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# Trends and Challenges in Publicly-Financed Care for Individuals with Intellectual and Developmental Disabilities

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## Systems of Care Innovations for Individuals with Intellectual and Developmental Disabilities Series

This report is part of CHCS' *Innovations in Systems of Care for Individuals with Intellectual and Developmental Disabilities* series, which was developed to help state and other policymakers identify and implement systems of care that improve outcomes for individuals with intellectual and developmental disabilities, their families, and their communities. The publications, supported by Schaller Anderson, an Aetna company, provide policy and technical resources to guide program identification and implementation. Other titles in this series available at www.chcs.org include:

- **Systems of Care for Individuals with Intellectual and Developmental Disabilities: A Survey of States**– Brief describes the results of a national survey of states regarding current delivery systems and planned innovations.

- **Structuring New Service Delivery Models for Individuals with Intellectual and Developmental Disabilities** – Brief outlines guiding principles and core elements of person-centered service delivery models that focus on valued outcomes.

## About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center dedicated to improving health care access and quality for low-income Americans. CHCS works with state and federal agencies, health plans, providers, and consumer groups to develop innovative programs that better serve people with complex and high-cost health care needs. For more information, visit www.chcs.org.

# Contents

There are roughly seven million individuals with intellectual and developmental disabilities (I/DD) in the United States, but only about 25 percent receive services through publicly-funded programs such as Medicaid and Medicare. The other 75 percent are supported by their families or live independently without publicly-funded supports and services. That said, the number of individuals with I/DD receiving publicly-funded services is growing at a rapid pace nationwide. There are various factors fueling this growth, including increased longevity, which heightens overall demand for services as aging caregivers lose the ability to care for loved ones. A second factor is a greater availability of non-institutional services and supports, which encourages families that would otherwise resist institutionalization to apply for benefits.[1]

In anticipation of an expanding population, this resource paper summarizes important trends and challenges facing the publicly-funded service delivery system for people with I/DD, including:

- The rebalancing of the I/DD system of care toward a greater reliance on home- and community-based services;
- The community-based services and supports offered through most state waiver programs for persons with I/DD;
- The evolving role of the case manager;
- The evolving role of direct-service workers and independent providers, including paid family members;
- Allocation of resources;
- Transition from school to adult systems of care;
- Meaningful day activities and integrated employment;
- The challenge of caring for older adults with I/DD and their caregivers; and
- Quality oversight and community integration.

# I. Deinstitutionalization

Prior to World War I, psychiatric hospitals were almost the only out-of-home placement alternatives available to individuals diagnosed with I/DD. Following that era, the development of separate state facilities came into vogue and grew to such an extent that by 1967 the census of state institutions was almost 200,000 residents, with an facility average facility of more than 1,400. However, in the late 1960s a number of media exposés uncovering inadequate conditions, overcrowding, and a lack of treatment triggered increasing demand for reforms. In response, in 1971 the federal government established the Intermediate Care Facility for Persons with Mental Retardation (ICF/MR) program, enabling states to apply for federal matching funds under Medicaid to provide "intermediate care" in a federally-certified, publicly-owned institution.

Predictably, most states embraced the program and the number of individuals residing in ICF/MRs increased dramatically during the 1970s. In addition to improving the quality of care, ICF/MRs resulted in significant decreases in the number of residents served within individual facilities because many of the previous institutions had been overcrowded according to the new federal standards. In 1977, privately operated ICFs/MR also became eligible for federal reimbursement and by 1993 most persons receiving ICF/MR services were served in privately-operated institutions, and that trend continues today. Then in 1981 the federal government initiated home- and community-based services (HCBS) waiver authority, allowing states to implement non-institutional, community-based services for Medicaid-eligible beneficiaries meeting certain criteria.

The passage of the Americans with Disabilities Act in 1990 and the Olmstead Supreme Court ruling in 1999 further encouraged the national trend toward deinstitutionalization.  In fact, from 1960 to 2008 the average daily census of large state-operated institutions for persons with I/DD declined by 78.2 percent and the total number of facilities decreased from 354 to 168.  In 1991, New Hampshire became the first state to close all of its public institutions, and since that time Vermont (1993), the District of Columbia (1994), Rhode Island (1994), New Mexico (1995), Alaska (1997), Hawaii (1999), Maine (1999), West Virginia (1999), and Michigan (2010) have followed New Hampshire's lead.[2]

Two key factors have contributed to the policy shift away from institutions: first, there has been an expanding philosophical shift away from institutions and in support of community living; and second, the high costs of institutional care have made it more difficult for states to support institutional services.[3]

## Opposition to Further Deinstitutionalization

High costs aside, there remains vigorous resistance to further deinstitutionalization on the part of local communities, public employee unions, and a significant percentage of family members of facility residents.  Advocates for institutionalized care argue that there are some individuals, such as those with significant behavioral issues and/or complex physical and mental disabilities, who cannot be safely supported in the community.[4]

In addition, research has indicated that the ability to find, train, and keep direct-support staff remains one of the biggest barriers to continued deinstitutionalization and the ability to sustain current community supports.  In most states, the wages of community support staff are consistently low, and institutional staff members have significantly better wages and benefits.  Other barriers include a lack of trained medical and behavioral health professionals to provide needed service to persons with I/DD, the prohibitive costs of simultaneously operating ICF/MRs and community-based service systems during the transition period, and local community resistance to locating persons with I/DD in neighborhoods as well as concerns about land use and economic development.  And there are also individualswho have lived in institutions for their entire lives and have now grown old, and moving them out of their familiar surroundings could prove painfully disruptive.[5]Time and careful planning are required for success in moving these individuals to the community.

Despite these obstacles, many states have implemented successful strategies for supporting people with significant needs in the community, including those with psychiatric disabilities (so-called "dually diagnosed" individuals).  In past years, states closed institutions by creating group settings in the community; today, the group home/community residence is increasingly viewed as an undesirable, unnecessary type of residential setting as compared to more typical homes designed and developed for individuals with I/DD.[6,7]

But even the most ardent proponents of community residences acknowledge that not everyone can be effectively cared for outside of the group home setting.  For example, individuals with severe autism often react inappropriately to the normal activities of home life, such as ringing doorbells, appliance noise, and dogs barking, etc., and instead require an environment that is calm, routine, and predictable.  To address this, states have sponsored or licensed the opening of specialized residential centers with campuses that include housing, schools, and recreational facilities that maintain a structured sensory environment to accommodate severe autism.[8]

## Fiscal Challenges in Transitioning from Institutional Care to HCBS

As mentioned above, states with a heavy reliance on the ICF/MR model of care confront significant financial barriers in transitioning to HCBS because they must support dual systems. As the institutional population declines, states must continue to keep facilities operational by investing in maintenance and repair and maintaining appropriate staffing ratios, while simultaneously expanding funding for home- and community-based waiver programs to serve an increasing number of individuals. States cannot achieve savings or redirect appropriations to community services unless they are able to effectively downsize facility operations and staffing as the population declines and, eventually, close the institutions.[9]

## Residential Alternatives to Institutional Care

The primary residential alternatives available to 1915(c) waiver enrollees with I/DD include:

- **Supported living services:** Supported living services provide individualized supports to adults with developmental disabilities who live in the home of their choice, such as living alone or with a roommate or remaining in their family home. Levels of support are based on the individual's needs and preferences, including up to 24-hours a day of training and support, which promotes opportunities for individuals to participate in the community in which they live.

