

Exploring New Paradigms for the Developmental Disabilities Assistance and Bill of Rights Act

Supplement to the 2011 NCD publication
*Rising Expectations: The Developmental
Disabilities Act Revisited*



National Council on Disability
2012 Supplement to 2011 Report

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Exploring New Paradigms for the Developmental Disabilities Assistance and Bill of Rights Act: Supplement to the 2011 NCD publication Rising Expectations: The Developmental Disabilities Act Revisited

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Introduction

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402), signed into law in 1963 and reauthorized most recently in 2000, is the nation's policy and civil rights framework for more than 4.7 million Americans with intellectual and developmental disabilities (ID/DD). When the law was passed in 1963, Congress established a set of principles and programs focused on improving the lives of people with ID/DD; protecting their civil and human rights; and promoting their maximum potential through increased independence, productivity, and integration into the community. Today, these goals must be revitalized and translated into a coordinated federal strategy focused on supporting citizens with ID/DD in achieving optimal self-sufficiency, economic advancement, and full participation in the community.

Overview of *Rising Expectations: The DD Act Revisited*

In 2011, NCD released a report entitled *Rising Expectations: The Developmental Disabilities Act Revisited*¹ (hereinafter *Rising Expectations*), which summarized the accomplishments and challenges of the DD system since the passage of the DD Act in 1963. In its synopsis, the report described the development of the DD system, which has evolved from a purely medical model to a multifaceted social model involving an interdisciplinary approach to identifying needs and delivering supports and services in the community. Despite some gains in disability rights, people with ID/DD continue to face considerable barriers to full integration, maximum independence, and self-determination. Major programs funded by the Federal Government that affect the lives of people with ID/DD have been in place since the inception of the DD Act. Most significantly, the growth of the Medicaid program has shifted the system of supports for people with DD from one that is funded predominantly by state funds to one that is funded predominantly by Medicaid—with joint federal and state funding. Currently, no federal policymaking or funding stream is focused on building effective community-based alternatives to Medicaid-funded supports for people with ID/DD. Although the

original intent of Congress was that the Administration on Developmental Disabilities (ADD) would span agencies that manage the key domains in the lives of people with developmental disabilities, today the power to affect DD programs is concentrated in the Centers for Medicare and Medicaid Services (CMS). Thus, policy related to citizens with ID/DD lacks coordination across federal departments and agencies.

Rising Expectations addressed three basic questions:

- What has the DD Act accomplished in the past 40 years?
- What are the strengths and weaknesses of the current structure?
- Is the existing structure suited to address the current and future social and policy environment?

This supplement builds on the original NCD report to explore opportunities for expanding the infrastructure to fully realize the underlying goals of the DD Act and to establish a comprehensive policy framework of clear, consistent objectives across federal agencies and within other major legislative statutes.

As *Rising Expectations* described, the nation's expectations, attitudes, policies, and services for people with disabilities have changed dramatically since the DD Act was passed in 1963, and they continue to evolve. Today, our society generally has greater faith in the competencies of citizens with ID/DD, and these citizens and their families have higher expectations about the types of lives they will lead. Graduating from high school, obtaining integrated employment at livable wages, developing meaningful social relationships and natural supports, and living independently in the community are common goals of citizens with ID/DD. Public policy and publicly financed supports must be realigned to more closely mirror the desires and expectations of citizens with ID/DD to contribute and participate fully in society.

Unfortunately, the majority of publicly financed support systems have not kept pace with evidence-based practices or the evolving, enhanced expectations of citizens with ID/DD and their families. Citizens with ID/DD continue to face barriers to accessing health care, housing, employment, and community supports focused on ensuring their full participation in society. Significant public policy issues remain, including inadequate supports for the transition from youth to adulthood, a disconnect between employment and income/asset limits, and a lack of coordination among key systems driving outcomes for citizens with ID/DD.

Purpose

The Developmental Disabilities Assistance and Bill of Rights Act was established under the premise that “Individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of achieving independence, productivity, integration, and inclusion into the community, and often require the provision of services, supports, and other assistance to achieve such.”² The legislation was crafted to establish an infrastructure that would improve access and responsiveness to the needs of people with developmental disabilities and their families, and to ensure that federal policy and programs presumed the highest level of expectations, competency, inclusion, and engagement of citizens with ID/DD.

This supplement expands on the challenges identified in *Rising Expectations* by offering specific recommendations for aligning systems and landmark statutes both within and outside the scope of the DD Act. The supplement examines specific regulatory and legislative strategies that could be deployed to ensure a solid, unified federal policy aimed at fully realizing the intent of the DD Act: to give people with ID/DD the information, skills, opportunities, and support to—

- make informed choices and decisions about their lives;
- live in homes and communities in which they can exercise their full rights and responsibilities as citizens;

- pursue meaningful and productive lives;
- contribute to their families, their communities, their states, and the nation;
- have interdependent friendships and relationships with others;
- live free of abuse, neglect, financial or sexual exploitation, and violations of their legal and human rights; and
- achieve full integration and inclusion in society as individuals, consistent with their unique strengths, resources, priorities, concerns, abilities, and capabilities.

This report is organized into three parts. Section 1 lays out a framework for addressing the structural challenges of achieving strong cross-system coordination of policies, programs, and services within the existing state and federal ID/DD infrastructure.

Section 2 explores policy options to coordinate various federal systems vital to the provision of programs, supports, and services aimed at improving outcomes for people with ID/DD across the lifespan, aligned with the underlying principles of the DD Act.

Section 3 is the conclusion.

Methodology

The recommendations outlined in this supplement are based on findings from the following research and intelligence-gathering activities:

- a comprehensive literature review analyzing trends, developments, challenges, and achievements of the DD Act since its last reauthorization in 2000;
- 25 interviews with individual stakeholders—self-advocates, family advocates, researchers, practitioners, and state and federal government officials; and

- five independent focus groups composed of 6–10 participants representing 15 states.

The supplement also provides an overview of relevant legislative proposals before the 112th Congress and an analysis of several existing and new federal program initiatives linked to the emergence of the DD Act and its fundamental goals.

SECTION 1. Reforming the Federal and State ID/DD Infrastructure

Despite significant gains, people with DD continue to face considerable barriers to full integration, maximum independence, and self-determination. Some of these barriers result from state programs and policies and the wide variation in financial commitment and supports from state to state. Other barriers result from national policies that are inconsistent with each other and with the current DD paradigm (NCD, 2011, p. 24).

NCD's *Rising Expectations* identified several challenges related to ADD's ability to implement the principles of the DD Act effectively under its existing structural constraints. First, there is a significant disconnect between outcomes desired from the DD Act and ADD's ability to direct services, influence program design, and guide policy development across federal systems. Second, given ADD's place in the organizational structure of the Department of Health and Human Services (HHS), it is limited to playing a minimal role through interagency coordinating functions. As noted in *Rising Expectations*, "Outreach to other departments is tenuous at best, with the burden being assumed by the comparatively minuscule resources of ADD and dependent upon the leadership of the agencies" (NCD, 2011, p. 25).

Reauthorization of the DD Act is essential to modernize the system. In addition, ADD needs a thoughtful reorganization and expansion of its authority to ensure a solid connection among the DD networks and state authorities on ID/DD services, as well as expansion of its leadership role to effectuate the alignment of federal policies, programs, and resources. As reported in *Rising Expectations*, "Given current policy and program structures, however, it is easier to raise expectations and awareness than it is to serve needs" (NCD, 2011, p. 24).

1.1. Increasing ADD's Authority and Prominence

Developing a coherent federal policy requires the leadership of a federal entity with the authority and influence to bring federal partners to the table. No such entity currently exists for ID/DD policy. The DD Act legislation established an important set of goals and rights for people with DD that could form the theoretical basis of a strong federal policy, but ADD lacks the authority and influence to broaden the reach of these goals beyond the DD Act programs themselves (NCD, 2011, p. 33).

As indicated in *Rising Expectations*, the federal infrastructure necessary to support the growing expectations of people with ID/DD is severely limited in scope, authority, and resources. One of the most significant impediments to fully realizing the objectives of the DD Act is a lack of a strong federal agency with the statutory and administrative authority to effectively lead and coordinate the Federal Government's role in addressing the needs of people with ID/DD.

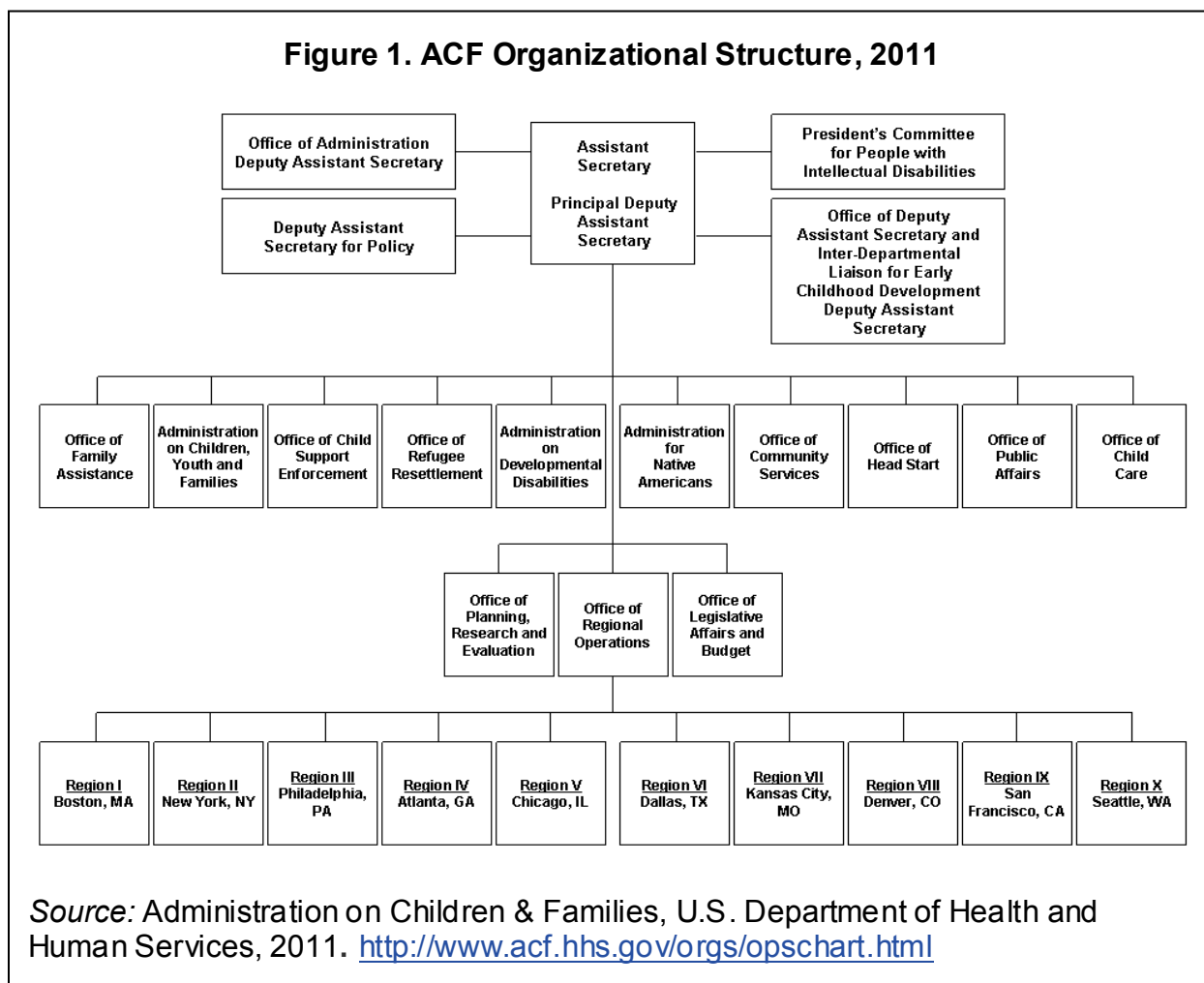
1.1.1. Reassessing ADD's Position in the Administration for Children and Families

ADD has been part of the Administration for Children and Families (ACF), an Operating Division within HHS, since the 1980s. The current organizational structure greatly impedes the ability of ADD's leaders to efficiently engage in high-level internal decision making within the HHS/ACF hierarchy. ADD also has little formal authority to engage other federal partners vital to the effective dissemination of policies, delivery of programs, and collective commitment to improved outcomes for people with ID/DD.

