals are an intrinsic part of the “family” and are actually at the center of the service delivery process. Increasingly, individuals with developmental disabilities (i.e., “self-advocates”) are speaking up to make their preferences known. It is, after all, important to accept that the opinions of care giving family members and individuals with disabilities may sometimes differ. We view these potential differences as an opportunity to facilitate reconciliation between families and self-advocates, resulting in an effective alliance.

Going forward, it will be essential to maintain the strong involvement of family members in shaping policy and practice, and to add to these voices those of self-advocates. The challenge to policy makers is to create meaningful opportunities for these voices to be heard and factored into policy decisions. Where such investment is lacking, family members and self-advocates will be hard pressed over time to influence the very system that affects their lives day-to-day.

➤ The “*next generation of family support*” must assure that family members and self-advocates are involved with setting policy and practice that affects their lives.

2. The need to promote community integration and personal empowerment. Over the past 30 years, best practice in the disability field has shifted away from a reliance on facility-based or congregate service approaches. Instead, current planners and providers emphasize the promotion of community integration and person-centered supports.

Until recently, however, professional judgment was more influential in decisions about the character of services and supports than were the choices and preferences of service recipients. In addition, the choices available to people with disabilities and their families were restricted to choices among items on a limited menu.

Emerging practice, however, suggests that family members and people with developmental disabilities must play leading roles in determining the substance of their lives, and that relevant and preferred supports should be provided as needed. Moving past traditional professional or industry-dominated approaches, the field is becoming more responsive to the demands of service recipients.

Family support practices have long reflected this primary principle. Phrases such as “family-directed” or “family-driven” reflect the level of empowerment sought. More recently, policies surrounding adults with disabilities have embraced this principle as well. Whether or not the individual resides at home with parents, the idea is to promote and honor self-determined lives. Here phrases like “self-directed” or “participant-directed” are used to illustrate the empowered role adults with disabilities may play in controlling their own lives.

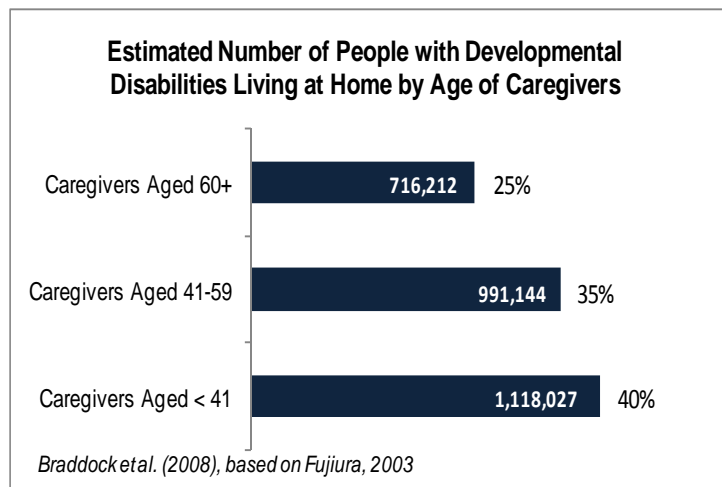
It is typical in our society that children grow and in their early twenties leave home. Parents provide support and protect their children, and as their children grow they expect growing independence and autonomy. Typical parents come to accept the individuation of the child. Yet adults with disabilities cannot so easily push away from family and home. They depend on the family for support and have no capacity to “run away” or “strike out on their own.”

Family Support practice must include strategies to assist families to recognize the stages of growth and development so that they can respect and support their children to be adults. Issues such as choice of friends, activities, sexuality, and managing funds, all challenge parents whose instincts and habits are to provide care and protect their child.

- The “*next generation of family support*” must have embedded in it ways to assure that family members and self-advocates can choose and direct the supports they receive. After all, research consistently shows that support is most effective when the receiver of such support can exercise control over it. In addition, family support practices must also help the family to support their child’s psychological and emotional development as they grow from children into men and women.

3. Increased demand for services coupled with present and forecasted state revenue shortfalls, resulting in enduring waitlists. Most of the 5 million people with developmental disabilities in the United States are supported by their families or live independently without specialized publicly-funded developmental disabilities services. Public developmental disabilities service systems provide services and supports to a relatively small percentage (about 20-25 percent) of all individuals with developmental disabilities. Public systems focus principally on people who have significant functional limitations and who require services over and above the supports that their families are able to provide or that they can obtain through generic human services programs.

Demand for publicly-funded developmental disabilities services is growing nationwide. Generally, it has been increasing at a rate greater than population growth alone. This increase in service demand is the product of several factors. One of the most important factors is the increased longevity, as the result of better health care, of people with developmental disabilities that is approaching that of the general population. This increased longevity has two ramifications for developmental disabilities service systems: (a) turnover among individuals receiving services is reduced (and, thereby, there is less capacity to absorb new demand), and (b) there is a growing cohort of individuals who live in households with primary caregivers who are themselves aging. Already, as the graphic above shows, about 25% of people with developmental disabilities living at home have caregivers over age 60.