- **Host home/Foster care:** The broad definition of a host home is "a home owned or rented by an individual or family in which they live and in which they provide care and support for one or more unrelated persons with I/DD." Host homes are responsible for providing up to 24 hours of care, supervision, and training for up to five individuals with developmental disabilities. Room and board funded with Social Security or other income is often a part of the service. And in most states, host home residents must have an Individual Support/Care Plan that is updated annually.

- **Group homes:** Group homes (a.k.a., Congregate Care), typically operated by non-profit agencies, provide room and board as well as an array of services to residents, which may include children as well as adults, depending on the state. They can vary in the number of individuals who live there as well as in the number of staff, which is typically based on the support needs of the individuals living in the home.

- **Community protection program:** The I/DD Community Protection Program provides intensive 24-hour supervision for clients who have been identified as posing a risk to their community due to the crimes they have committed. This program provides an opportunity for participants to live successfully in the community and continue to remain out of correctional facilities or other justice system settings.

# II.    Community Support Services for People with I/DD

Support for children and adults with I/DD who reside in the community varies greatly across the nation. States have great latitude in determining what services and supports will be included in their family support program as well as in determining whether children, adults, or both, will be eligible to receive the supports. Many states also offer individuals and/or their circle of support the option to self-direct one or more of these services. In addition to habilitation services (see below), the most common services and supports that states may offer to families with children and/or adults with I/DD include:[10]

- Financial services (e.g., cash subsidies, vouchers);

- In-Home supports (e.g., personal assistance, homemaker services);

- Respite services;

- Assistive technology and home modifications;

- Adaptive medical equipment;

- Therapies (PT, OT, speech);

- Family counseling/training;

- Parental support groups;

- Skilled nursing;

- Transportation;

- Recreational activities;

- Adult day services; and

- Early intervention (a.k.a., community-based rehabilitation services).

## Habilitation Services and Supported Employment

Habilitation services are designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home- and community-based settings. States vary in how they design and structure these programs, but common features include:

- **Community habilitation:** Provides groups of children and/or adults in independent living with training on skills such as health and safety, socialization, money management, housekeeping, and computer literacy that arenecessary to reside successfully in home- and community-based settings. The services are tailored to the valued outcomes and needs of the individual and are typically provided in a non-certified community location.

- **Residential habilitation:** Provides in-home, intensive training in skills like social behaviors, self-care, basic safety, personal hygiene, budgeting, shopping, household management, etc. The service is typically provided by a residential habilitation worker who is assigned to the individual and works one-on-one on a regularly scheduled basis. The services may be offered either in a facility or in an individual residence and the amount of the service can vary depending on individual needs and state regulations.

- **Supported employment:**Defined by the Centers for Medicare & Medicaid Services (CMS) as employment support services for individuals who, because of their disabilities, need intensive ongoing support to obtain and maintain a job in competitive, customized, or self-employment in an integrated work setting in the general workforce for which the individuals is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals without disabilities. CMS and the Social Security Administration have promoted the employment of individuals with disabilities through implementation of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). TWWIIA strengthened the employment options for people with disabilities by instituting a Medicaid Buy-In option enabling workers to retain Medicaid health care benefits and by creating the Ticket to Work program under which the Social Security

Administration provides beneficiaries with a Ticket they may use to obtain the services and jobs they need from newly designated Employment Networks.

# III. Case Management

The concept of case management for persons with I/DD as it evolved during the 1970s and 80s entailed assigning eligible beneficiaries to a single case manager who served as a monitor, advocate, and service coordinator. Evaluations of this case management approach have reflected very mixed and often negative results in terms of outcomes data and cost-effectiveness, but it has nonetheless remained a core component of most state I/DD systems of care.[11]

At present, case management for persons with I/DD entails two key responsibilities: 1) providing an interface or connection between individuals with disabilities and the publicly-funded service and support system; and 2) assuring that these services meet reasonable standards of quality and address the needs of eligible beneficiaries. These activities typically include:[12]

- **Targeting and outreach:** Identification of individuals for whom case management will be most effective;

- **Screening and intake:** Determination of the individual's eligibility for services and need for case management;

- **Comprehensive assessment:** In-depth evaluation of the individual's current situation, including strengths and limitations and need for services and support;

- **Care planning:** Development of a care plan to include the most appropriate services and supports that will address all the needs identified during the assessment process;

- **Service arrangement:** Provision of information, referrals, or actively arranging the individual's access to services and supports;

- **Monitoring:** Evaluation of the quality of services and supports and determining whether the goals established within the care plan are being met; and

- **Reassessment:** Re-evaluation of the goals and care plan developed during the comprehensive assessment.

Importantly, as self-directed services and control have expanded in recent years, the role of supports brokering or assisting individuals and/or their circle of support to self-direct their services has also become increasingly prominent. The new role entails developing person-centered care strategies that shift much of the decision-making balance in favor of the individual and his or her family/caregiver.[13] Clearly, the trend in case management is evolving from a prescriptive role to a more supportive model, but under certain circumstances this also can place the case manager in the unenviable position of having to reconcile two competing roles: 1) acting as a "gatekeeper" in assessing needs and making recommendations or decisions on behalf of the state and/or health plan; and 2) acting as an advocate on behalf of the individual. States that have adopted sophisticated systems for conducting assessments and care planning have helped to address these potential conflicts and have freed case managers to work as partners with beneficiaries.[14]

## Rethinking Case Management

Currently, there are two major trends shaping the conceptualization of what case management is, could be, and should be. The first is an increasing commitment to consumer empowerment and the second is expanding caseloads during an era of fiscal pressures. Given this, a growing number of governmental entities across the country are asking whether a model of individual case management continues to make sense. There is also a growing acknowledgment that not everyone wants or needs high-touch case management, and that among those who do, especially those at high risk for institutionalization, not everyone needs the same level of intervention or the same set of case management skills and expertise. One example, outlined in the box below, illustrates state reform efforts in this direction.[15]

Based on a 2011 national survey of states conducted on behalf of CHCS, a review of the practical and research literature and the opinions of the authors, seven best practices in case management were identified and are summarized in the next section.