Administrative constraints prevent ADD's leadership from exercising any authority over its budget—all resources are controlled and disseminated by ACF. Prioritization for resources among all the programs housed under the ACF umbrella is highly competitive and overly complex. ADD's leaders must divert energy from their central role of

overseeing programs authorized under the DD Act toward securing resources, decision-making authority, and relevance in an environment in which ADD is just one of a multitude of priorities.

Under this system, ADD has suffered in recent years from budget decreases and human resource constraints, while the objectives and expectations of stakeholders in the ID/DD community have continued to evolve. Providing ADD with its own federal administrative authority—including a budget and resources that reflect the percentage of the population the agency represents and the portfolio for which it is responsible—are the first steps in system transformation. Figure 1 shows the ACF organizational structure in 2011; ADD was previously one of 10 key program offices that report to and are managed by ACF. The other nine offices are the Office of Family Assistance (OFA);



Administration on Children, Youth and Families; Office of Child Support Enforcement; Office of Refugee Resettlement; Administration for Native Americans; Office of Community Services; Office of Head Start; Office of Public Affairs; and Office of Child Care. ACH has regional offices in Boston; New York; Philadelphia; Atlanta; Chicago; Dallas; Kansas City, MO; Denver; San Francisco; and Seattle. However, these regional offices did not support ADD programs.

1.1.2. Increasing ADD's Authority

Elevating ADD at the federal level so that it has both the statutory and administrative authority necessary to fully realize the aims of the DD Act would allow the establishment of the following:

- Unified national goals to focus the attention of leaders, service providers, researchers, and practitioners on the critical issues facing people with ID/DD and their families.
- The development of a clear, coordinated national research agenda on ID/DD.
- Authority for ADD to work across federal agencies to ensure that all domains of public life possess the focus and competencies to include people with ID/DD through inclusion and integration.
- Authority and resources for ADD to centralize evaluation of various federal and state public services to determine which public investments are most effective in achieving desired outcomes for people with developmental disabilities.
- Guidance and support to state ID/DD authorities to assist in the development of effective service systems through dissemination of policy guidance, provision of training and technical assistance to state systems, and investments in transformative system-change demonstrations.

- The ability to effectively collaborate with various federal agencies to develop joint guidance, coordinate data collection efforts, develop consistent objectives and common performance measures, and implement stringent evaluation methods.

Reauthorization of the DD Act creates an opportunity to significantly elevate and expand ADD's authority, to empower the agency to deliver on the ambitious agenda set forth in the DD Act.

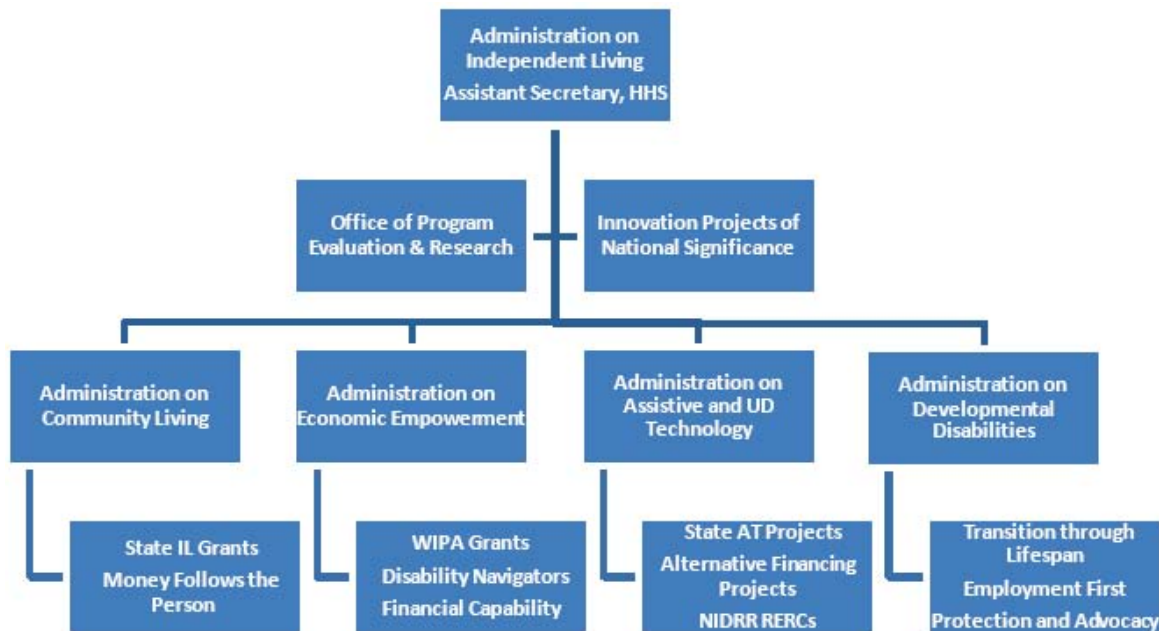
1.1.3. Restructuring the Federal Government Response to Disability: Implications for ADD

Numerous proposals have been developed in recent years to improve the coordination of federal programs and agencies focused on disability policy. One proposal calls for the creation of an entity that would consolidate several existing federal programs into an entity that has statutory and administrative authority to coordinate policy goals, program objectives, data collection requirements, and performance measures.

Figure 2 outlines a model for such an entity that includes the following four core divisions:

- Administration on Community Living, which would be responsible for state independent living grants and other national initiatives, managed by HHS, and focused on supporting people to live in the community, such as the Money Follows the Person demonstration program.
- Administration on Economic Empowerment, which would be responsible for workforce incentives and financial capability programs.
- Administration on Assistive and Universal Design Technology, which would include state assistive technology projects, alternative financing initiatives, and rehabilitation engineering research centers currently operated by the National Institute for Disability and Rehabilitation Research.

Figure 2. Possible Organizational Structure of an Independent Living Administration¹



Source: Prepared by Michael Morris of the National Disability Institute for both the National Council on Independent Living and the Collaboration to Promote Self-Determination (2010).

- ADD, whose portfolio would be expanded to include a focus on transition issues across the lifespan, the promotion of Employment First strategies, and expanded protection and advocacy services.

Conceptually these four divisions would report directly to an assistant secretary-level position.

One important issue is where such an entity would be located within the Federal Government. The Senate draft reauthorization of the Workforce Investment Act (WIA), introduced in June 2011, authorizes an Independent Living Administration (ILA) under the Office of Special Education and Rehabilitative Services in the Department of Education. Under this proposal, the ILA is tied to the vocational rehabilitation system; therefore, it could not be used to transition federal entities such as ADD to the ILA.

Other proposals have suggested housing such an entity within HHS. Coincidentally, HHS recently announced a reorganization of its internal structure that brings together several program offices that provide supports to the aging and disability communities under a newly-created operating division called the Administration on Community Living (ACL). ACL would be led by an Assistant Secretary, who will report directly to the Secretary of HHS. ACL will include the Administration on Aging, Office on Disability Policy, and ADD as well as policy, research and evaluation components. Proponents of this reorganization believe that ACL will significantly elevate ADD's role within HHS and address some of the bureaucratic challenges the office has experienced while under the auspices of ACF.

Regardless of its location, strong bipartisan support exists for the creation of a centralized entity that can bring various federal programs and agencies together under one umbrella. Certainly, the newly created ACL repositions and elevates ADD to a new playing field and ensures that ADD is on equal footing with the AOA at the federal level. ACL would also ensure a greater balance in authority within HHS between these program offices and the Centers for Medicare and Medicaid Services (CMS), which provides the primary funding and reimbursement of both medical and nonmedical long-term supports and services to both the elderly and individuals with disabilities.

While the creation of the ACL is a tremendous step forward in elevating the role of the ADD, a gap will remain in coordination among services specific to the ID/DD population that are housed outside of HHS and the ACL. An additional step worthy of administrative dialogue is to determine whether other program offices and activities of the federal government should eventually be shifted into the ACL. Certainly, the model in Figure 2 provides a more comprehensive consolidation of numerous federal programs and initiatives that could serve as a framework for future expansion of ACL as it evolves over time.

1.1.4. Ensuring Flexibility for ADD to Collaborate Across Federal Systems

To optimize its effectiveness in the future, ADD must have the authority, flexibility, and resources to enter into meaningful cooperative agreements and solid partnerships with the federal agencies that govern programs essential to the progress of citizens with ID/DD. This includes collaborating with other entities in HHS, as well as working with the Departments of Education, Housing and Urban Development (HUD), Labor, Transportation, and Treasury, and the Social Security Administration (SSA). While ADD currently lacks sufficient authority or funding to engage in large collaborative efforts, it does have the ability to reach out in formal, proactive ways to these agencies as an advocate to ensure that the needs of people with ID/DD are incorporated into policies and programs. Currently, ADD has been rather limited in its ability to persuade other agencies to prioritize citizens with ID/DD, but a general consensus exists among stakeholders that ADD's central role should be to function as a "bully pulpit" and ardent advocate across federal agencies on behalf of people with ID/DD.

1.1.5. Promoting Effective ADD Leadership

Despite the constraints related to ADD's lack of authority, flexibility, and resources, ADD leaders have made significant efforts over the past two years to increase the Federal Government's response to citizens with ID/DD by focusing heavily on public outreach and strategic planning. In 2010, ADD hosted five regional two-day interactive forums entitled Envisioning the Future that engaged key ID/DD stakeholders — including self-advocates, family advocates, practitioners, researchers, state and federal officials, and representatives from various DD network components — to learn more about what the field would like to see ADD prioritize as part of its five-year strategic plan. The forums culminated with a national stakeholders meeting in Washington, D.C., followed by a public comment process through which the agency received more than 4,000 comments from stakeholders across the country.