Establishing a “Next Generation” of Family Support Services

In addition, each year, significant numbers of youth with developmental disabilities exit special education systems and need ongoing services and supports as young adults. Other people seek services because their families cannot continue to support them or need extra assistance. It is not uncommon to observe year-over-year increases in the expressed demand for developmental disabilities of 4 percent or more.

At present, the challenge these circumstances place on policy makers is compounded by a weak economy resulting in state revenue shortfalls. McNichol & Lav (2008) at the Center on Budget and Policy Priorities report that 43 states presently forecast state budget gaps totaling over \$78 billion, with three additional states (MO, TX, WA) anticipating gaps in 2010. Many of the states listed in the Table have already cut public health programs, K-12 education, higher education, and state workforce levels. In addition, programs for seniors and people with disabilities have not been immune. At least seven states are cutting medical, rehabilitative, home care, or other services, or significantly increasing their cost to individual recipients.

SIZE OF TOTAL FY2009 BUDGET GAPS

State	<i>Total Budget Shortfall for FY2009</i>	<i>Gap as Percent of FY2009 General Fund</i>	State	<i>Total Budget Shortfall for FY2009</i>	<i>Gap as Percent of FY2009 General Fund</i>
Alabama	\$1.2 billion	15.00%	Mississippi ¹	\$114 million	2.20%
Arizona ¹	\$3.1 billion	30.80%	Missouri	\$342 million	3.80%
Arkansas	\$107 million	2.40%	Nevada	\$1.4 billion	19.60%
California	\$30.6 billion	30.30%	New Hampshire	\$250 million	8.00%
Colorado	\$99 million	1.30%	New Jersey ¹	\$3.7 billion	11.40%
Connecticut	\$542 million	3.20%	New Mexico	\$253 million	4.20%
Delaware	\$369 million	10.10%	New York	\$6.4 billion	11.40%
D.C.	\$227 million	3.60%	North Carolina	\$800 million	3.70%
Florida	\$5.5 billion	21.50%	Ohio ¹	\$1.9 billion	6.80%
Georgia ¹	\$2.7 billion	12.90%	Oklahoma	\$114 million	1.70%
Hawaii	\$232 million	4.00%	Oregon	\$142 million	2.10%
Idaho	\$131 million	4.40%	Pennsylvania	\$565 million	2.00%
Illinois	\$3.8 billion	13.40%	Rhode Island	\$802 million	24.50%
Iowa	\$350 million	5.50%	South Carolina	\$804 million	11.70%
Kansas	\$137 million	2.10%	South Dakota	\$27 million	2.20%
Kentucky	\$722 million	7.80%	Tennessee ¹	\$1.2 billion	10.40%
Maine	\$265 million	8.60%	Utah	\$354 million	5.90%
Maryland	\$1.3 billion	8.80%	Vermont	\$122 million	10.00%
Mass.	\$2.6 billion	9.20%	Virginia	\$2.2 billion	12.80%
Michigan	\$472 million	4.80%	Washington	\$413 million	2.70%
Minnesota	\$ 1.4 billion	7.90%	Wisconsin	\$998 million	7.10%

States generally operate their developmental disabilities service systems under fixed capacity limits. Only a handful of states (e.g., AZ and CA) provide 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. Already, Prouty et al (2007) reports that nationally 88,349 people are on wait lists for out of home residential services. To meet this need, we would need to expand our residential systems by about 20%.

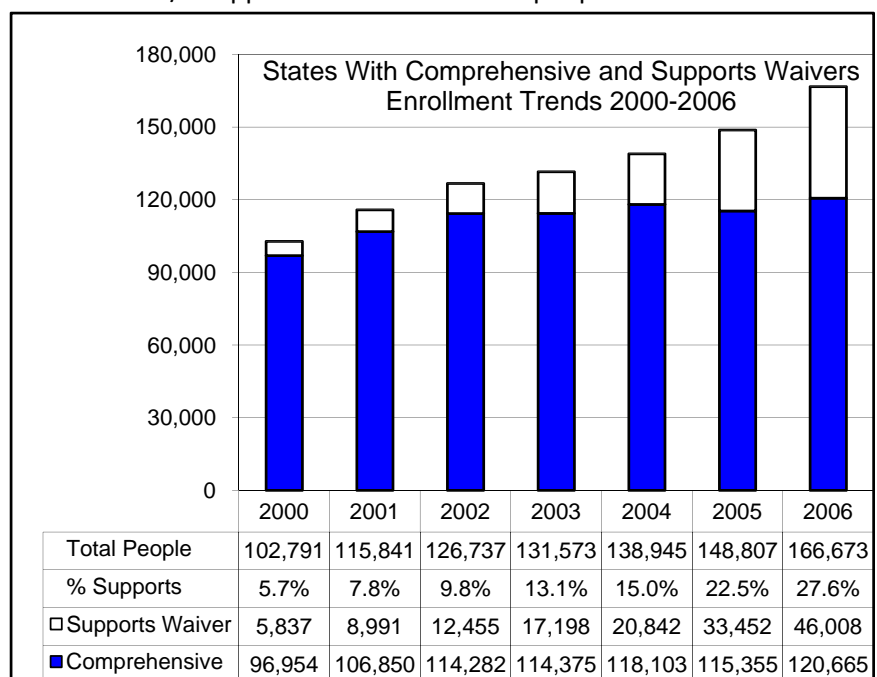
- Given the budget shortfalls faced by states, policy makers will be even harder pressed to address rising service demand. As result, the “next generation of family support” must address this significant challenge.