### Rethinking Case Management in New Jersey

New Jersey's approach to case management for persons with I/DD consists of stratifying beneficiaries into one of three levels of case management support that are designed to be proportional to the needs of individuals in different situations. The three levels of case management include:

- *Primary case management.* This level is targeted at beneficiaries who are determined to be at high risk while residing in foster care placements or group homes with limited socialization opportunities, or have been designated as having "urgent" status on the wait list for HCBS. The state limits case manager caseloads for these beneficiaries at 35 to ensure that in-person visits occur at least monthly.

- *Program case management.* This moderate level of case management is designed for beneficiaries living in situations in which they have frequent encounters with a range of people, such as group homes, day programs, or participate in the state's self-determination program. Caseloads are limited to 90 individuals per case manager to ensure quarterly in-person visits, but in practice case managers typically have multiple beneficiaries living in the same setting and often interact with a provider agency's operations so oversight takes place regularly.

- *Resource case management.* This low level of case management is intended for beneficiaries who have a limited need for service outside of the occasional question or referral. The types of beneficiaries in this category include children receiving in-home services or adults living with their parents who might be receiving respite care or some other support. Caseloads are limited to 250 individuals with a goal of at least one in-person visit per year to monitor the individual's status and assist with any questions or issues.

### Best Practices in Case Management for Persons with I/DD

Best practices in case management for persons with I/DD include:

- Promoting choice and self-determination;

- Supporting self-directed care;

- Stratifying individuals into appropriate levels of case management to ensure that limited resources are targeted to those with the greatest need for services and supports;

- Adopting IT systems that facilitate the flow of information among all involved stakeholders from initial intake, screening, and assessment to care planning, monitoring, and quality oversight;

- Employing team-based or multi-disciplinary case management models that can channel an individual case manager's skill and expertise in the most appropriate, cost-effective manner;

- Employing remote monitoring and other telehealth technologies to enhance communications between case managers and individual and

- Promoting individual and family/caregiver choice of case managers, which typically entails contracting with private case management agencies while ensuring there is no conflict of interest in service allocation/authorization.

# IV. Direct Service Workers and Independent Providers

Direct service workers (DSWs) are paid to assist eligible beneficiaries with a wide range of health and human service needs, including services and supports for persons with I/DD. In the past, DSWs were often referred to as "paraprofessionals" because many lacked a formal post-secondary education. However, this label has become increasingly less common owing to the professionalization of the industry (e.g., training, codes of ethics, worker-related professional associations, and career ladders, etc.) and in recognition that in some health and human service settings DSWs have post-secondary education or degrees. The title "Direct Support Professional" or "DSP" is increasing in use among employers, advocacy organizations, and in recent legislation passed by the U.S. Congress.[16]

Not only have their titles changed in recent years, but so too has the nature of their work. The transition from institutional settings to community-based alternatives has led to greater geographic dispersion of the workforce and a need to assume greater responsibility and independent problem-solving and decision-making, thus increasing the challenges faced by DSWs. In spite of these increased demands, DSWs serving persons with I/DD continue to confront a high level of societal stigma related to the type of people they serve coupled with modest wages and benefits, a low level of training, and little opportunity for advancement. In essence, direct-service work is often regarded as little more than glorified housekeeping and babysitting, which makes recruitment difficult and long-term retention challenging. It is thus no surprise to find that there is a severe shortage of qualified applicants seeking work as DSWs in the field of I/DD.[17]

## Independent Providers

In the context of I/DD services, "independent providers" are direct-service workers who are not employed by a home health agency and instead work for themselves. In a growing number of cases, the independent provider is a family member or friend of the individualwho is receiving services. Because of concerns over appropriate background checks, insurance, and quality oversight, in the past state Medicaid programs have typically not allowed the use of non-agency personnel, but given the trend toward self-direction combined with a severe shortage of direct-service workers in most regions of the country, many states have either ended this prohibition or are actively considering doing so.

Most self-directed programs do not require workers to undertake any formal training, although an increasing number of states are making training available to workers.Some states have also initiated new approaches to support both beneficiaries and workers in home- and community-based settings, especially those involved in self-directed programs. These approaches often include developing comprehensive worker registries that help workers locate people who need support and assist beneficiaries in identifying potential direct-service workers to provide support. Developing professional associations to enhance opportunities for networking, professional development, policy advocacy, and empowerment is another

strategy used in some states. These associations often affiliate with the National Association of Direct-Service Professionals (NADSP) or the Direct Care Alliance.[18]

## Paid Family Caregivers

The paid family caregiver model can offer multiple benefits to individuals and the service delivery system. The model was created to increase flexibility and individual choice to remain in the family home when desired. Additionally, the model increases the ability to meet the needs of individuals who live in rural areas, have unique service delivery needs, or who have specific faith or cultural preferences. While a family caregiver model may not be appropriate for or preferred by all beneficiaries, it can have a positive and effective outcome in meeting individual preferences and needs.[19]

Despite the potential advantages, there are also understandable concerns about the potential for abuse, neglect, and/or exploitation when paying family members or friends to provide services. This is especially worrisome during periods of economic hardship and high unemployment, when distressed family members may exert pressure on beneficiaries to employ them even though it is not their preference. Moreover, owing to a general paucity of on-sight supervision, it is not difficult to envision circumstances in which services are not being provided sufficiently or appropriately, but the problem nonetheless goes unreported because of the personal relationship. An evaluation of the original Cash and Counseling demonstration in Arkansas, Florida, and New Jersey found that beneficiaries typically terminate the employment of family members or friends whose work is unsatisfactory, but it also notes that some beneficiaries need support to do so.[20]

A secondary issue for states is placing a limit on the number of hours that paid family caregivers can work. The primary concern is that family caregivers will receive compensation for performing tasks that they would have done in any case. States also want to ensure that family members are not running home-based businesses or conducting other activities while charging the state for providing care. And finally, some states limit the number of hours to encourage beneficiaries to develop a wider support system, lessen fatigue among providers, and ensure the availability of a back-up plan in case the caregiver experiences an unexpected medical issue or becomes too elderly to continue carrying out his or her responsibilities. The standard limit among most states that reimburse family caregivers is 40 hours per week.[21]

# V. Resource Allocation

Ideally, beneficiaries would receive the services and supports they need in accordance with each individual's preferences and abilities and state I/DD systems would equitably distribute available resources across all beneficiaries based on these needs and preferences. And although most states base funding and supports on individual needs to some extent, the relationship is often murky and individuals with similar needs are frequently allocated differing funding levels with no discernible rationale other than what are known as "system factors" (e.g., regional variation, case manager decisions, provider influence). These system factors also may include historical differences in provider payments for the same services, inappropriate levels of reimbursement for similar services (e.g., group homes versus family homes), and distortions in service authorization policies and practices. Consequently, service awards often appear arbitrary and unfair.[22]

To address this, states are increasingly seeking to develop and implement a standardized process for evaluating individual support needs and a protocol for allocating resources that is equitable and efficient.