Throughout the regional sessions and at the national stakeholders meeting, participants emphasized that ADD should focus on enhancing its central role as the “national watchdog” for the interests of citizens with ID/DD across federal policies, programs, and agencies, and should advocate for the full inclusion and economic advancement of people with ID/DD.

The Envisioning the Future forums are an example of ADD’s attempts to increase national awareness of the principles of the DD Act and the importance of empowering citizens with ID/DD and their families in federal public policy. ADD’s five-year strategic plan has not yet been released, but the agency’s commitment in recent months to establishing a vision is noteworthy; it offers a tremendous opportunity to reflect on and strengthen the agency’s stature as the leading federal voice advocating for the rights of citizens with ID/DD.

1.2. Strengthening the DD Network Through Expansion and Coordination

In addition to ADD, the DD Act authorizes four other main programs:

- State Councils on Developmental Disabilities (subtitle B);
- Protection and Advocacy Systems (subtitle C);
- University Centers of Excellence in Developmental Disabilities (subtitle D); and
- Projects of National Significance (subtitle E).

The first three programs comprise the backbone of the DD network in the United States. While this network has contributed immensely to the implementation of the Act, several statutory gaps have prevented the network and ADD from reaching their collective potential. Three key strategies for improving the collaborative effectiveness of ADD and the DD network are (1) the development of a coordinated planning process; (2) the

establishment of a consistent data collection and performance measurement system; and (3) the inclusion of the state ID/DD authorities and self-advocacy organizations as formal components of the network.

1.2.1. Requiring Coordinated Planning Among DD Network Partners

The DD Act calls for separate and distinct planning processes in each of the three elements of the DD network and does not allow for the alignment of these planning processes nor require shared accountability among the various DD network components. The Act must be amended to enable ADD to reframe the planning process across all network partners. An ideal model would allow all elements of a state's DD network to collaborate on shared goals related to education, health, community living, and employment, while preserving their discrete roles and responsibilities for particular outcomes. For example, the state DD network could use a coordinated planning process to develop one specific goal in the areas of education, health, community living, and employment that all components of the network would work on collectively. In a coordinated planning model, it is extremely important to strike a careful balance between prioritizing shared network goals and continuing to ensure accountability for achieving individual results related to the core competencies of each partner.

Implementing a planning process that ensures shared goals and accountability across the state DD networks would go a long way toward fostering greater focus on a common set of objectives and projected outcomes. Furthermore, a coordinated planning process would likely result in a more efficient blending of resources among the various components of the DD network and foster increased sustainability through collective responsibility.

One technical adjustment that should be made is to modify the timing of the planning process, so that plans from state DD networks are developed in five-year intervals, with a fifth of the states submitting each year. Given ADD's constrained resources, this

would allow the agency to conduct a higher quality review and provide better feedback to state DD networks during their planning processes.

1.2.2. Pursuing Uniform Data Collection, Consistent Performance Measurement, and Shared Accountability

ADD invests heavily in the data collection efforts of the DD networks, but the emphasis has traditionally been on outputs rather than outcomes. As a result, the agency is constantly challenged to demonstrate through data the impact the networks are having on implementation of the DD Act in the field. It is clear that the DD networks are playing a critical role in the evolution of several important initiatives at the state level, but a lot of this work is anecdotal or not adequately captured under the performance measurement tools required by the Office of Management and Budget (OMB). The DD network needs to collect the kinds of data that demonstrate the true impact, effectiveness, and achievement of the individual components and the overall network.

In response to this challenge, ADD has focused on improving overall data collection efforts, including the development of a uniform set of key indicators. Each network will be held accountable for making progress toward each indicator, by a certain increment, in alignment with the principles of the DD Act. The University Centers of Excellence in Developmental Disabilities (UCEDDs) and the state DD councils have established workgroups, working with ADD staff, to develop a logic model and alternative data collection methods. The P&As have an independent workgroup developing recommended standards. Additionally, more than half of all state DD councils have begun to use the DD Suite data management system to manage and compile outcome data. DD Suite is an enterprise performance management system designed specifically to manage DD council projects and data more efficiently and effectively, and to streamline completion of annual federal reports. It is a user-friendly tool for collecting, monitoring, and managing data from projects; collecting federal performance data; completing the State Plan and Annual Program Performance Report (PPR) and creating internal reports for monitoring and analyzing council projects. State DD councils are

currently required to submit their state plans on DD Suite; now, and beginning in fiscal year (FY) 2012, PPRs must also be completed on DD Suite.

A coordinated planning process with mutual objectives and expectations will help in the creation of a consolidated data collection effort. However, beyond strengthening the data collection efforts of ADD and the DD network, it is important to develop an evaluative model that can combine data from various federal sources (including RSA-911, CMS, Department of Education, and SSA. Such a model would allow ADD and its federal partners to assess ID/DD outcomes, identify policy barriers and service gaps, and complete ongoing trends analyses to determine whether the quality of life of people with ID/DD and their families is improving over time. Several challenges must be addressed in developing such a model.

First, ADD currently has no legislative authority to require federal partners to work toward a more synergistic data collection/sharing model. Thus, the success of a collaborative data collection process across federal systems depends on the willingness of various federal agencies and their networks in the field to invest the time and resources. Second, the diversity in type and definition of variables, collection samples, and timelines among various federal data collection systems would have to be addressed in a way that preserves the legitimacy and credibility of a coordinated data collection and evaluation model.

These combined strategies would allow the Federal Government to effectively measure the impact of ADD, the DD network, and other federal agencies that serve citizens with ID/DD on service delivery and outcomes. Furthermore, a more sophisticated data collection effort could provide information necessary to demonstrate the importance of continued federal investments in ADD and the DD network.

1.2.3. Empowering and Guiding State ID/DD Authorities

Support services for people with developmental disabilities are designed, funded, and managed primarily by state governments, generally through a state developmental disability office. These offices are often a component of a state human services or health agency. People with developmental disabilities receive medical services through the state Medicaid agency, and may receive time-limited services from the state's vocational rehabilitation office, but the state ID/DD authorities are the primary entities with the responsibility to meet the support needs of people with ID/DD.

State ID/DD authorities serve more than a million children and adults annually and manage over \$42 billion in public funding, mainly through Medicaid waiver resources (Kaiser Foundation, 2011). The state ID/DD authority is often the primary, if not exclusive, system that people with ID/DD and their families rely on for publicly financed supports. Because these people are typically born with their disability and have the disability throughout their lives, their relationship with the state DD services agency lasts decades.

The DD Act evolved out of a series of measures adopted in the 1960s and early 1970s that initially provided grants to states to stimulate community developmental disabilities services at the state and local levels. As states began to use Medicaid 1915(c) home- and community-based services (HCBS) waivers to secure federal financial participation in noninstitutional services for people with developmental disabilities, the focus of the DD Act moved away from direct services toward planning, protection, and advocacy. As a result, ADD has maintained a funding and policy relationship with planning entities such as the state DD councils, but has little or no connection with the state ID/DD authorities that provide services for this population.

In fact, no federal agency has a direct connection or authority over state ID/DD authorities. CMS, which oversees the primary funding source for ID/DD services (1915(c) waivers), exercises authority over specific Medicaid reimbursement policy and establishes health and safety and other requirements for Medicaid-funded HCBS programs but is not

empowered to take a holistic, population-specific policy approach to the service systems it funds. Furthermore, in practice, CMS provides oversight and maintains formal relationships with only the state Medicaid agencies, which delegate their authority for operating 1915(c) waiver programs that serve people with ID/DD to the state authorities. Ultimately, the relationship of CMS to the state ID/DD authorities, as channeled through the state Medicaid agencies, is one of insurer or purchaser rather than full policy partner.

1.2.4. Establishing a Funding Stream for Self-Advocacy

Recognizing the value of the growing self-advocacy movement, NCD recommended in *Rising Expectations*, that HHS support the movement in a manner that does not rely solely on the resources of the DD network partners. The funding should be focused on capacity building, and the integrity of the self-advocacy movement can only be preserved if funding is related to grassroots, community-based advocacy development. Thus, this funding should support local self-advocacy organizations and technical assistance to local self-advocacy organizations, rather than through the traditional state-level formulation of the other DD network partners. Similar to the Centers on Independent Living program, funding at the local level, rather than at the state level, will ensure a more competitive funding process and help preserve the independence of self-advocacy groups.

Self-advocates can and should play a more pivotal role in helping shape policies, programs, research, and public investments in areas that directly affect their lives. For example, self-advocates could greatly inform the development of community-based participatory research models (Nicolaidis and Boisclair, 2011).³

1.2.5. Improving Sustainability Through Collective Responsibility

Shared accountability for common objectives and the implementation of a coordinated planning process, coupled with improved data collection systems and an expanded DD network, are likely to greatly enhance the case for increasing federal investments in the

various programs authorized under the DD Act. However, sustainability must also be a shared responsibility—the DD network, states, and community partners must think innovatively about how to sustain promising practices over time. For example, the DD Act does not require a match among state or local partners competing for a Project of National Significance grant. Without this requirement, no incentive exists to ensure the continued sustainability of the initiative once the grant period ends. In the current fiscal environment, sustainability is a tremendous challenge; all stakeholders in the ID/DD system must be committed to addressing this issue through innovation and the development of additional resources.

1.3. NCD Recommendations to Improve the ID/DD Infrastructure

To increase ADD's effectiveness as the preeminent federal agency tasked with promoting the interests of citizens with ID/DD in federal policy, NCD recommends:

- Congress should give ADD stronger administrative authority to effectively lead and coordinate federal policy related to addressing the needs of citizens with ID/DD.
- HHS should leverage the newly-created ACL to further elevate ADD's administrative influence and responsibilities within HHS.
- ADD should enter into cooperative agreements and partnerships with other federal agencies through the use of various administrative tools.
- Congress should expand ADD's authority to facilitate stronger coordination among the three key components of state DD networks by establishing a uniform planning process among state DD councils, protection and advocacy systems, and University Centers on Excellence in Developmental Disabilities (UCEDDs).
- ADD should pursue a uniform data collection process among the various elements of the DD network and expand existing efforts to develop more

effective tools to measure and evaluate the impact of services, programs, and initiatives on people with ID/DD.

- ADD should initiate and lead efforts to build a system to foster increased cross-system accountability for outcomes for people with ID/DD by encouraging multiagency agreements regarding the collection, tracking, and recording of data on people with ID/DD.
- Congress should acknowledge and include state ID/DD authorities as an additional component of the DD network, with operational funding provided by and under the jurisdiction of ADD.
- Congress should provide a separate and distinct funding stream for capacity building and infrastructural support to local self-advocacy organizations, and should acknowledge these entities as an additional component of state DD networks.
- The DD network should formally and more significantly engage self-advocates in the formation of policies, practices, research strategies, and public investments that directly affect their lives. For example, NCD recommends that UCEDDs should expand and leverage existing initiatives with self-advocates using community-based participatory research models.
- Congress should focus on improving the sustainability of Projects of National Significance (PNS) by passing legislation requiring grantees to solidify a local or state match as a condition of receiving federal grant funding for PNS endeavors.