4. Need to utilize Medicaid efficiently. Medicaid serves as a primary funding engine for developmental disability services. States use state funds to earn Medicaid Match of between 50% and close to 80%, depending on the state. Presently, states utilize about 78% of their available funds for developmental disabilities services to match for Medicaid reimbursement. The total in play for the services amounts to \$43.83 billion in services in Medicaid programs (Braddock et al., 2008).

These programs can include ICF-MR services, but more often involve use of the Home and Community Based waiver authority. Waiver initiatives in states presently serve about 450,000 people nationally. Most are served with “comprehensive waivers” that can offer a wide array of services, including out-of-home residential services offering 24/7 support.

Increasingly, however, 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 (Smith, Agosta & Fortune, 2007). Most significantly, these waivers do not offer residential services or 24/7 support and the number of people served is capped, as is the amount of money that may be allocated to the individual. Typically, as by the accompanying graphic, the amounts allocated per individual are far less in supports waivers (on average \$14,000 per person annually) than that allocated to individuals served within comprehensive waivers (about \$47,000 on average per person annually).

This strategy allows policy makers to stretch the resources they have and



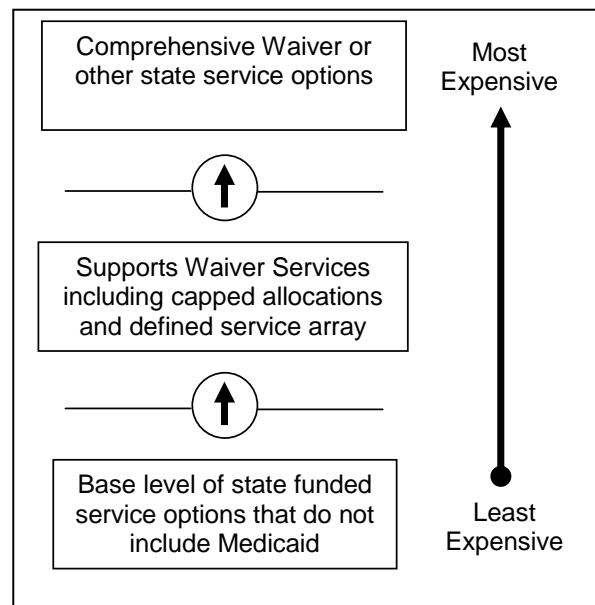
reach more people, most notably people living at home with an array of “in-home supports.” Seventeen states presently administer supports waivers with other states seeking to do so. As illustrated by the graphic above, supports waivers are increasingly carrying more of the service load in states.

Medicaid is a dominant presence within the developmental disabilities field. 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. Consider that:

- Medicaid can only serve the “beneficiary,” which is to say “the individual with disabilities.” “Families” do not qualify for Medicaid.
- Not everyone is eligible for a Medicaid waiver.
- Not everyone can get into a waiver even if they are eligible. There are wait lists.
- Medicaid doesn’t meet every need a person/family has. As a result, human needs in systems tend to be recast as “what is Medicaid reimbursable.”
- *No matter how much money we have, it will never be enough to meet present and future service demand.*

Still, Medicaid is an essential component to any state’s support system. A major challenge for states is determining how to incorporate support waivers in the larger service system so they will complement comprehensive waivers and other state-funded options to create a seamless, cost effective approach to supporting people with disabilities in the community. Currently, states are using supports waivers as one service option among several to primarily address cost containment and wait list goals.

Several state leaders, however, view supports waivers as an option within a range of supports that includes the comprehensive waiver and other state funded options, configured from least to most costly (see graphic). Ideally, these options would fit together to provide a seamless, cost effective approach whereby individuals would be matched to the option that most effectively meets their needs. Individuals might start by securing modest amounts of state funded services that may suffice without any use of waiver services. If more supports are needed, individuals could be enrolled in a supports waiver. Finally, if still more supports were needed the individual could be enrolled in the more costly comprehensive waiver.



- The “next generation of family support” must include efficient use of Medicaid, but cannot rely exclusively on this funding resource. We must find ways to complement Medicaid with other available resources.