At present, there are two primary methods for accomplishing these objectives: "Level-Based Budget Allocations" and "Individual Budget Allocations" (LBA and IBA).

**Level-Based Budget Allocations**: The LBA method entails stratifying beneficiaries into different assessment levels reflecting the intensity of their resource needs, including medical and/or behavioral health needs. All individuals falling within a single level are assigned the same allocation, unless finer distinctions are made within levels. Ideally, total waiver expenditures and hours of support will vary according to changes in the assessment level.

**Individual Budget Allocations**: Because each individual has unique needs and circumstances, some states prefer to set individualized budget allocations under the presumption that those with greater needs should have access to more resources. Importantly, the allocation must never be based on the need for a particular provider, but should instead be person-centered, with individuals/caregivers choosing how to spend the allocation and deciding which providers should be engaged. The individual chooses the provider and the money moves with the person.

And because each individual has different needs and abilities, the provider reimbursement rates that are used in developing IBAs/LBAs should be based on differing intensities of support needs or other factors influencing the delivery of services, such as how difficult individuals may be to serve and/or their geographic location rather than fixed fee-for-service rates. And most importantly, the budgets that individuals are awarded must be sufficient to purchase the services they are meant to fund.[23]

## Prospective versus Retrospective Budgeting

Whether or not a state elects to employ the LBA or IBA approach, it must further decide whether a specific budget allocation should be defined prior to the development of a plan of care—a process known as "prospective budgeting"—or whether the plan of care should define the dollar allocation, or "retrospective budgeting." Wyoming and Florida are examples of states that use the first approach while New Hampshire and Vermont employ the latter.[24]

There are advantages and disadvantages to both approaches. An apt analogy would be shopping for groceries without a budget, which may result in having to remove items from the cart or substituting them for a less expensive alternative if there are insufficient funds to pay for the selected items. On the other hand, shopping without a budget can result in spending less than the available funds, which is less likely to occur under a prospective budgeting approach where there is an incentive to match demand with supply (i.e., supply creates its own demand or "regression to the ceiling").

For obvious reasons, most states favor the enhanced budgetary certainty offered through the prospective approach. Not unlike the prospective capitation payments that states typically make to Medicaid managed care plans, this approach enables states to place a predefined global cap on the level of waiver-based service spending for each person (or category of beneficiary if using LBA), which may in turn determine the size of the waiting list (if any) for waiver-based services.

## Resource Allocation Tools

States currently use a variety of instruments for allocating resources according to beneficiaries' assessed needs for services and supports, most of which involve the statistical prediction of individual service costs based on regression analyses. Commonly used tools include the "Inventory for Client and Agency Planning" (ICAP), Developmental Disabilities Profile (DDP), North Carolina Supports Needs Assessment Scale (NC-SNAP), the Maryland Individual Indicator Rating Scale, and the Supports

Intensity Scale (SIS), among others.  When evaluating a tool, states need to consider a number of factors:[25]

- The scope of the tool (i.e., national versus state-specific);

- The tool's reliability, validity, and standardization;

- The tool's comprehensiveness (i.e., applied to all services and supports or to specific waivers, populations, or services); and

- How the tool is administered and by whom (e.g., state agency, provider, third-party contractor, etc.).

In addition, states must decide how often beneficiaries should be reassessed, how the implementation process should unfold, and what to do when new beneficiaries are added.[26]

A key factor in the reliability of resource allocation instruments is consistency in the manner in which they are administered and interpreted.  This is especially important in states that have a newly adopted system for allocating resources inasmuch as some beneficiaries may experience a reduction in services and supports based on the assessment.  If there are questions or inconsistencies about the accuracy of the results, the entire methodology will be thrown into doubt.  To avoid this, states should first simulate the results of the tool, determine how funding patterns will be altered, and obtain feedback about the potential implications.  It is also important to have alternative strategies in place for "outliers" who have unique support needs that the tool does not address.[27]

Based on extensive research and evaluation of resource allocation methodologies, the American Association of Intellectual and Developmental Disabilities (AAIDD) has developed the Supports Intensity Scale (SIS) instrument to gauge the intensity of support an individual needs based on his or her ability to perform life activities combined with medical and/or behavioral support needs and other factors.  At present, 18 states and 17 foreign countries have adopted the instrument and a number of others are actively considering doing so.  Importantly, the SIS tool works best when combined with other information such as whether unpaid supports are available or whether an individual requires close supervision owing to involvement in the criminal justice system.  Other tools (e.g., Wyoming's DOORS instrument, South Dakota's Service Based Rates) may also accomplish the same objective, with the overriding goal to allocate resources equitably and efficiently based on an objective assessment of individual needs.[28]

# VI. Transitions from School to Adult Systems of Care

Young adults with I/DD often struggle during the transition process from high school to adulthood.  After age 21, young adults with disabilities "age out" of the myriad services and supports provided by law through the school system and transition to the state agency responsible for providing services and supports to adults with I/DD—an abrupt change that many characterize as akin to "dropping off a cliff."  And depending on the state in which the individual resides and the level of need, the transition to adulthood can mean being placed on a waiting list for an HCBS waiver slot or, less commonly, being placed in an ICF/MR.

Supports and services aside, the low rates of graduation and employment among young adults with I/DD following graduation are often exacerbated by a pervasive lack of opportunities.  For example, in New York State just 16 percent of adults with I/DD who do not have a high school diploma participate in the labor force.[29]

Nationwide, the statistics are worse. Only 11 percent of parents of adult children with I/DD report that their child is employed full time (19 percent part time) and just 40 percent of parents believe their adult child with I/DD received an education that adequately prepared him or her for adult life. This compares to 79 percent of parents of children without I/DD who believe their child's education achieved this result.[30]

It is thus not surprising that the majority of young adults with I/DD experience a precipitous and understandably stressful transition to adult life from the comfortably-structured and familiar setting of school. The transition is a complex maze, requiring the coordination of multiple stakeholders and service delivery systems coupled with increasing demands, higher levels of accountability, and a decrease in available resources to support youth in their transition.