SECTION 2. Cross-System Focus to Improve Outcomes Across the Lifespan for People with ID/DD

The DD Act outlines eight specific areas of emphasis on which the core components of the DD network must focus: quality assurance, education and early intervention, child care, health, employment, housing, transportation, and recreation. In response to demands and issues that have arisen since the statute's 2000 reauthorization, NCD recommends that the categories be consolidated and that ADD and the state DD networks be allowed to focus more holistically on comprehensive priority areas related to addressing the needs of people with ID/DD. NCD recommends that the areas of emphasis be consolidated into four core areas that cover the lifespan from infancy through aging (figure 3):

1. Early intervention and education
2. Transition from youth to adulthood
3. Competitive, integrated employment
4. Ongoing long-term supports, including but not limited to sustained education, training, and employment; health and wellness; housing; transportation; and recreation.

Figure 3. Across-the-Lifespan Policy Framework



Source: This framework and figure was developed by the author of this paper solely for use in this NCD publication.

Any reauthorization effort should consider how to embed the principles of the DD Act in a meaningful way into federal programs and activities related to these four core areas. For example, the requirement in the DD Act that “all programs for individuals with developmental disabilities should meet standards that are designed to ensure the most favorable outcome for those served” should be expanded to provide specific criteria for each of the federal systems tied to these four core areas.

This section identifies key opportunities to develop a cohesive, comprehensive federal policy across various federal agencies and legislative statutes in each of these four areas to ensure a consistent, unified federal commitment to realizing the goals and underlying principles of the Developmental Disabilities Assistance and Bill of Rights Act. The recommendations are not exhaustive; the intent is to identify emerging opportunities over the next two to five years for a coordinated federal response to address the needs of citizens with ID/DD. The emphasis is on cross-agency collaboration and coordination of federal objectives and resources, using strategic tactics deployed through both regulatory and legislative vehicles.

2.1. Recommendations to Improve Early Intervention and Education Opportunities

2.1.1. Stronger Cross-Agency Collaboration

Early intervention and access to education are critical areas of federal focus, shared by the Centers for Disease Control and Prevention (CDC), the Department of Education, ACF and ADD. While interest in early intervention services has skyrocketed among families, federal funding for such activities has not kept pace with demand.⁴ Many children with behavioral or developmental disabilities are missing out on vital opportunities for early detection and intervention.⁵ According to CDC, 17 percent of children in the United States have a developmental or behavioral disability such as autism, intellectual disabilities, or attention deficit/hyperactivity disorder. However, less than 50 percent of these children are identified as having a problem before they

start school, by which time significant delays may have occurred and opportunities for treatment been missed.⁶

The Individuals with Disabilities Education Act (IDEA) Amendments of 1990 to 1997 require states to provide early identification and services to the following infants and toddlers:

- Those with developmental delays.
- Those with established conditions associated with developmental delays.
- At the state's option, children at risk for developmental delays.

States that do not serve the at-risk population are encouraged to track and monitor these children's development, so they can be referred in the future, if necessary. IDEA also mandates that states refer children, free of charge, for a comprehensive, multidisciplinary evaluation by a team that, with the family, will determine which services are needed for the child (via the Individualized Family Service Plan). Furthermore, it requires states to implement coordinated, family-centered, and culturally competent community-based systems of care to provide early intervention services for children identified as having developmental problems.

ADD can and should work across public health and education systems as an advocate for greater coordination of existing developmental screening and early intervention activities. Strategies to ensure a clearer connectivity among ADD, the state and federal ID/DD infrastructure, and other state and federal agencies to address early intervention needs of children with ID/DD and their families are critically important.

Recommendations

- **ADD should work with the Administration for Children and Families, CDC, and the Department of Education's Office of Special Education Programs (OSEP) to**
 - review current federal efforts related to early identification and early intervention;
 - evaluate the ability of systems to work collaboratively at the local and state levels to maximize resources and ensure full coverage; and
 - identify policy and implementation barriers that impede the ability of systems to work collaboratively, including variation in core objectives, target populations, performance outcomes, and evaluation/accountability measures.

- **CDC should work with ADD to inform current data collection processes related to the outcomes of developmental screening and early intervention of children with ID/DD to better capture the effectiveness of specific publicly financed interventions on developmental outcomes.**

This collaboration should include CDC aligning data collection efforts to the definitions of developmental disabilities outlined in the DD Act so as to avoid confusion and ensure greater coordination with ADD's data collection systems.

- **OSEP should obtain input and feedback from ADD in its current revision process of the IDEA accountability reporting system.**

Since early 2011, OSEP has been developing proposed changes to the State Performance Plan/Annual Performance Report (SPP/APR) process as it relates to Part C (early childhood intervention and preschool education). To ensure that any changes to Part C indicators result in systematic improvements that address the needs and improve outcomes for children with ID/DD, ADD can play an instrumental role in reviewing proposed revisions and representing the interests and perspectives of children with ID/DD and their families.

- **ADD should serve in a strong advocacy role to ensure that improvements to existing early intervention monitoring standards are captured in any future reauthorization of IDEA.**

In 2002, a committed group of advocates, parents, State Education Agency directors, monitoring experts, and Part C directors worked with OSEP to develop recommendations to improve monitoring requirements outlined in IDEA. The recommendations resulted in an innovative monitoring model that incorporated principles, indicators, sanctions, and incentives for state early childhood intervention and preschool programs to focus on improving outcomes for children with ID/DD. The working group also recommended that legislative language be added to IDEA that requires states to use data to inform and effectuate systems change. These recommendations were not included in the last reauthorization of IDEA (IDEA-2004); thus, monitoring and evaluation challenges persist.⁷ ADD should play a pivotal role in encouraging a reconsideration of these recommendations in future IDEA reauthorization efforts.

2.1.2. Improved Educational Outcomes

Among the strongest predictors of postschool employment success for young people is whether they earn a diploma. Only 34 percent of students with intellectual disabilities, 40 percent of students with multiple disabilities, and 56 percent of students with autism graduated from high school with a regular high school diploma during the 2007–2008 school year (U.S. Department of Education, 2010). Among all students, those with the most significant cognitive disabilities are the least likely to graduate with a regular high school diploma (ADD, 2011, p. 3).

Federal public policy and resources should reflect a stronger commitment to the implementation of fully inclusive education practices, which benefit all students, including students with ID/DD. Public policies should promote students with special needs as part of the general education population and not as a segregated

subpopulation. Overwhelming evidence demonstrates that fully inclusive schools—in which students with special needs are engaged in the general educational setting and have access to the general curriculum—have higher academic performance outcomes for students with disabilities as well as their peers who do not have disabilities (Wagner et al., 2006). In contrast, placing students in segregated classrooms according to diagnosis or special needs leads to detrimental outcomes (Freeman, SFN, 2000).

Public education should have the highest expectations for all students and promote full access to a free and appropriate public education in the most inclusive setting possible. To realize this vision, ADD must assume a stronger leadership role in public education policy by working directly with the Department of Education on regulatory guidance, policy framing, and implementation of various legislative statutes that affect students with ID/DD. The reauthorization of the DD Act, IDEA, and the Elementary and Secondary Education Act (ESEA) should include provisions that affirm a connective role and shared responsibility between ADD and the Department of Education to coordinate on policy issues that affect students with ID/DD.

Recommendations

To improve the educational opportunities and advancement of students with ID/DD, NCD recommends:

- **Increase the federal commitment to the full inclusion of students with ID/DD in general educational settings (including but not limited to curricula, classrooms, personnel development, outcome data, diploma opportunities) through consistent focus in both administrative action and statutory changes through the reauthorization of the DD Act, IDEA, and ESEA.**

Reauthorization of the DD Act creates a tremendous opportunity to reflect on the educational needs of children and youth with ID/DD and, through legislation, to establish a stronger, more proactive collaboration between the nation's developmental disability and education systems. However, the DD Act is not the only legislative reauthorization vehicle through which cross-system collaboration

and intensified focus on the educational needs of students with ID/DD can be strengthened. The reauthorization of both IDEA and ESEA offer important opportunities to facilitate greater engagement of the DD system into the planning processes, goals, incentives, and evaluation of the nation's public education system.

A specific approach to engaging the DD system in inclusive education efforts is to include the system in creating Individualized Education Programs (IEPs) for students with ID/DD. Another strategy is for ADD and the DD network to collaborate with the educational system to develop incentives and penalties to encourage school districts to offer more inclusive educational settings for all students, including students with ID/DD. School districts must have both meaningful incentives and more stringent performance measures tied to funding to encourage their transformation to fully inclusive settings as a key strategy for effectuating systemwide education reform. For example, using performance measures that evaluate the level of inclusion over time as a prerequisite to receiving a National Blue Ribbon School award would help make inclusion a top priority among school districts.

Preparing teachers to implement Universal Design for Learning (UDL) in classrooms that have both students with disabilities and peers who do not have disabilities is essential to ensure greater inclusion of students with ID/DD. Both general education and special education teachers require enhanced professional training and ongoing mentoring supports to enable them to effectively implement inclusive education practices. The University Centers of Excellence in Developmental Disabilities (UCEDDs) could play a more prominent role in working with universities to provide this additional training during teachers' educational experiences.

- **Leverage legislative reauthorization vehicles and cross-agency activities to promote family and community involvement in the successful inclusion of students with ID/DD in public education.**

Families are an essential component of the successful inclusion of students with significant intellectual or developmental disabilities into general educational settings, but the families of students with significant disabilities are often disenfranchised and isolated from other families in the educational system. ADD and the Department of Education should work collaboratively to provide incentives to school districts to reach out to these families in culturally sensitive and meaningful ways. Additionally, Title II of the DD Act should be enhanced to focus on supporting families of students with ID/DD through education, advocacy, and information-sharing activities to help families navigate the public education system.

- **The Department of Education, in conjunction with ADD, should strengthen relevant indicators to better measure local school district performance in meeting the needs of students with ID/DD.**

OSEP should request ADD to review and provide feedback on any proposed revisions of the IDEA accountability reporting system (the SPP/APR) process) as it relates to Part B (education and transition) to ensure that any changes or enhancements to Part B indicators result in systematic improvements that respond to the needs of and outcomes for students with ID/DD. Specifically, ADD should promote indicators that establish a baseline with respect to inclusion, access to assistive technology, use of UDL, access to age-appropriate general education curricula, and postsecondary outcomes.