5. Need to address workforce shortages. Direct support professionals form the core of the nation’s long term support system. After family members, these workers provide a large share of the hands-

on support needed by people with developmental disabilities. And they are increasingly hard to find.

Chronic low wages and meager benefits along with sometimes difficult working conditions make recruitment and retention of workers difficult, even when unemployment rates are high. Today, many policymakers, service providers, self-advocates and family members describe the problems with attracting and retaining workers as a crisis. Finding a qualified worker has become a second-order priority. Instead, recruiting “anybody at all” to provide the support has become the primary goal for many. This includes families and self-advocates living at home who may qualify for services (e.g., respite support, personal aides) but cannot find anyone to provide support. Family members often report, for instance, that finding respite workers is nearly impossible. Likewise, self-advocates report great difficulty with finding personal aides to provide essential support.

Given present population demographics, including an aging labor force and increased demand for workers across disciplines to work these and other related jobs, difficulty in recruiting direct support workers is likely to worsen over time as the number of people needing long-term supports increases relative to the population.

These circumstances lead us to conclude that even if we could afford to pay for 24 hour out-of-home residential services for everyone, we very likely would not be able to find the staff to fill the jobs. And so, going forward, how will we support children and adults with developmental disabilities living at home with family members?

- The “*next generation of family support*” must generate new sources of support for people, beyond relying exclusively on paid workers made available through the traditional service system.

6. Need for improved interagency collaboration. It has become obvious that effective responses to human needs often cut across multiple public agencies. Moreover, there is a growing awareness that the array of services developed over the past three decades lacks cohesion and has created a patchwork of fragmented services. For instance, in a report to President Bush entitled *Delivering on the Promise*, the U.S. DHHS (2002) reported that a significant barrier to success is the fragmentation in our service systems that frustrate service recipients and policymakers alike. DHHS reports that approaches to financing and managing long term care services and supports results in compartmentalized programs that force individuals and their families to piece together supports as best they can.

This outcome is generally viewed as fiscally inefficient by policy makers and unsatisfactory to individual service users. Far too often family members and self-advocates are challenged to negotiate multiple agencies at once, often a frustrating task and made more so when the policies of one agency seem to conflict with those of another.

In response, there is a call for improved coordination and collaboration within the public sector, and the expanded use of community supports available through the private sector and within informal helping networks. This point is made even more salient when today's concerns over state budgets are taken into account. No single state agency should be counted on to configure and administer a comprehensive family support program on its own.

An effective response that takes full advantage of all available resources will require teamwork among state agencies. The service systems most frequently called upon to participate in these

collaborations are education, health and mental health, child welfare, developmental disabilities, and juvenile justice. Given the emphasis at ADD for family support, this certainly includes State Developmental Disability Councils, Protection and Advocacy systems and University Centers on Excellence in Developmental Disability Services. As a result, policy makers and researchers alike must focus on the need to breach the gaps among categorical programs, combine funding streams, and coordinate teams across administratively separate agencies.

Yet nationally, states have been slow to react to this necessity. Even while states may sponsor multiple efforts to support families, existing programs generally operate independently from one another and without any apparent tie to some underlying set of principles or objectives that would blend these resources into a single cohesive response to families. While the current times call for coordinated effort and efficient team work, states find their family directed resources scattered and unfocused.

- The “*next generation of family support*” must equally work at assuring that public agencies are acting most efficiently to meet individual and family needs. ADD’s Family Support 360 projects have focused hard on this particular challenge.

Addressing These Challenges by Launching the Next Generation of Family Support

Leading policy makers understand that individuals with developmental disabilities who live at home have specialized needs, as do their families. Over the past three decades, the nation's response to these individuals and their families has shifted dramatically. In the past, families had two stark choices: to place their family member with a disability in an institution or keep the family member at home with little or no support. Times have changed. There is now a diverse array of Federal, State and privately funded community programs for children with disabilities and their families that together can provide multiple and diverse supports.

A broad and flexible menu of services is necessary because family support means different things to different families. The guiding premise, therefore, of progressive and responsive family support programs is to provide *whatever it takes* for individuals with developmental disabilities and their families to live as much like other families as possible. We understand that the number of needs that individuals and families have should not be confused with the magnitude of any single need or the degree of its impact. The needs of individuals and families are complex and cannot be simply categorized into a small number of service options (e.g. in-home or facility-based respite care). Family supports must be flexible enough to accommodate any individual and family on their own terms and in ways that enable and empower the individuals and family members to take control of the help they receive.