## Transitioning to Adult Services: There's More to Life than TV

This past year, Richard P. of Patterson, NJ, a 21-year old with cerebral palsy, was scheduled to graduate high school. In preparation for this transition, Richard and his mother met with his case manager, at which time they were provided a list of programs designed for persons with cerebral palsy. But to their dismay they found that the list did not include any programs geared for young adults and a number of them were instead intended for people with behavioral issues. Consequently, Richard spent the summer at home watching TV while his mother became increasingly worried because she needed to return to work in September. Luckily, in August she learned about an opening at the Cerebral Palsy Center of North Jersey in nearby Wayne, which accepted Richard into its day program. So all ended satisfactorily, but Richard's mother remains disappointed with how little the state did to assist them.[31]

## Best Practices for Transitioning Students

States have adopted a variety of strategies to lessen the disruption when young adults make the transition from school to adulthood. Examples include:[32]

- **Specialized instruction programs**: In Albany, New York, the Fundamental Specialized Instruction (FSI) program for cognitively delayed students commences during middle school and continues through high school and post-secondary school until the student reaches age 22. The program focuses on teaching students basic academics along with speech, language, and occupational therapies, social work strategies, cooperative learning opportunities, and work-study experiences.[33]

- **Apprenticeship and job readiness programs**: Many states have implemented these programs to provide on-the-job training and assistance with arranging placements with local businesses and government agencies. For example, Ohio developed an intensive employment training program for select students that dramatically increased the rate of employment among participants, and a number of universities and colleges have initiated similar programs that combine class work, social skills, and job training.[34]

- **Support for returning students**: Owing to the high dropout rate among students with I/DD, a number of states have adopted programs to locate those who have dropped out and offer them an alternative path back to school, including online training, GED courses, evening courses, and child care.

- **Dedicated agency staff**: Some states have designated an agency staff member to focus solely on transitioning students with I/DD. Responsibilities typically include serving as transition counselors, providing training or technical assistance to beneficiaries, and acting as a liaison to coordinate services among multiple agencies.

- **Transition plans and employment connections**: These initiatives help to bridge students' transition plans with actual employment or connect them with appropriate community resources that support employment (e.g., vocational rehabilitation, Department of Mental Health, adult education centers, etc.). New Hampshire reports that these programs work best when schools have a transition coordinator with established ties to the community.[35]

- **Family involvement**: Nearly all states actively seek and encourage families to participate in the transition process. This involvement takes a number of forms, including advocacy, assistance with training, and serving on various committees, councils, and stakeholder groups.

- **Data collection and analysis**: States such as Pennsylvania and Virginia collect data on a wide range of topics such as attendance, disciplinary referrals, postsecondary activities, assessments, quality of life factors, independent living information (e.g., driver's license, money management, etc.), and parental satisfaction, among others, to identify and prioritize areas for training and resource allocation.[36]

- **Advance planning for state I/DD agencies**: In Vermont, agency staff tracks the number of students with I/DD who are due to graduate each year as a means of alerting legislators about upcoming funding demands to enable them to make the necessary appropriations and avoid any gaps in the delivery of needed services and supports.[37]

- **Future planning guides for families**: In New Hampshire, the Community Support Network, Inc., which provides administrative services for the state's 10 regional agencies, distributes the "New Hampshire Future Planning Guide" to assist families with the development of a "future plan," including a life plan and letter of intent. The tool assists families on such topics as legal and financial planning, guardianships, public benefits, special-needs trusts, and health care coverage.[38]

In general, stakeholders involved with the transition process recommend that states begin the planning process early; develop collaborative relationships with schools, state agencies, parents, and other stakeholders; and allow local flexibility by listening to the community and local businesses to tailor supports based on the students' needs as well as community needs.[39]

# VII. Meaningful Day Activities and Integrated Employment

## Meaningful Day Activities

While there are varying definitions, in essence Meaningful Day Activities (MDA) support the participation of persons with I/DD in activities and functions of community life that are desired and chosen by the general (i.e., non-disabled) population. (The term "day" does not exclusively denote activities that happen between 9:00 am to 5:00 pm on weekdays.) MDA include: purposeful and meaningful work, skill development, educational activities, and community inclusion activities that are directly linked to the vision, goals, and desired personal outcomes documented in the individual's care plan.

Examples of activities that are inconsistent with the MDA definition include:

- Activities that the general population would not engage in on a regular basis for extended periods of time;

- Extensive time spent in skill building or other work-related activities that isolate the person from non-disabled peers, such as working in sheltered workshops or performing volunteer work in isolated settings with other persons with I/DD; and

- Spending extensive periods of time in leisure activities that isolate the person from non-disabled peers, such as mall walking, window shopping, watching television, or engaging in activities that are age inappropriate (e.g., coloring in children's coloring books).[40]

## Integrated Employment

Policymakers involved in issues relating to I/DD recognize that employment is a critical component of community living for people with intellectual and developmental disabilities. It is not only the means to economic self-sufficiency, it also is an important way for individuals to contribute to their communities, build a network of social relationships, and create opportunities for lifelong learning.Unfortunately, many Americans with I/DD are struggling to access employment opportunities. According to the January 2011 Current Population Survey, the percentage of people with disabilities who are employed is estimated to be 17 percent, compared to 63 percent for people without disabilities, and the likelihood of participating in integrated employment is even lower. There are also wide variances across states, with only two percent employed in Arkansas versus 77 percent receiving integrated employment services in Oklahoma.[41,42]

### *Sheltered Workshops*

Segregated day activity programs and sheltered workshop environments were once considered progressive and innovative, but they no longer address the goals and expectations of persons with I/DD and their advocates. Nonetheless, hundreds of thousands of persons with I/DD participate in these programs, which are based to some extent in the now-antiquated notion that persons with developmental disabilities are incapable of performing "real work" in an integrated setting. Workshops also have the effect of segregating people with I/DD from community settings where they make friends and build relationships. For this reason, I/DD agencies, advocates, policymakers, and other stakeholders are actively seeking to transition persons with I/DD from segregated workplaces into more integrated and emotionally fulfilling alternatives.[43]

### *Employment First*

Employment First is an initiative that many states have adopted that focuses on integrated, community-based employment as the first option and priority goal for individuals with I/DD. The initiative defines employment as a job in an integrated community setting that provides opportunities to earn competitive wages and benefits equal to the job's responsibilities and that encourages a person to work to his or her maximum potential. It further assumes that both formal and informal job supports should be available to meet individual support needs, and that any job should be developed as part of a larger career plan. States that have adopted this approach ensure that vocational rehabilitation, HCBS providers, and educational service systems work together in developing strategies across programs so that beneficiaries are supported to access integrated, community-based employment opportunities rather than expending available resources on funding sheltered work and day services.[44]

In states that are focusing on integrated employment opportunities, successful strategies include promoting flexibility in funding, collecting data focused upon integrated employment, offering rewards and incentives, and adopting innovative practices and training methods. Additional strategies include:[45]

- Promoting interagency collaboration and coordination to focus on the transition of youth and working age adults with I/DD into integrated, competitive employment, including processes that encourage the blending of funds between agencies and departments;

- Identifying and disseminating promising practices and partnerships where community colleges are providing inclusive education and job training;

- Coordinating the viability and adoption of assistive technology for persons with I/DD; and

- Developing and implementing evaluation strategies to determine the effectiveness of models for interagency collaboration.