- **Improve federal response to IDEA enforcement by expanding cross-agency investments in protection and advocacy efforts related to IDEA compliance.**

An overwhelming demand persists among families of students with ID/DD for support from the protection and advocacy sector to ensure that school districts comply with IDEA principles. Most families lack the financial resources to hire an

attorney to negotiate on their behalf during conflicts with school districts that refuse services the student is eligible to receive. Thus, families often turn to Protection and Advocacy for Individuals with Developmental Disabilities (PADD) or Protection and Advocacy for Individuals with Mental Illness (PAIMI) programs, which receive funding from HHS. Although as many as 50 percent of PADD cases and 11 percent of PAIMI cases are related to IDEA compliance and enforcement issues, the Department of Education provides no dedicated funding stream to support protection and advocacy agencies' education work.⁸ As a result, the protection and advocacy network is often unable to provide support to legal cases related to topics such as employment, abuse and neglect, independent living, and denial of services. The Department of Education should request a separate funding stream in its annual budget to support the continued work of the protection and advocacy network on IDEA compliance cases. The additional funding, with the approval of Congress, would ensure that protection and advocacy entities can focus resources from ADD and other federal agencies on other categories of legal cases beyond IDEA compliance that currently cannot be pursued.

2.2. Ensuring High Expectations and Opportunities for People with ID/DD As They Transition from Youth to Adulthood

Today's youth with ID/DD have expectations of future employment, yet continue to struggle to access competitive integrated employment. Data from the National Longitudinal Transition Study-2 (NLTS2) show that 86 percent of students with disabilities who are of transition age definitely believe that they will work in their adult years. When adding in those that feel they will probably work, that percentage moves to 96 percent (Kiernan, 2010). Even with a diploma, youth with intellectual disabilities demonstrate the lowest rate of paid employment among students with disabilities (29.8 percent), 1 to 4 years after exiting high school (Newman et al, 2010). In one recent study of 338 high school graduates with

developmental disabilities, only 14.2 percent were employed in positions paying at least minimum wage (Simonsen, 2010) (ADD, 2011, p. 3).

Educational and vocational guidance in preparation for adulthood is critical for all youth, including those who have significant disabilities. The discussion of transition should begin as early in a person's life as possible. Evidence-based research has conclusively documented that people with disabilities who were educated in inclusive settings, exposed to work experience and career exploration, and participated in a paid work experience while in school had better postsecondary and employment outcomes (Cimera, 2008).

When state education, vocational rehabilitation, workforce development, Medicaid, and other public agencies work closely together to support and promote the growth and development of youth with significant disabilities, these youth benefit from the synergistic coordination of supports and are able to achieve better outcomes. To ensure effective coordination among these entities, systemic changes must allow for flexible braiding of resources and the entities must agree that publicly financed supports should focus on enabling youth to achieve optimal outcomes associated with postsecondary education, integrated employment, independence, self-sufficiency, and economic advancement.

Of all students with disabilities, those with ID/DD have the poorest postschool outcomes (Hart, Grigal, and Weir, 2010). Until the past decade, the option of attending college—especially the opportunity to participate in typical coursework—was rarely available to high school students with ID/DD. The usual options for students with ID/DD, especially those past the age of 18, had previously been limited to segregated life skills or community-based transition programs.

2.2.1. Postsecondary Education As a Tool for Effective Transition

The number of post-secondary education (PSE) programs designed for students with ID/DD has increased exponentially in recent years, and today there are approximately 250 PSE programs for students with intellectual disabilities in 37 states. 149 of these programs responded to the 2010 National Survey of Inclusive PSE programs conducted by the Institute for Community Inclusion (ICI). Of these respondents, 50% are four-year colleges or universities, 40% are two-year colleges, and 10% are considered trade/technical schools.⁹ Forty-five percent of respondents indicated that they served only adults with ID, 26% served dually enrolled students (meaning students who were enrolled in both high school and college simultaneously), and 29% served both of these groups. The 2010 survey responses indicated that programs vary considerably in terms of level of student integration, access to typical courses, and disability services. For example, 49% indicated that students did have person-centered planning. It is difficult to fully evaluate the effectiveness of the programs, as only 52% of the PSE programs indicate that they collect outcome data.

Inclusive PSE options have great potential to improve transition outcomes for youth with ID/DD. Of all disability groups, youth with intellectual disabilities have the lowest rates of education, work, and preparation for work after high school. Nationally, interest is growing in postsecondary education as a way to improve employment and other key life areas for people with ID/DD, as those who participate in PSE tend to obtain better jobs with higher wages. Research has demonstrated that comprehensive transition and postsecondary programs have had a positive effect on student rates of employment, wages, social networks, and self-determination skills (Guenette, 2003). Recent studies indicate that the strengths of this model of service delivery are employment training and community participation—in one state, 87 percent of students were employed or in training positions, and 100 percent were involved in integrated community activities

(Zafft, Hart, and Zimbrich, 2004). Another study found that participation in PSE correlated positively with competitive and independent employment (Zafft et al., 2004). This data indicates that these programs are offering new hope and leading to greater employment, independence, and community living for students with intellectual disabilities.

Vocational rehabilitation (VR) agencies can also play an important role by supporting the inclusion of youth with ID/DD in postsecondary programs and including this participation in the student's Individualized Plan for Employment (IPE). The following information from ThinkCollege.net demonstrates the positive effect PSE is having on the attainment of integrated employment by youth with significant disabilities.¹⁰

- In 2007, of the 36,154 youth with ID/DD between the ages of 16–26 years who completed vocational rehabilitation services, 1,223 (3.4%) participated in some type of PSE program and 537 (1.5%) successfully completed a nondegree program, associate degree, vocational/technical certificate, bachelor's degree, or graduate degree program. Of the 537 people who attained higher education as a component of receiving vocational rehabilitation services, 312 (or approximately (58%)) went onto competitive employment, earning an average of \$338 per week. The data shows that attending PSE resulted in a 48 percent employment rate and average wages of \$316 a week. In contrast, youth who did not receive PSE services but left VR services to take a job (32%) had an average weekly income of \$195.
- Data from the national vocational rehabilitation database (RSA 911) shows that youth with ID who participated in PSE were 26 percent more likely to leave VR services with a paid job, as compared to youth who did not participate in PSE, and they earned an average of 73 percent more per week. However, despite positive employment outcomes for youth with ID who receive PSE, the percentage of youth who receive these services as part of their IPE is low.

- Further study is needed on the impact of PSE on employment outcomes for people with ID/DD, especially with regard to the role of vocational rehabilitation. Lifelong learning promotes academic, professional, and personal development, and helps all citizens enjoy lives of dignity and purpose.

Initial federal investments to support the continued expansion and evolution of PSE programs targeting students with ID/DD must be sustained and leveraged with coordinated VR resources. The availability of internships, apprenticeships, and skilled training through PSE programs drives significant positive outcomes for students with ID/DD by broadening their exposure to a wide array of vocational and professional opportunities in the community.

The amendments to the Higher Education Opportunity Act (HEOA) that allow non-degree-seeking students with ID/DD to pursue work-study and federal grant assistance, have greatly enhanced the ability of students with ID/DD to access PSE programs. Unfortunately, the process that PSE programs must complete in order to receive approval for offering such assistance is quite complex. Therefore only six PSE programs have been authorized to provide federal student aid packages for non-degree-seeking ID/DD students. Steps must be taken to simplify this process, and to encourage more PSE programs established for ID/DD students to take advantage of the federal student aid provisions authorized in HEOA.

2.2.2. System Change: Transitioning Toward Excellence in Achievement and Mobility

In February 2011, to address some of the systemic barriers and support the transition of youth with ID/DD to adulthood, Rep. Gregg Harper (R-MS) introduced a trio of bills known as the Transitioning Toward Excellence in Achievement and Mobility (TEAM) legislation. The legislation—which includes the TEAM-Education Act (H.R. 602), the TEAM-Empowerment Act (H.R. 603), and the TEAM-Employment Act (H.R. 604)—was developed after 18 months of discussions with a group of national advisors, including

self-advocates with ID/DD; parents and family advocates; providers of transition services; practitioners currently working in publicly financed systems in the areas of education, VR, and Medicaid systems; and researchers. The TEAM legislation is the first comprehensive legislative package aimed at cross-system transformation and alignment of planning processes, objectives, funding streams, desired outcomes, and performance measures to improve transition outcomes for youth with ID/DD. The legislation seeks to strengthen accountability, clarify expectations, expand flexibility, and align systems to ensure that publicly funded assistance is used effectively to provide young people with a significant disability with the opportunity, encouragement, and support to pursue a postsecondary education, become gainfully employed in an integrated setting, and contribute to and engage in meaningful ways in typical community settings after they leave high school.

- The TEAM-Education Act (H.R. 602) would amend the Individuals with Disabilities Education Act by requiring that transition components be included in IEPs for all IDEA-eligible students at the age of 14, expanding the definition of transition services to include customized employment strategies and self-determination activities, and clarifying the fact that local education authorities may use discretionary dollars to bring in transition expertise or contract out transition services. H.R. 602 would require school districts to include a representative of the state ID/DD authority on the IEP team for every student with an intellectual or developmental disability from age 14 until the student leaves the school system.
- The TEAM-Empowerment Act (H.R. 603) would amend the DD Act to establish transition planning and service divisions within the state ID/DD authorities to establish a formal role and responsibility on the part of the state authority for the effective transition of youth with ID/DD to adulthood. H.R. 603 would require state authorities to work with these youth to develop Individual Transition Plans to improve outcomes and increase self-determination. The bill would increase accountability of these authorities by allowing the commissioner of the ADD to

provide guidance and assistance to state ID/DD authorities, to help them be effective partners in the transition process of youth with ID/DD.

- The TEAM-Employment Act (H.R. 604) would amend the Rehabilitation Act to realign preferred outcomes for people with significant disabilities and streamline public funding by requiring the VR systems to actively engage with other state entities. The bill would promote innovation and accountability through demonstration grants focused on system reform.

The TEAM legislation takes important steps to remove the current policy barriers and prioritize the use of publicly funded supports to encourage postsecondary education and competitive, integrated employment as a preferred outcome for youth with ID/DD transitioning to adulthood. Some critics of the trio of bills have expressed concerns about the prohibition on federal funds to support segregated outcomes, such as day habilitation or center-based employment settings. State VR entities have raised questions about the ability of the VR system to take on many of the responsibilities the new laws would place on the system.

2.2.3. System Change Through Reauthorization of the Workforce Investment Act

Transition to adulthood of youth with significant disabilities will be a driving policy issue as Congress considers the reauthorization of the Workforce Investment Act. In 2011, the Senate Committee on Health, Education, Labor, and Pensions (HELP) released a comprehensive draft reauthorization package that includes major changes aimed at transforming the vocational rehabilitation system to enable it to focus on improving outcomes for youth with significant disabilities. Several dramatic enhancements have been added to the legislation to facilitate the transition of these young people into adulthood, including the following:

- Direct emphasis on the preferred outcomes of competitive, integrated employment and postsecondary education for all youth, including youth with significant disabilities.
- Required cooperative agreements among VR and other state agencies (including state ID/DD authorities) critical to the provision of transition, employment, and long-term supports and services to citizens with significant disabilities.
- Establishment of a holistic set of preemployment transition services to prepare youth with significant disabilities for entry into the general workforce.
- Creation of local transition coordinators in the VR system to ensure the effective delivery of preemployment transition services for youth with significant disabilities and to increase links between the VR system and special education.
- Targeting of 10 percent of all state VR resource allotments toward implementation of the transition components of the legislation.
- Establishment of national system-change demonstration projects on the transition of youth with significant disabilities.
- Funding directives to encourage more intensive state focus on the expansion of supported employment services to youth with significant disabilities most at risk of being placed in sheltered work or at risk of not securing employment in the general workforce.