More specifically, the term “family support” means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to:

- support families in the efforts of such families to raise their children with disabilities in the home;
- strengthen the role of the family as primary care-giver for such children;
- prevent involuntary out-of-the-home placement of such children and maintain family unity; and
- reunite families with children with disabilities who have been placed out of the home, whenever possible.” 42 U.S.C 15092 (a)(3)

Given these underpinnings, the best family support systems already in operation across the nation have a number of common features, such as:

- *Principles to guide program operations.* There is a clear need within states for a set of "framework principles" to guide the design and delivery of services. Dunst, Trivette & Thompson (1990) provide an analysis of these principles by sorting them into six categories, including those that: (a) enhance the sense for community, (b) mobilize resources and supports, (c) emphasize shared responsibility and collaboration, (d) protect family integrity, (e) call for supports to strengthen family functioning, and (f) emphasize certain preferred practices, such as those where individuals are *enabled*, but also are free to *exercise their power* -- to be empowered. Families and individuals, after all, are the leading experts regarding their own life circumstances, needs and preferences.
- *Family and personal control and oversight at the state and local levels.* In effective family support systems family members and individuals with disabilities play a vital, if not leading role, in the decision-making process. Family members and individuals, who are the recipients of family supports, must take the lead at both the state and local levels through participation in state and/or local opportunities to guide policy and practice.
- *Complementing administration and practice.* Establishing rules and practices that are consistent with stated purposes and directions is also a challenge. Above all, program actions must minimize the cost -- financial and otherwise -- to families and individuals for seeking and acquiring the support they require. Aside from procedures to *determine eligibility and enroll individuals* into the program, service practices must be *family and individual focused and flexible*, and must *utilize existing community resources*.

While state family support programs vary considerably in their design, the programmatic trends clearly favor: (a) *simplicity* to assure that the program is easily accessed and used, (b) *widespread availability* (c) *flexibility* to accommodate the existing diversity in family configurations and needs, and (d) a *willingness to have individual families play a leading role in deciding what supports are needed* (Agosta & Melda, 1995).

ADD's interest in family support dates back to the early 1980's when it funded numerous initiatives to help families and state leaders work together to establish inaugural family support systems – including the support of HSRI to educate policy makers around the country regarding the needs of families. ADD's recent efforts are closely related to the “Families of Children with Disabilities Supports Act of 1994.” It was authorized to be appropriated for Fiscal Year 1995 within Part I of the Individuals with Disabilities Education Act. It was never funded and the authorization ended in October 1998. Several of the principals associated with this proposal were closely involved with developing this legislation, and so have distinct knowledge regarding its origins and intents.

While the original Act was ultimately not implemented within the framework of IDEA, it was placed under the authority of ADD within Title II of the Developmental Disabilities act of 2000. The Act stresses a number of strong policy principles. For instance, the Act emphasizes: (a) family involvement as leaders in all decisions related to family support policy and practice, (b) innovation in delivering flexible supports to families, (c) collaborative effort across human service agencies, and (d) fiscal responsibility tied to developing efficient, yet effective means for supporting families.

The current ADD initiative to create “one-stop centers” to assist the families of those with developmental disabilities builds on this tradition. These centers were initiated through planning grants

in 2004. The resulting implementation projects are referred to commonly as “**Family Support 360 Centers.**” As the accompanying graphic shows, the present ADD initiative includes 21 implementation grantees receiving funds to provide supports to families and nine planning grants that received more modest awards to continue with program planning. In addition, ADD has recently acted to expand the effort to establish FS 360 efforts focused on military families and bases.

The projects are not identical in their specific objectives and strategies. Each site functions within its own unique state system context. Wisconsin, for instance, maintains a relatively mature family support system. The FS Center there, located in Madison, works to extend and expand practices within the system consistent with FS 360 principles. To contrast, Idaho is extraordinarily rural and maintains a modest state family support system. The FS 360 Center there, located in Moscow, seeks more to effect change across the entire state.

Similarly, some FS 360 Centers focus on particular types of families, while others do not. Centers in OR, MO, UT, for example, focus on Latino families, while the NM Center works with American Indians. Meanwhile, Centers in MN, MI and MA serve a more diverse array of ethnic minorities. And the VT Center focuses on parents with developmental disabilities.

Centers may also differ in terms of their position and role within state systems. The FS Center in CO, for example, has been successful at working within the state’s TANF system. Meanwhile, in SD the FS Center there has influenced the overall state family support system.

Regardless of their differences, however, the FS 360 projects share a number of common objectives or policy themes. Overall, Centers were charged with establishing a “one stop” site where families can come and apply for a range of services and/or get a wide range of their support needs addressed. In essence, the Centers were meant to be a place where families could go and not get a “run around,” but instead work with staff to weave a variety of supports together from multiple sources. Given this intent, all Centers set out to:

- Provide a meaningful role for families. All Centers are premised in a commitment to family direction and leadership.
- Conduct an analysis of existing State and Federal laws affecting families. Principals at each Center completed analyses of the laws and programs affecting families to become knowledgeable of the federally based programs that can be utilized by families (e.g., Social Security benefits, food stamps, Medicaid waivers and state plan services, EPSDT, rehabilitation services, TANF).