## Employment First in Washington State

"Everyone in the U.S. should have the opportunity to work and make a real wage," says Ray Jensen, director of King County's Developmental Disabilities Division in Washington State.  He and others in the field are trying to change the focus from what persons with I/DD are unable to do to what they can do.  Jensen's activities are part of a larger effort in Washington to focus all publicly-funded resources for persons with I/DD to finding and keeping paid employment in the real world as opposed to sheltered workshops or recreational activities like bowling or excursions to the mall.  Although the state continues to fund support staff for sheltered workshops, it is phasing them out in favor of finding their clients jobs in places like Fred Meyer, Starbucks, and PETCO.

In 2008 Washington spent roughly $50 million on employment-related services for people withdevelopmental disabilities.  Some 3,700 beneficiaries currently hold paying jobs, but most of these individuals are relatively high-functioning; among those with more severe disorders, only 17 percent have found work (30 percent in Seattle).  In part, this can be attributed to the recessionary job market when prospective employers can typically select from a surfeit of applicants, many of whom are overqualified for the position.  At the same time, many families of adult children with I/DD are asking whether the state is going too far in believing that people who have difficulty communicating or using the bathroom will be able to find and keep a job.  After repeated objections, the state softened its position somewhat and allows beneficiaries who have made no progress in finding employment after one year to be eligible for publicly-funded recreational activities instead.

## Person-Centered Career Planning

Not everyone wants to work, especially in menial positions with low pay and prestige that hold little interest or satisfaction to the employee.  This is as true among people with disabilities as it is among the general population.  Person-Centered Career Planning is an approach to career development that helps people with I/DD develop and pursue opportunities that interest them.  It uses individuals'dreams, goals, personal preferences, interests, and needs as the cornerstone of the career planning process.  At its core, Person-Centered Career Planning is founded on the belief that the job seeker must be the primary director of his or her career and if the desires, abilities, and dreams of the person are not taken into account, it is likely that he or she will not stay in the position or that the job will prove to be a tiresome burden rather than an opportunity to earn money, participate in the broader community, make friends, continue to hone skills, and achieve personal satisfaction.

**Person-Centered Care Planning: Making Dreams Real**

Sara was a 35 year-old woman with a significant developmental disability who had been working in a sheltered workshop for over 10years.  One day she told her employment specialist that she wanted to do something new.  When asked what she wanted to do, Sara could not answer.  Asked about her interests, she said she liked to do needlepoint, spend time with her nieces and nephews, and go shopping.  Asked about her dreams, Sara exclaimed, "I want to become the mayor of Boston, and I want to rebuild the city under water!"

Instead of dismissing her dreams as unrealistic, the employment specialist instead asked why it appealed to her to rebuild the city underwater and why she wanted to be the mayor.  Further conversation revealed that Sara felt comfortable under water and loved politics because her brother had worked in a senator's office while attending college.  Armed with this knowledge, the employment specialist helped Sara to find a new job in a large college library and she also joined the volunteer squad for a political campaign and started to meet regularly with a nutritionist to lose weight.

Perhaps Sara was simply lucky to find an integrated, competitive alternative to a sheltered workshop that matched her interests.  But without even trying to pinpoint her interests and desires and match them with available opportunities, in all likelihood Sara would still be employed at the workshop, dreaming of doing something different.

# VIII. Caring for Older Adults with I/DD

There are an estimated 641,000 adults age 60 and older with I/DDin the United States and their numbers will double over the next two decades as members of the "baby boom" generation reach retirement age.  This is an unprecedented development inasmuch as the average life expectancy of people with developmental disabilities was just 22 years in 1931, compared to 59 years in 1976 and 66 years in 1993.  At present, the causes of death for all individuals with developmental disabilities mirror those of the general population (i.e., coronary heart disease, type 2 diabetes, respiratory illnesses, and cancer), except for those with Down syndrome, who typically die earlier due to dementia-related causes (over half of those with Down syndrome are expected to live into their 50s and roughly 13 percent will reach age 65).  One study found the average age of death for persons with I/DD is now 63.3 years for males and 69.9 years for females.[46,47]

Despite their limitations, the issues confronting aging persons with I/DD are not dissimilar from those of their non-disabled counterparts, including locating safe and affordable housing, living independently, accessing assistance when it is needed, leading productive and meaningful lives, and staying healthy.  However, the situation is especially challenging for older adults with I/DD owing to an array of issues unique to this population, including aging caregivers, work-related issues, and medical and behavioral health problems.

## Aging Caregivers

As they age, families of individuals with I/DD become less able to provide care as they are forced to deal with their own health problems, physical disabilities, and other age-related issues.  Unsurprisingly, older family caregivers often fear the day when they will no longer be capable of providing care to their relative (typically their child).  And because this is the first time in human history that so many persons with I/DD are outliving parents who have historically functioned as their primary caregivers (at present, 25 percent of caregivers are over age 60), policymakers are scrambling for solutions.[48]

Following a parent caregiver's death:

- The support needs of the individual with I/DD increase;

- There is a high probability of a change in residence and work;

- Siblings frequently become primary caregivers, especially if there has been a reasonably close relationship between the person with I/DD and the sibling and some previous involvement in care planning and support;

- The grieving process is often dealt with inadequately; and

- The adjustment goes much smoother if future plans had been put in place prior to the death.

Planning ahead involves arranging for future residential, legal, and financial circumstances in addition to health care, vocational/leisure activities, and community supports. Without adequate plans and supports, individuals with I/DD can face emergency placements in inappropriate settings and inadequate financial and legal safeguards when primary caregivers can no longer provide care. And although there has been an increase in funding for family support programs over the past decade, these programs represent a miniscule portion of spending for developmental disabilities services and often target families of children with I/DD rather than adults.[49,50]

In an effort to promote advance planning among aging caregivers and adults with I/DD, the Rosalynn Carter Institute for Caregiving has developed a planning curriculum entitled "The Future is Now" that consists of five 2½ hour workshops that cover five topics: 1) Taking the Big Step; 2) Building Relationships and Skills; 3) Housing; 4) Work, Retirement, and Leisure; and 5) Who will be the Keeper of the Dream? A randomized control study found that the workshops significantly contributed to families completing a letter of intent, taking action on residential planning, and developing a special needs trust. Moreover, the caregiving burden significantly decreased for families that attended the workshops in comparison to the control group and the daily "choice-making" of individuals with disabilities increased in the one-year follow-up.[51]

## Work-Related Issues

Given that many aging individuals with I/DD are unemployed, under-employed, or participating in day or sheltered programs with little or no pay, the prospect of retirement may take on a different meaning than it does for persons who have been employed most of their adult life and who may have retirement income. Like others, aging adults with I/DD differ widely in their desire to retire, with many preferring to continue to work or engage in vocational activities. This is often related to the need for ongoing socialization and support and not simply because of a desire to keep on working.[52]

## Physical Health Issues

There are many physical health factors associated with developmental disabilities, and these often manifest in chronic health conditions as persons with I/DD age. For example, recent studies have documented a higher incidence of disease and death for aging adults with I/DD for a number of health conditions, such as difficulty eating or swallowing; dental disease;gastroesophageal reflux;esophagitis;respiratory disease and infections (leading cause of death);and constipation. A number of chronic conditions also seem to be more widespread among persons with disabilities than in the general population, including non-atherosclerotic heart disease, hypertension, hypercholesteremia, diabetes, obesity, reduced mobility, bone demineralization, and osteoporosis. In addition, thyroid disease;effects of taking multiple psychotropic drugs;and deaths due to pneumonia, bowel obstruction, and intestinal perforation have a higher prevalence among aging adults with I/DD.[53]

Some specific syndromes and diagnoses are inherent (e.g., epilepsy;sensory problems like poor vision and hearing;poor heart function in people with Down syndrome), while others are avoidable but overrepresented among the developmentally disabled (e.g., obesity, diabetes, poor dental health). Also, symptoms of aging like diminished hearing;the development of cataracts;respiratory difficulties;the onset of menopause;and obesity-related diseases like high cholesterol and diabetes can all occur earlier in those with Down syndrome than in the general population.