Several practitioners and advocacy leaders have called for an expansion of VR transition services to youth with significant disabilities through the age of 26 years. Transition provisions outlined in the legislative proposal have inconsistent age eligibility requirements. State VR agencies currently provide transition supports in many cases through age 26—any decrease in the age of eligibility for services in the WIA reauthorization would be regressive to the status quo. This is a particularly important

policy concern for people with significant disabilities who continue to participate in secondary education until the age of 22, then enter a postsecondary education program. Any reduction in eligibility age for the use of preemployment transition services or other VR supports could put many of these people at great risk of being pushed out of integrated environments where they are thriving.

There is growing concern about the capacity of state vocational rehabilitation agencies to implement new strategies to improve transition outcomes for youth with ID/DD unless resources to scale up existing VR agencies are available and opportunities to provide training to VR counselors on evidence-based best practices are increased.

Despite these concerns, the HELP Committee's efforts to develop a series of comprehensive reforms to the Workforce Investment Act represent a firm commitment to improve outcomes for youth and young adults with ID/DD.

Recommendations

To improve the Federal Government's role in and impact on the transition of youth with ID/DD into adulthood, NCD recommends:

- **Research:** The Department of Education's Office of Special Education and Rehabilitative Services (OSERS) and the National Institute on Disability and Rehabilitation Research (NIDRR) should invest in further research to evaluate the effect of postsecondary education opportunities on the transition outcomes of youth with ID/DD.
- **Funding for expansion:** Congress should increase funding to support the expansion of the Department of Education's Transition and Postsecondary Programs for Students with Intellectual Disabilities, which were authorized as part of the Higher Education Opportunity Act. Additionally, the U.S. Department of Education should take steps to simplify the administration of the provisions

authorized in HEOA that allow non-degree ID/DD students to receive federal student grants and access work-study options.

- **Cross-agency coordination:** Congress should pass legislation that promotes a comprehensive focus across federal systems on improving transition outcomes for youth and young adults with ID/DD, and provides incentives for the transformation of state and local transition systems by fostering and supporting innovation and increased cross-agency coordination.
- **Role of VR agencies:** Congress should use the reauthorization of the Workforce Investment Act as an opportunity to expand the role and responsibilities of state VR agencies in identifying opportunities and supports for youth with ID/DD to ensure their successful transition into postsecondary education and integrated employment opportunities after high school.

2.3. Recommendations to Improve Employment Outcomes

According to the January 2011 Current Population Survey (CPS), approximately 17 percent of American citizens with disabilities are employed, compared to 63 percent of individuals without disabilities. For individuals living with ID/DD, the likelihood of participation in integrated employment is even lower, with state ID/DD agencies reporting that only 22 percent of the individuals served by these agencies participate in integrated employment (ADD, 2011, p. 3).

Despite public funding for the provision of employment services for people with disabilities who require significant supports, the employment rate of people with ID/DD remains low. Four out of five people with significant disabilities are not considered part of the labor force (ACS, 2008). A review of trend data from 2003 through 2009 confirms that participation in sheltered or facility-based employment and nonwork services grew steadily, suggesting that employment services continue to be viewed as an add-on

service rather than a systemic change (Butterworth, Smith, Hall, Migliore, and Winsor, 2009; Mank, 2003). As the Institute for Community Inclusion (ICI) reported in its 2010 publication *StateData: The National Report on Employment Services and Outcomes*,

In FY2009, an estimated 20.3 percent of individuals receiving day supports from state IDD agencies received integrated employment services. The data demonstrate a decline in the estimated percentage of people served in integrated employment services (from 23.7 percent in 1999), suggesting that the growth seen in supported employment between the mid-1980s and mid-1990s has not continued. The data also demonstrate an increase in the percentage of people served in facility-based and non-work settings. The service setting with the highest reported percentage of individuals receiving services in FY2009 was community-based non-work (42.6 percent), followed by facility-based non-work (36.1 percent) and facility-based work (27.1 percent). Variability in the number of states that are able to report data in these three individual service categories limits our ability to pinpoint the specific setting in which growth is occurring; however, an analysis using data from states that are able to report data in each of the three service categories suggests that the percentage of individuals served in facility-based and non-work settings is increasing. (Butterworth et al., 2011, p. 8)

The new ICI data confirms that states continue to vary widely in their commitment to integrated employment—nationally, it is estimated that only 20.3 percent of those who receive day supports from state IDD agencies participated in integrated employment services during FY2009 (Butterworth et al., 2011, p. 20). This number has slowly declined after reaching 25 percent in FY2001.

To reverse this inequity in our country and optimize the self-sufficiency of people with ID/DD, we must take steps to ensure that they have meaningful opportunities to secure

postsecondary education, integrated employment, and economic advancement. People with ID/DD should have the opportunity to pursue competitive, integrated employment.

2.3.1. Employment First: Integrated Employment As the Desired Outcome

People with ID/DD, their families, employers, and, increasingly, state and federal policymakers recognize the value of employment for people with disabilities and the significant contributions they make to the national workforce and the economy. The engagement of these people in the labor pool has a considerable financial impact, generating income that is returned to the economy in the form of tax revenues and reducing their reliance on public resources for needed services and supports (Cimera, 2007). The return on employment-related expenditures—currently estimated by the Social Security Administration (SSA) to be less than 0.5 percent—will increase as more people with intellectual and other significant disabilities enter and remain in employment (ACS, 2009).

States furnish a wide range of employment-related services and long-term supports under Medicaid waiver programs. In addition, funding for job training and placement is typically available from state offices of vocational rehabilitation, One Stop Career Centers, and other state and federally funded programs providing transitional assistance from school to employment, although this funding is usually time-limited.

- The ongoing recession and soaring unemployment rates present even greater challenges for citizens with ID/DD who wish to engage in competitive, integrated employment.
- The data shows that people with developmental disabilities who are employed in regular community jobs has fallen nationwide in recent years. Equally disturbing is data suggesting that the focus of service provision has, in many regions, shifted away from employment and job supports toward continued reliance on

prevocational services, segregated day habilitation, and community-based nonwork activities—these kinds of services do not help participants access productive career paths or meaningful work in the community (Butterworth et al., 2011).

Unemployment is not the only economic challenge that disproportionately affects people with ID/DD. Because of the way Social Security, Medicaid, and other means-tested public supports were created, citizens with ID/DD are sentenced to a life of cyclical poverty if they wish to be deemed eligible for supports under these programs. Current asset limits attached to eligibility requirements for Supplemental Security Income (SSI) and Medicaid create disincentives to work that ultimately discourage people with ID/DD from seeking employment. Only about 9 percent of those who receive SSI are employed, with average annual earnings of less than \$500 a year. Less than 0.005 percent of those who receive SSI ever leave the system and move onto employment.

According to recent projections, annual income maintenance payments to SSI recipients will reach a startling \$1 trillion by 2018.

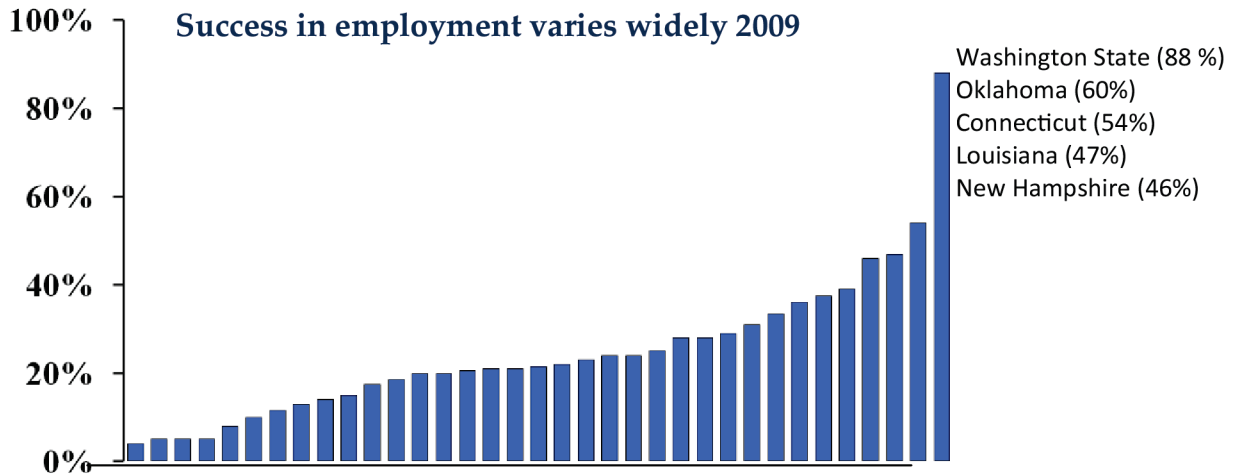
States and the Federal Government could more effectively support the capacity of people with ID/DD to live and work in the community if they redesigned home- and community-based Medicaid waiver programs to focus on self-determination, person-centered service planning, individual budgeting, and participant-directed service delivery. Policymakers are taking stock of the intent and purpose of the services provided, as well as the outcomes that are being achieved. Increasingly, support dollars are being seen as investments in people's lives and the means by which those with even the most intensive needs can become productive and contributing members of society. Accordingly, the emphasis of public funding in many states is being shifted to support activities that enable people with developmental disabilities to fully participate in work and become active members of their communities. However, as Rusch and Braddock noted, "While supported employment has made significant gains since its formal introduction in 1984 (P.L. 98-527), segregated services continue to outpace the growth of supported employment" (Rusch and Braddock, 2004, p. 48).

Several forward-thinking state DD agencies are implementing comprehensive Employment First policies to guide the funding and delivery of supports to eligible persons throughout the state's service delivery system. Employment First strategies consist of a clear set of guiding principles, policies, and practices promulgated through state statute, regulation, and operational procedures that identify employment in typical work settings as the priority for state funding and the focus of supports furnished to people with developmental disabilities during the day. States use Employment First policies to operationalize a commitment to the principle that public funds are most appropriately used as investments in people's lives, helping them access integrated employment, full community participation, and optimal well-being.

Employment First policies anchor the service delivery system, focusing funding, resource allocation, training, daily assistance, and even the provision of residential supports on the overall objective of employment and strengthening the capacity of those who receive publicly financed supports to enter the workforce and become contributing members of society. These state initiatives have shown that when supports and funding streams are focused on getting people with ID/DD into integrated employment, a greater proportion of citizens with ID/DD end up going to work. The key is to make sure that the commitment among local, state, and federal public partners is solid and sustained over time. A diversion of investment or low expectations for people with disabilities can perpetuate impediments in current policies, practices, and programs. Figure 4 shows the disparity among states in terms of their rates of participation in integrated employment services, ranging from Arkansas at 4 percent to Washington at 88 percent. Other states with high participation rates in integrated employment services are Oklahoma (60%), Connecticut (54%), Louisiana (47%), and New Hampshire (46%).