Family Support 360 Projects	
21 Implementation Grants	9 Planning Grants
Alaska	Connecticut
Colorado	Delaware
District of Columbia	Illinois
Hawaii	Iowa
Idaho	Mississippi
Maryland	New Jersey
Massachusetts	North Dakota
Michigan	Ohio
Minnesota	Tennessee
Missouri	
New Hampshire	
New Mexico	
North Carolina	
Northern Mariana Island	
Oklahoma	
Oregon	
Rhode Island	
South Dakota	
Utah	
Vermont	
Wisconsin	

- Conduct effective outreach and recruitment. Each Center set out to engage traditionally difficult to reach families.
- Provide information and referral to targeted families. All Centers provide families with common information about available services. This includes information about services offered through Federal, State and County auspices, as well as information on supports offered through other community serving organizations and from family-to-family.
- Provide staff assistance capable of providing an effective “one stop” experience. Centers worked at providing staff, often thought of as “family navigators,” to build plans with families capable of accessing support from multiple sources.
- Develop and monitor family plans. Each center sought to work comprehensively with at least 50 new families each year. This would not include many others who participate at Centers only casually or periodically. For these families receiving “comprehensive support” Individual Family Support Plan are developed that state the desired outcomes sought by the family.
- Develop Memorandums of Understanding with local public agencies. All Centers worked at crafting working MOUs with county or state public agencies to promote strong collaboration between partners.
- Seek additional funding for Center activities. Financing may be secured in several ways: (a) participation in existing public services programs, that would involve financing by public means (e.g., Medicaid, food stamps, TANF, Social Security benefits, County run family support, schools), (b) contributions in time or materials made by community serving organizations (e.g., donations of furniture, lumber to construct a ramp), and (c) supports offered within peer exchange networks where time and materials are exchanged.

No formal evaluation of these projects has been undertaken. Members of the *Family Support 360 Sustainability Committee*, however, meet regularly by teleconference to consider what might be done to sustain and expand the FS 360 experience. .

During its work, the Committee completed surveys of the Centers in 2006 and 2007 to gain insight into their activities and lessons learned. Based on our 2006 survey, we learned that:

- FS 360 Centers have primarily functioned without significant funding from state developmental disability service system, including no use of Medicaid funding. The absence of such funding has resulted in these Centers seeking creative means for finding resources to support families.
- FS 360 Centers have developed staff as “family navigators,” who are expert at working without traditional developmental disability services funding. These navigators typically develop maps of local community assets, including public service agencies, faith-based and other community serving organizations, and businesses that can be used to address family needs.
- FS 360 Centers find that families and individuals often have support needs that fall outside of what traditional developmental disability systems would address. Put another way, families and individuals often have needs whose remedy is not “Medicaid reimbursable.”
- FS 360 Centers routinely assist families to apply for and receive services from a variety of public service agencies, serving to weave the system together more cohesively.
- FS 360 Centers develop and utilize resources available outside the auspices of the public service system, including faith-based and other community serving organizations, and businesses.

- FS 360 Centers develop effective opportunities for families to provide support to one another. This occurs most casually in peer support meetings, but also more systematically within planned “peer support exchange networks.”

More recently in 2007, we conducted a survey of FS 360 Centers to get a better idea of what type interactions Center staff had with families in the past year. We sought unduplicated counts of the numbers of families served. In particular, we wanted to know how many families received comprehensive planning services or more casual support, or interacted with their local Center only periodically. By considering such information in relation to the grant allocations awarded the Centers we could estimate the “per family” cost associated with services delivered.

As shown below, from July ‘07 through July ‘08 overall 5,499 families were served at a cost of about \$752 per family. If only families receiving “comprehensive plans” are considered, 1,426 families were served at a cost of about \$2,903 per family. In addition, we also asked Center staff to provide examples of their more memorable achievements with families. These data provide an extraordinarily rich archive of accomplishments, revealing that FS 360 staff routinely work with families to blend together resources around families involving supports from public agencies, various community resources, and the families themselves.

Family Support 360 Centers	
Numbers of Families Served by Service Type (20 Of 21 Centers responding)	
(July 07 through July 08)*	
1,426 families	Received <u>Comprehensive Assistance</u> This includes assistance where: (a) staff spoke directly with a family to discuss their needs, priorities or goals, (b) a plan was formed to meet needs stated by the family, and (c) action was taken to meet the family’s needs. Generally, the families you count here are those reported to ADD to meet the “50 families a year requirement.” They may also receive “Casual Assistance” or participate in activities.
2,766 families	Received <u>Casual Assistance</u> This includes simple and regular help that staff provided families to offer information, refer them to other agencies or achieve a simple goal. No “comprehensive plan” was developed. They may also participate in various Center activities.**
1,915 families	Participated in <u>Various Center Activities</u> This may include parent-to-parent meetings, fundraisers, group activities, specialty training and so on. The families counted here did not receive “Comprehensive” or “Casual” Assistance. These families were involved with the Center <u>primarily</u> through the activities they attended.
5,499 served overall at a cost of \$752/family (based on a budget of \$4,140,000)	
* One grantee utilized October 06 through September 07 dates. Another grantee reported from November 1, 2007 through April 30, 2008.	
** One grantee was unable to provide these numbers.	
*** Five grantees were unable to provide these numbers.	