## Behavioral Health Issues

In general, older adults are more prone to depression and other behavioral health issues than younger persons and this tendency is even more pronounced among individuals with I/DD, although it is often under-assessed, under-diagnosed, and left untreated. Furthermore, it is often challenging to identify behavioral health problems among aging individuals with I/DD because they are generally less capable of describing and conveying their feelings. Symptoms of conditions like depression may be expressed as physical complaints instead (e.g., headaches). Anti-depressant medication is generally effective in addressing these conditions, but considerable care has to be taken to prevent potentially harmful interactions with other prescribed medications.[54]

## Best Practices in Caring for Older Individuals with I/DD

Based on a 2011 national survey of state I/DD agencies conducted on behalf of CHCS, a review of the practical and research literature, and the opinions of the authors, best practices in caring for aging adults with I/DD include:[55]

- **Aging in place**: States should implement policies to promote "aging in place" to allow older individuals to stay connected to their support systems, friends, and communities. Services considered vital to aging in place include care management, evidence-based disease prevention and health promotion services, education, socialization, recreation, and civic engagement opportunities.[56]

- **Collaboration between state agencies**: Because of the lack of coordination/communication that often exists between I/DD agencies and Senior Service agencies like Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs), states need to encourage enhanced collaboration between them to ensure that there is an effective range of supportive services to address the changing needs of aging persons with I/DD.

- **Seamless, portable funding:** Multiple funding streams need to be coordinated/integrated to ensure that dollars follow individuals throughout their life course and support the needs and preferences of individualsat different stages of life. Advocacy and ombudsman services should also be made readily available to assist beneficiaries and their families with accessing services and funding from various support programs.

# IX. Quality Oversight

A well-functioning system of continuous (i.e., 24/7) quality oversight is critical to prevent incidents of physical and sexual abuse, neglect, and exploitation involving individuals with I/DD.

Interestingly, the transition from large institutions to community settings would appear to make the exercise of quality oversight more challenging, with many more locations to oversee and with direct-

service workers typically performing their duties away from the watchful eye of supervisory staff. But even though it is counterintuitive, placing individuals in the most integrated setting possible, such as foster homes or small group homes located in typical neighborhoods and apartment buildings, may actually enhance quality oversight owing to the very lack of geographic and social isolation. As individuals with I/DD go about their daily lives and engage in such activities as going to work, taking a walk, shopping for groceries, or mailing a letter, they are visible to others in the community, and even if they do not socialize, people nonetheless tend to notice signs of abuse and/or neglect. To be sure, not everyone with I/DD lives in such highly integrated settings, and neighborhoods often resist the development of small group homes, but as current trends continue there is at least anecdotal promising evidence that some of the most egregious incidences of abuse and exploitation may concomitantly diminish.[57]

A vital element in quality oversight is the direct-service workforce itself. When state and non-profit agencies experience difficulty in attracting and retaining trained professionals of good character, problems invariably develop. Solutions such as offering more attractive pay and benefits, better training, and enhanced opportunities for career advancement seem obvious, but given the financial straits that most states are currently experiencing, implementing them is a challenge. But again, the trend toward increased integration may at least help to compensate for these obstacles.

Another promising strategy is to enlist the assistance of individuals with I/DD, their families, and other stakeholders in the quality oversight process through satisfaction surveys, participation on committees and workgroups, quality forums, and assisting agency personnel with hands-on monitoring activities such as paying informal visits to group homes or making telephone contact on a random basis to inquire about safety and well being.

## Quality Performance Benchmarks

In a recent study commissioned by the State of Illinois, the Human Services Research Institute (HSRI) identified seven high-level performance benchmarks against which to evaluate the delivery system's readiness for provision of community-based services and supports for persons with I/DD. These include:[58]

- Individuals have timely access to needed services;

- Services are provided in the least restrictive setting possible;

- Services and supports are person-centered and include opportunities for individuals and families to self-manage their services;

- Services support "valued outcomes" such as personal independence, employment, and community integration;

- Sufficient infrastructure is in place to allow ready access to needed services;

- Services continuously meet essential quality standards under an effective quality oversight process; and

- Systems promote economy and efficiency in the delivery of LTSS.

Using HSRI's template as a point of departure, the following sections discuss some of these performance standards in greater detail.

### *Timely Access to Services (Wait Lists)*

Owing to budgetary constraints and limited infrastructure, the vast majority of states have a fixed capacity for serving individuals with I/DD, which forces them to cap the number of beneficiaries through

the use of waiting lists.  Unfortunately, because of decreased rates of turnover among beneficiaries already receiving services, some state waiting lists have become quite lengthy and beneficiaries often wait years to access services.

States vary in their approaches to managing wait lists.  Common strategies include:

- **First-come, first-served**: In these states, parents often sign their child up for waiver services upon diagnosis of an I/DD even though they may not need the service for 20 years.  States can spend valuable administrative resources managing a wait list with individuals who cannot access the service for years.  One strategy is to limit applications to individuals who would be eligible within three years.

- **Prioritize applicants**: The most common categories include individuals transitioning from an institutional placement, crisis and emergencies, transitioning from the schools or child protective services.

- **Managed care**: Arizona's ALTCS managed long-term care program, which includes persons with I/DD, does not maintain a waiting list.  And although Texas's Star Plus managed long-term care program for elderly and physically disabled beneficiaries excludes individualswith I/DD, it succeeded in eliminating the waiting list for waiver services by contracting with private MCOs to more effectively manage care and services.  However, states adopting this approach must exercise caution when initially developing capitation rates because prioritizing the most severe cases can have a substantial impact on the financial viability of MCOs in the absence of appropriate risk adjustment.