Although Employment First policies are being adopted by many states, definitions of "integrated employment" and the approaches used to accomplish operational objectives vary, reflecting the unique characteristics of each state's service delivery system. To support states that are committed to changing systems and infusing an Employment First paradigm into policy and practice, the State Employment Leadership Network (SELN)

Figure 4. Percentage of People with ID/DD Participating in Integrated Employment Services by State, 2009¹¹



Source: Data shared by NASDDDS Executive Director Nancy Thaler in July 2011 during an NCD-hosted Congressional Briefing on the state of long-term supports and services for individuals with ID/DD in honor of the 12th anniversary of the Olmstead decision. Data originated from: Butterworth, J., Cohen Hall, A., Smith, F.A., Migliore, A., Winsor, J.A. (2011). *StateData: The National Report on Employment Services and Outcomes*. Institute for Community Inclusion (UCEDD), Boston, MA: University of Massachusetts. Pg. 19.

was created in 2007 through a partnership between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion (ICI). SELN provides training and technical assistance to 26 states on promising practices and lessons learned in other states, including ideas and strategies related to goal-setting, data collection, policy development, and performance measurement. The network focuses on a wide range of policies, operational practices, funding methodologies, and training procedures designed to significantly increase the number of people with developmental disabilities who are employed in integrated community jobs. In 2009, ICI and NASDDDS compiled a list of key Employment First strategies that states have been implementing in recent years (see table 1).¹²

**Table 1. Examples of State-based Approaches
to Implementing Employment First
(analysis of the State Employment Leadership Network, 2009)¹³**

Employment First Strategies	States
Adopting rules reaffirming that integrated employment is considered the primary service option for adults receiving day habilitation services and supports.	Colorado
Including requirements that integrated employment be addressed in each recipient's Individual Service Plan (ISP) each time the plan is developed, revised, or reviewed.	Colorado
Developing and implementing specific target goals, including identifying a percentage of people who are in nonwork and sheltered employment that will move to integrated employment by a designated time, with specific benchmarks established at two intervals over a five-year period.	Florida
Providing mandates to local offices, in the form of an administrative directive from the agency leadership, requiring the redirection of at least 5 percent per year from Adult Day Training to employment.	Florida
Establishing, through state code, the goal of full-time employment as the optimal outcome of day service delivery, but allowing for part-time employment when deemed in the best interest of the individual consumer or voluntary work on a temporary basis if no jobs are available.	Oklahoma
Including statutory provisions requiring that people with ID/DD have access to employment and the training necessary to sustain employment.	Pennsylvania
Identifying employment as the first day service that should be explored.	Tennessee
Identifying employment as the most appropriate service unless there is a compelling reason for recommending another service.	

Employment First Strategies	States
Including provisions to ensure that choice is essential and assistance is provided to help consumers find and change jobs that reflect their interests and skills.	Tennessee
Including provisions to ensure that jobs offer advancement (career development) if the person so chooses.	Tennessee, Washington
Requiring that services support a job for everyone who wants one.	Tennessee
Providing supports to pursue and maintain gainful employment in integrated settings in the community shall be the primary service option for working age adults, with deviations requiring authorization.	Washington
Requiring that steps be taken toward integrated employment for those not currently working in such settings.	Washington
Ensuring the capability to track changes and work status over time.	Pennsylvania, Washington
Furnishing technical assistance to providers if Employment First as a practice is to be successful.	Washington

Source: Kiernan, B. and Moseley C. (2009) “Employment First: A Policy Position for States – Focusing on Integrated Employment as the Desired Outcome”. Prepared for the State Employment Leadership Network and the Collaboration to Promote Self-Determination in 2009.

ADD can play a pivotal role in helping these state systems foster an expanded focus on Employment First strategies across the country. Proponents of these strategies have long advocated for the establishment of a federal Employment First policy in the form of legislation, regulatory guidance, or an Executive Order. ADD could lead the discussion about establishing a federal Employment First policy and possibly even including an Employment First section in the DD Act when it is reauthorized. ADD can also promote the continued evolution of Employment First strategies by leveraging resources to

provide additional support for such endeavors. ADD has recently demonstrated a strong commitment by awarding five-year Partnership in Employment Systems Change grants to six states. These grants reflect a strong commitment on the part of the agency to promote a solid focus on employment systems change, especially given ADD's current budget constraints.¹⁴

Employment is a cross-agency responsibility of the federal government.

Recommendation

- **NCD recommends that the Administration issue an Executive Order directing all federal agencies involved in the education, training, and employability of citizens with ID/DD to implement an Employment First platform to prioritize a focused commitment to the employment of people with ID/DD in integrated employment.**

2.3.2. Reconceptualizing Supported Employment Services

Reauthorization of the Workforce Investment Act (WIA) provides an extraordinary opportunity to reform the vocational rehabilitation system with the goal of reconceptualizing the role of supported employment services (SES) to ensure an expanded and more effective use of these services to realize the aims of Employment First policy. Recent attempts by Congress to craft WIA reauthorization legislation take several important steps toward this aim, including the following proposals:

- Extend supported employment services to 24 months.
- Require cooperative agreements among vocational rehabilitation and other state agencies critical to the provision of transition, employment, and long-term supports and services to citizens with significant disabilities.

- Strengthen data collection and reporting requirements to capture more detailed, outcome-oriented data, stratified by disability type, to better evaluate the effectiveness of the VR system in helping people with disabilities complete employment objectives (emphasizing attainment of competitive, integrated employment).
- Focus the attention of research and training activities on supporting providers of sheltered employment who want to transform into providers of community-based employment and supports that lead to competitive, integrated employment, with restrictions on the use of training dollars and technical assistance that perpetuate segregated or sheltered employment practices.
- Integrate various federal programs focused on the employment and independent living of individuals with ID/DD into the newly-established Administration on Community Living within HHS in order to ensure a strong coordination of policies and resources.

Recommendations

As Congress continues to consider WIA reauthorization, NCD recommends:

- **Multisystem collaboration:** Identify and address pressure points in the implementation of vocational rehabilitation that prevent state VR agencies from collaborating with state education agencies (SEAs), Medicaid systems, ID/DD authorities, and local and state workforce investment boards toward a common goal of dramatically improving integrated employment outcomes for citizens with significant disabilities.
- **Presumption of eligibility:** Modify current statutory language regarding presumption of eligibility to prevent state VR systems from deeming a person ineligible for employment services, including prevention of such determinations through the inappropriate use of assessment.

- **Expansion of the assessment process:** Expand the assessment process related to eligibility determination for VR services to allow a more customized approach to employment placement through a comprehensive, exploratory discovery process. Discovery is used as a guide for customizing an employment relationship for an applicant with an employer.¹⁵ This process takes into account all the applicant's life experiences rather than single instances of performance. The discovery process begins with a provider representative who meets with the applicant and family at the home. These visits, along with other discovery activities, give the individual and the family, as appropriate, information about their powerful roles in the process and allow the provider to compile basic information that is necessary to begin the process.

A comprehensive profile is developed that describes the person in a narrative manner. For students, this document is a work in progress during the transition years of the school career; it is passed on from teacher to teacher until graduation. For adults, the profile provides information vital to planning and can be used instead of traditional, comparative vocational assessment procedures.

- **Time limits and structure of supported employment services (SES):** Rebalance and increase VR funding to create more flexible, individualized, and realistic time limits on the provision of SES, allowing for sequencing and customization of services (episodic or continuous) to reflect the unique needs of the individual. This would include addressing challenges related to the current order of selection policies implemented by state VR agencies so the most vulnerable people are protected and have ongoing access to SES and customized employment strategies.
- **Performance measurement and accountability:** Create a tiered incentive system to credit VR systems for the successful placement of people with significant disabilities into integrated employment. Such a system would include the establishment of a "partial closure" to reflect that the person has been placed

in a time-limited integrated employment setting and is receiving services aimed at preparing him or her to successfully pursue integrated, supported employment within a reasonable timeframe. Additionally, To encourage VR counselors to take on difficult cases, they would be credited for their involvement in successfully placing clients with the most significant disabilities in a way that adequately captures any additional time or work effort involved.

- **Alignment of SES between VR and Medicaid-funded long-term services and supports (LTSS):** Coordinate funding mechanisms and streamline SES processes with CMS and state ID/DD agencies.
- **Ensure provision of VR services, including but not limited to SES, for those who actively pursue self-employment:** Ensure that people who choose to pursue self-employment or entrepreneurship can access SES as needed to enter and sustain this self-determined, self-directed career path. Clarification in legislative language should affirm that such a path is considered a successful employment outcome.

2.3.3. Promoting Employment in the Context of Medicaid Reform

The crisis in Medicaid spending has sparked a national debate about whether the time has come to undertake a comprehensive reformation of the Medicaid system. A cross-disability dialogue with CMS and congressional leaders has led to several policy recommendations on reforming the focus of Medicaid supports for working-age beneficiaries with significant disabilities.

Recommendations

With the aim of realigning Medicaid funding to foster increased community-based outcomes for citizens with ID/DD, NCD recommends that Congress and the Administration consider the following policy proposals endorsed in 2011 by 13 national organizations:¹⁶

- **Promote Employment First principles through strong systems coordination, aligned guidance, and consistent definitions and objectives related to the use of public funds.**

Federal agencies mandated with providing employment supports should achieve consensus on a clear definition of “employment” to establish a baseline against which states can be measured. Clear guidance should be disseminated jointly by CMS, the Department of Justice, the Department of Labor, the Rehabilitation Services Administration (RSA), and SSA stating that publicly financed supports should prioritize areas essential to ensuring optimal independence through sustained integrated employment, economic advancement, and community living.

- **Develop a model for the establishment of a national Medicaid buy-in program.**

Congress should authorize and CMS should craft a model national Medicaid buy-in (NMBI) program for all states, based on state initiatives that have been in existence since the 1990s. The NMBI would specify a minimum level of earnings and include asset-building provisions that each state could expand on. The model should include analysis of a shared responsibility for the state administration of the NMBI between county Medicaid offices and state or local One-Stop Career Centers and economic development departments. The buy-in program should focus on wraparound services not available through private insurance and on the full range of necessary individualized LTSS.

- **Provide incentives for integrated employment through an enhanced FFP Rate.**

CMS should establish an enhanced Federal Financial Participation (FFP) rate of 90 percent for all Medicaid-funded employment preparation, placement, and job coaching costs incurred in states when consumers prepare for, enter, and remain in integrated employment. This could be funded by decreasing FFP rates for

instructional and other large segregated/congregate home- and community-based services (HCBS).

- **Place time limits on HCBS funding for prevocational training and preparation services and placements in sheltered workshops.**

Ample data supports the reality that the longer a person is out of the competitive workforce, the more difficult it is to return. Currently, thousands of American citizens are unnecessarily being placed in sheltered work environments when they are capable of much more than the system presumes. CMS should reevaluate the vetting process for establishing whether and when a person is placed in prevocational services to ensure that opportunities for employment supports leading to postsecondary education or integrated employment are fully exhausted first. NCD also recommends that prevocational training services in sheltered workshops be time-limited, to reflect a systemic focus on supporting people's advance into integrated employment.