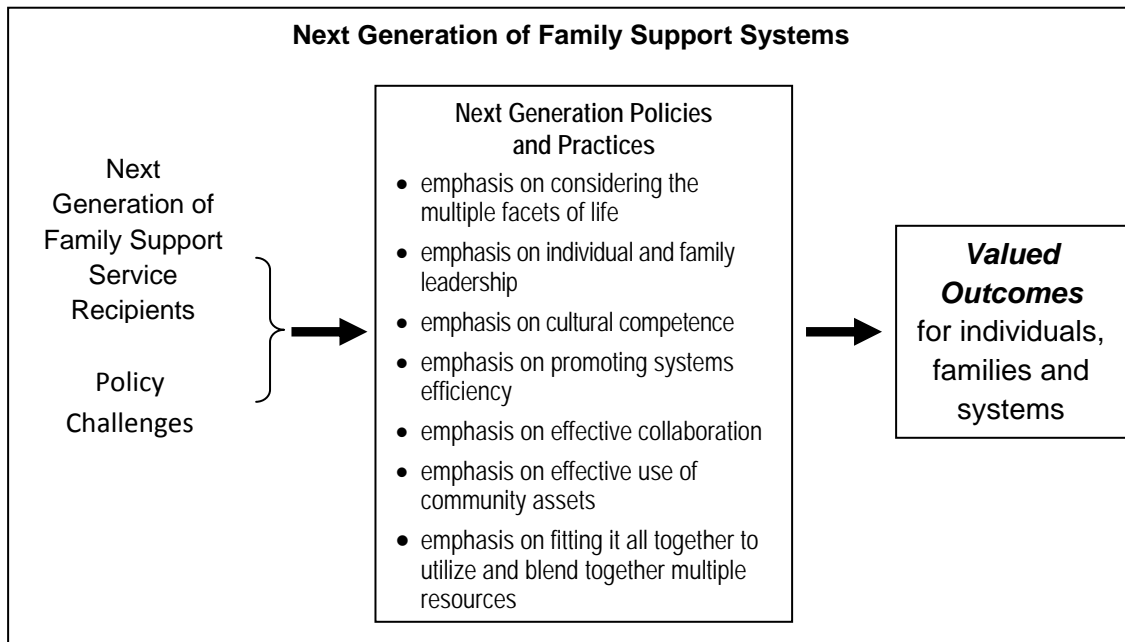
Admittedly, these surveys were not undertaken as part of a well considered evaluation strategy. The *Sustainability Committee* simply worked together to gather the information it could. Still, these findings illustrate that if only families receiving comprehensive plans are considered that the FS 360 projects fall within typical per family state expenditures for traditional family support programs.

However, when the overall number of families reached is taken into account, these programs appear to be extraordinarily cost effective.

We emphasize too that the Committee could not estimate the value of the supports contributed by numerous community partners working with the Centers or the value of the supports families offered to one another through exchange networks. If this type of “community match” were calculated and factored in, the FS 360 Centers would appear to be even more cost effective.

Plainly, the FS 360 Centers have outlined an effective means for supporting individuals with developmental disabilities and their families. These Centers provide a blueprint for the nation going forward to establish the “next generation of family support” policy and practice.

Based on the lessons learned within the family Support movement and the collective work of these Centers since 2004, we expect that the next generation of family support systems will incorporate the following benchmarks (see graphic on the next page):