HSRI recommends that individuals with I/DD who have emergency or crisis needs be able to access services within 90 days, and within six to nine months for those with critical near-term needs.  However, to achieve this goal states must first have processes in place to track and trend the number of eligible applicants requesting services.  For example, Illinois and Pennsylvania have adopted a tool known as the Prioritization of Urgency of Need for Services (PUNS), which stratifies applicants into one of three categories based on their individual needs as well as their caregiver's circumstances:

- Emergency (services needed as soon as possible or within the next six months);[59]
- Critical (services needed within one year (Illinois) or two years (Pennsylvania)); and
- Planning (services needed within five years).

As stated, having a tracking system is just the first step to ensuring access to services. States also need a workable process to make services available. Illustrating this point, although Illinois and Pennsylvania have tracking systems, their ability to provide services is not equal to the identified level of need. In 2010 Illinois reported there were more than 15,000 individuals with unmet emergency and critical service needs on its waiting list.[60]  Pennsylvania fared slightly better, with 15,888 persons on waiting lists in all three PUNS categories as of October 2011.[61] States must adopt enhanced strategies for identifying and intervening with individuals who have emergent or critical service needs.[62]  Additional best practices include:

- **Determine financial eligibility**: Because waiver enrollment under 1915(c) cannot be retroactive (it can be under an 1115 waiver), a person moving off the wait list to a waiver program who has not been determined financially eligible may experience significant delay until the receipt of services.

- **Check for Medicaid claims**: Often neglected as a component of wait list management (and as protection in adverse actions), states fail to match their waiting lists to claims for state plan services, some of which support individuals living in the community with services such as personal care, home health aide, nursing, durable medical equipment, etc.  A number of years ago, Ohio matched its waiting list to Medicaid claims and found a significant number were accessing these services outside the waiver.

### *Acute Medical and Behavioral Health Services*

In addition to HCBS waiver services, accessing appropriate medical care is an ongoing challenge for people with developmental disabilities, especially the aging.[63]Strategies for ensuring that persons with I/DD are able to access individualized, community-based health services include, but are not limited to, the following:[64]

- Providing information about where to access appropriate health services;

- Providing adequate reimbursement for health services;

- Providing access to transportation;

- Limiting provider patient loads;

- Making services available in natural settings (e.g., home, school, community, agency, clinic); and

- Providing training and resources to support providers.

Thus, an effective quality management system should include access standards relating to HCBS waiver services as well as physical and behavioral health care services.

### *Most Integrated Setting*

In 1999, the Supreme Court's Olmstead decision ruled that states must ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs.  In most cases, this means that individualsshould have the opportunity for placement in a community setting rather than an institution, and preferably in an individual or small group setting with less than six residents.  Most states have made significant strides toward achieving this goal, and, as mentioned above, some have closed all or nearly all of their large, publicly-owned facilities for individuals with I/DDs.  Noteworthy exceptions include Texas, Illinois, New Jersey, and Iowa.[65]

### *Person-Centered Services*

Person-centered service delivery (inclusive of "personal futures planning") means that the specific needs of each person are identified based on an individualized assessment and customized care plans are developed through a person-centered planning process that incorporates the desires and preferences of the individualand his or her circle of support.  Three key attributes of a person-centered planning and delivery system include:

- **Portability of funding**: Anindividual's funding is not restricted to specific service models and can be used to purchase services and supports in a variety of settings (i.e., money follows person).

- **Provider choice**: Individualsand their caregivers can select among qualified providers available in their community and can change providers if they wish.

- **Service flexibility**: Care plans are customized in accordance with an individual's individual needs, preferences, and capabilities and can be adjusted over time as circumstances and preferences change.

The person-centered planning process will involve the individualand his or her family members, friends, peers, teachers, and other stakeholders in making decisions about where to live and with whom, where to work, and how he or she will be involved in the community, including friendships, recreation, and transportation. These preferences and choices then form the foundation for a clearly defined series of steps to implement these decisions.[66] This is a very different approach than the traditional process of finding suitable options based on what is available among institutions, group homes, sheltered workshops, and day programs. Susan L. Parrish, director of the Developmental Disabilities Training Institute at the University of North Carolina, explains this distinction clearly:

> *Honoring the desires of the individual and his or her family is a vastly different proposition from putting a person into a residential facility and then giving them whatever that facility offers. In some facilities, if occupational or speech therapy is offered, then the person will automatically get that. That is a different approach from saying, 'Well, here is an individual, and what is it that they want to achieve with their life? What can we scaffold around them to help them to achieve their desires?'[67]*

Person-centered service delivery is a relatively new concept in I/DD systems of care and continues to evolve.[68]

### *Valued Outcomes*
The term "valued outcomes" is amorphous, but surveys of individuals with I/DD, families/caregivers, and advocacy groups consistently express a desire for community integration, gainful employment, and personal independence. Thus, valued outcomes systems of care are designed to assist individualsin achieving these objectives while concomitantly protecting them from harm and ensuring access to needed medical and behavioral health services.[69]

A related consideration is the extent to which systems of care address functional and other limitations that can hamper or prevent individuals from pursuing their goals. A barometer of a system'seffectiveness is the extent to which these barriers are being addressed without minimal short- or long-term institutionalization. Strategies for accomplishing this include the operation of crisis networks and providing support to community-based organizations in addressing medical and behavioral challenges. In many states, little or no data is available to gauge the extent to which valued outcomes are being achieved for individuals. One initiative for addressing this is the 25-state National Core Indicators project co-sponsored by HSRI and the National Association of State Directors of Developmental Disabilities Services that provides states with proven tools for measuring system outcomes as well as benchmarks for performance.[70]

### *Access to Services*
This is a straightforward performance metric that gauges the ability of beneficiaries to access needed services with a minimum of delay and bureaucratic hassle. Access measurements include such processes as eligibility and enrollment, service planning and authorization, service delivery, and dispute resolution. Proven strategies for improving access in each of these processes include:

- **Single point of entry (SPOE) system**: Many states have either developed or contracted with local entities to offer beneficiaries and their families a "one-stop" resource to obtain information about eligibility, services, and enrollment and, in some instances, to perform tasks like

conducting eligibility assessments, developing care plans, performing service authorizations, and assisting beneficiaries and their families in accessing needed services.[71]

- **Infrastructure/Resource development**: In many states and localities one of the primary obstacles to accessing services is a lack of resources to deliver needed services. This is especially true of direct-service workers with sufficient training and experience in serving the I/DD population. States have implemented a number of strategies to expand their I/DD infrastructure, including offering enhanced pay and benefits to direct-service workers, expanding training and career advancement opportunities, and offering incentives to community-based organizations to develop additional service capacity, including expanded residential alternatives.[72]

- **IT systems**: To an even greater extent than the elderly and physically disabled population, the service delivery system for individuals with I/DD is highly complex, and a well-functioning and effective IT system is all but essential to operating and overseeing a responsive, accessible system. IT processes are particularly valuable for case management and quality-related tasks such as analyzing patterns of service utilization, integrating quality assurance and management functions, and generating timely and accurate quality management reports.[73]

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