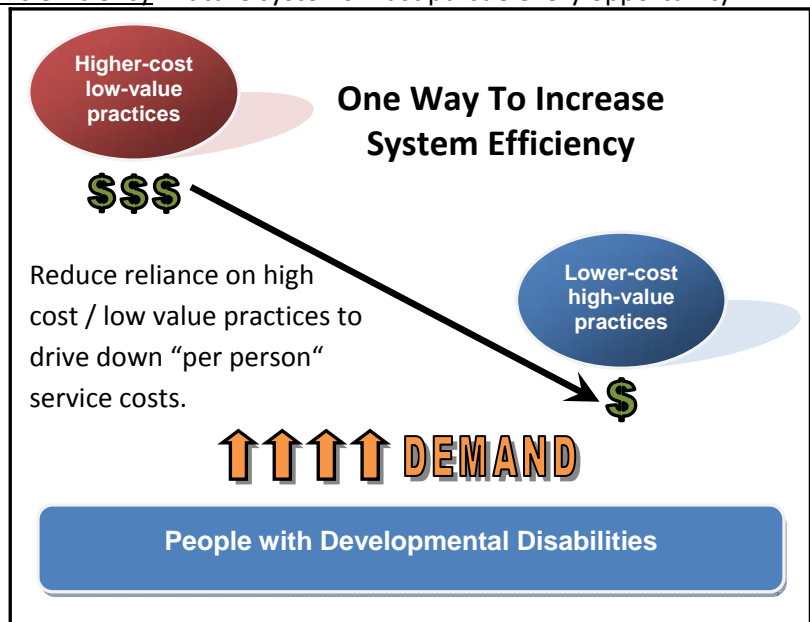


- An emphasis on considering the multiple facets of life. Until recently, the needs of people with disabilities and their families were often measured and accommodated as though the facets of one's life (e.g., self, family, home, school, leisure) could be separated and treated in isolation. An alternative view places the individual within the full context of his or her life. Turnbull et. al. (2003) argues that a family life-span view provides the basis for understanding the challenges faced by individuals with disabilities and their families and for crafting a comprehensive response. 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. These challenges typically span across job, health, family, personal, social and financial domains. To cope successfully and achieve an acceptable quality of life, individual families can apply their own personal resources together with available services or informal supports.

The challenge to policymakers 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. To achieve this, all human service systems must be well coordinated.

- An emphasis on individual and family leadership. Consistent with the Developmental Disabilities Act, this principle concerns the evolving relationship between professionals and service recipients. Past approaches placed professionals in the lead with service recipients taking a passive role. Over the past two decades, this balance has begun to shift. Many now believe that actions leading to establishment of an effective *support system* must begin with the premise that people with disabilities and their families must play a vital, if not leading role, in the decision-making process.
- An emphasis on cultural competence. There is a popular presumption in our culture that we are a "melting pot" of diversity. The theme speciously suggests a collective drive toward a homogeneous culture, when just the opposite seems true. Our nation is home to many cultures and annually welcomes thousands of immigrants. In effect, we are a more a "mixing bowl" than a melting pot, and rather than minimizing or eliminating our cultural differences, diversity must be acknowledged, celebrated and accommodated.

- An emphasis on promoting systems efficiency. Future systems must pursue every opportunity to seek real value for the dollar. In part, promoting. 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. Certainly, not all high cost services have low value. Individuals, for instance, with extraordinary medical conditions or behavioral challenges may cost a lot to support. The money, however, may be very well spent if their health and well-being is enhanced.



- An emphasis on effective collaboration. Our service systems are terribly fragmented. Rather than offering cohesive responses to need, systems typically sort needs into neat categories and assign responsibility for meeting needs to this or that public agency. 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 the resources.
- An emphasis on effective use of community assets. Future systems must seek to discover and utilize every capacity within our community. One of the strongest assets any community has is its people. 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.

- An emphasis on fitting it all together to utilize and blend together multiple resources. Going forward, making available well coordinated and efficient public services will be a primary commitment. These services will be complemented by other community supports made available through faith-based and other community serving organizations. In addition, future support systems must offer individuals and families opportunity to offer mutual support to one another through peer support networks or exchange networks. In this context, we



describe our approach as a “three legged stool” (See graphic) The blend of supports offered sit within the seat and are supported up by each of three legs: public services, community supports, and individuals and families helping one another. Working with each of these resources, future family support staff will bring services and supports together around families to build a cohesive response to each family’s needs.

Concluding Remarks

Every community, locality and government authority finds itself in the same troubling circumstances. Yet plainly, we cannot successfully confront the challenges we face by continuing to do business as usual. Times have changed and the systems that we put into place decades ago are not up to the challenge. Accepting the new reality, however, does not mean that we should become its victims. We can choose either to muddle ahead or to seize the opportunity to move the system forward. The latter course challenges us to take a hard look at every dimension of current family support systems to ensure that scarce resources are put to best use while canvassing new opportunities and looking outside the “system” to support people and families.

Inevitably, we will need to redesign systems to work more efficiently to achieve purposeful outcomes. And we must do so with limited, slow growing budgets. Moreover, achieving needed system reform will likely require additional expenditures in some instances before cost efficiencies may be realized. For instance, helping service providers to phase out legacy practices in favor of more progressive approaches may also require additional funds. Devising means for individuals and families to offer mutual support will cost money to establish. And if government is serious about promoting self-direction and partnering with self-advocates to shape future policy, it must invest in self-advocacy. In general then, while change may impose choice, it also requires willingness to invest in it.

The specific challenges and context facing each government authority and therefore the specific solutions are different. Opportunities to promote community integration and self direction, efficiency, collaboration and community will also differ. Still, what is called for to address the challenges faced by

individuals with disabilities, family makers and policy makers is broad systems change, not more tinkering. It is time to expand and deepen family and person-centered responses to disability by making “family support” a major pillar of the developmental disabilities systems, not just an afterthought.