- **Work with SSA and other federal agencies to fund state-centric work incentives, technical assistance centers, and other collaborative strategies.**

CMS and SSA should lead and fund competent entities that will implement and maintain real-time information services across program areas that support employment of people with significant disabilities. Informed decision making on employment, jobs, benefits, and building assets requires real-time, on-demand information services from public, private, and nonprofit sectors collaborating at the local, state, and national levels.

- **Improve data collection systems across state programs.**

CMS, SSA, RSA, and the Department of Labor should collaborate on data collection and analysis to better understand and evaluate how states are faring in addressing the needs and expectations of people with disabilities who work or plan to work and are receiving Medicaid supports. Resource realignment is best informed through common performance and outcome measures.

- **Promote promising evidence-based practices.**

CMS should direct states to adopt promising practices that result in true integration as part of the infrastructural requirements to receive increased FFP rates through the Balancing Initiative and other incentive programs (such as Community First Choice), and should develop outcome and performance measures that meet the expectations of beneficiaries. Infrastructure and capacity-building should continue to be tied to supporting and improving employment outcomes at the individual level.

- **Improve evaluation and accountability of state Medicaid plans and waiver applications.**

CMS, with assistance from ADD, should increase its scrutiny of the evaluation, review, and approval of state Medicaid plans and Medicaid waiver applications, including applying aggressive scrutiny to evaluating reimbursement rates for various services to ensure that the rates are reasonable, cost-effective, and balanced among service options. These regulatory agencies can go only so far, however, in trying to influence the prioritization of services and supports that are home- and community-based. To really achieve the goal of sharply reducing the congregate, segregated, facility-based institutional bias of waiver funding requires statutory changes. Consumers and families should be encouraged to participate in the development and review of applications before they are submitted.

- **Enforce state compliance with the *Olmstead* decision in relation to employment supports and residential services.**

CMS issued an Informational Bulletin on September 16, 2011, to state Medicaid programs that clarified the *2012 Home- and Community-Based Services Waiver Technical Guide* and included the following changes: it divides the definition of supported employment services to distinguish between individual and group SES; encourages the realignment of funds toward innovative, evidence-based practices, including customized employment strategies for people with ID/DD and

other significant disabilities; and states that prevocational services should be time-limited and focused solely on preparing a person for the general workforce. These changes could have an enormous impact on prioritizing Medicaid waiver funds to focus more intently on the delivery of services aimed at achieving competitive, integrated employment for people with ID/DD. CMS, in collaboration with HHS's Office for Civil Rights (OCR) and the Department of Justice, should direct CMS regional offices to actively promote integration and aggressively discourage states from implementing strategies that perpetuate segregation in work and housing.

- **Use the Money Follows the Person (MFP) Balancing Initiative to expand the focus on integrated employment for citizens with ID/DD.**

CMS should continue to incentivize and direct states to merge their Medicaid Infrastructure Grant (MIG) infrastructure and capacity-building efforts with MFP initiatives to achieve targeted outcomes and performance measures in the areas of supported, integrated community living, and integrated employment. States may use MFP funds to provide employment supports, and CMS recently developed a tool to educate state Medicaid agencies on models for using MFP resources to increase their focus on integrated employment outcomes for people with ID/DD (see table 2). Congress should allow CMS to expand the eligibility criteria for MFP to include people who, without additional supports, would be at risk of institutionalization.

Table 2. Opportunities to Promote and Support Employment in MFP Through Policies and Services¹⁷

Resource/Policy	MFP Demonstration Period	FMAP/MFP Support	Post-MFP 365-Day Demonstration Period
Employment specialists	Infrastructure	100% administrative	Employment specialist as part of the administrative element of MFP infrastructure or state infrastructure using rebalancing resources.
MFP benefits counselors	Infrastructure	100% administrative	Evidence-based practice that supports employment; beneficiaries understand the impact of employment/earnings on benefits.
Benefit counseling service	Supplemental service or HCB service	State's standard or enhanced FMAP	State not obligated to continue but may be on HCBS plan of care.
Medicaid community programs (HCBSW, State Plan, 1915i, etc.)	How does financial eligibility in the state's community program compare with financial eligibility for NF?	State's existing FMAP	MFP rebalancing resources to support increased access and capacity to HCB supports. Do the existing or new programs support the proposed groups with earnings?
Supported employment services	HCBS	State's enhanced FMAP	State not obligated to continue but may be on HCBS plan of care.

Resource/Policy	MFP Demonstration Period	FMAP/MFP Support	Post-MFP 365-Day Demonstration Period
Customized employment support services	HCBS	State's enhanced FMAP	State not obligated to continue but may be on HCBS plan of care.
Cash and counseling/ flexible budgeting model	Infrastructure building costs for states that do not currently have such a model	100% administrative	Cash and counseling infrastructure to prioritize MFP; over time it will become part of the state's rebalancing system.
HCBS services as part of the cash and counseling model	HCBS	State's enhanced FMAP	State not obligated to continue but may be on HCBS plan of care.

MFP=Money Follows the Person

FMAP=Federal Medical Assistance Percentage

HCBS=home-and community-based services

HCBSW=home-and community-based services waiver

NF=nursing facility

*Benefits counseling: If a state chooses an MFP benefits counseling option, costs associated with that model may not be combined with or duplicate any other federally funded program.

**Cash and counseling/flexibility model: State planning would be necessary to develop the infrastructure to support the service delivery model, including how the employment specialists and cash and counseling/flexible budgeting model would eventually function within the state's overall infrastructure as part of rebalancing activities.

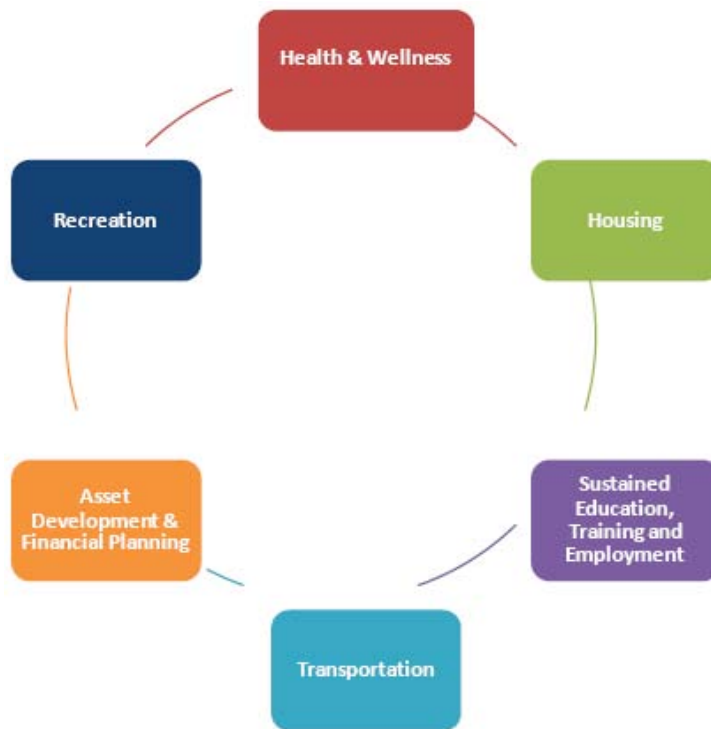
Source: (2011). Shea, A. Disability & Elderly Health Programs Group, Centers for Medicare & Medicaid Services.

2.4. Ongoing Supports Over the Lifespan

People with ID/DD should have access to opportunities and the necessary supports to participate in community life, have interdependent relationships, live in homes and communities of their choosing, and make contributions to their families, communities, states, and the nation. With education and support, communities can be accessible and responsive to the needs of people with ID/DD and their families, and are enriched by the full and active participation in and contributions of these people. Federal policy related to the provision of LTSS for citizens with ID/DD should be based on a holistic framework that customizes supports according to the individual needs of beneficiaries. The supports should be focused on helping the person achieve independence, economic advancement, optimal self-sufficiency, and full community participation. With regard to the DD Act, the focus of the DD network and other systems that provide ongoing supports to citizens with ID/DD should be framed in an updated, comprehensive model that emphasizes cohesiveness over the lifespan. Figure 5 shows the comprehensive supports required in the lifespan model, including health and wellness; housing; sustained education, training, and employment; transportation; asset development and financial planning; and recreation.

The original NCD report, *Rising Expectations*, contained an in-depth exploration of the DD system's capacity to provide ongoing supports. This supplement offers additional policy considerations related to Medicaid reform and the provision of LTSS for citizens with ID/DD. Additionally, the Collaboration to Promote Self-Determination convened several consumer and family-directed national disability organizations in 2010 to outline a set of values and guiding principles for framing the future provision of publicly financed LTSS for citizens with ID/DD; these are summarized in table 3.¹⁸

Figure 5. Model: Comprehensive Supports Over the Lifespan



Source: Serena Lowe, President, AnereS Strategies, LLC.

**Table 3. Value Framework and Guiding Principles
for the Provision of LTSS**

Core Values	Connecting, Guiding Principles
<p>Equality</p> <ul style="list-style-type: none"> • Lack of personal control or autonomy, deprivation of human dignity, segregation, and abuse (including seclusion and restraint) should not be experienced by any population or tolerated by our society for any reason. 	<ul style="list-style-type: none"> • Personal autonomy, access, accountability, and responsibility over one’s life decision-making processes, including control over publicly funded and personal resources required to support a person in his or her personal needs and pursuits, result in better outcomes (improved quality of life, for example).
<p>Choice</p> <ul style="list-style-type: none"> • A fundamental part of providing supports is to discover and honor individual choice. Options that foster a “separate but equal” scenario or that promote exclusion from mainstream society are not options that foster true individual choice or empowerment. 	<ul style="list-style-type: none"> • Publicly financed supports should eliminate institutional biases that perpetuate segregated outcomes, which limit the ability of people with disabilities to fully actualize or pursue their own goals and motivations, and restrict their opportunities.
<p>Competence</p> <ul style="list-style-type: none"> • Competence should be presumed in everyone, and public policy should have the highest expectations for both the system and individuals. 	<ul style="list-style-type: none"> • Public systems that help people with disabilities maintain meaningful employment in an integrated setting, earn a sufficient income, generate assets, live independently, forge strong community relationships in inclusive settings, and attain optimal self-sufficiency will see a decreased reliance on public supports and financing over the long term.

Core Values	Connecting, Guiding Principles
Community <ul style="list-style-type: none"> The provision of supports should be measured according to how nearly the life of a person with a disability is in the community to the lives of peers without disabilities. 	<ul style="list-style-type: none"> People with disabilities are chronically underrepresented in all aspects of society; as a result, their quality of life (in terms of employment, wealth, and health indicators) is significantly lower than that of any other subpopulation in the United States (stratified across race, age, and gender).
Home <ul style="list-style-type: none"> Everyone deserves a home, not a homelike setting. 	<ul style="list-style-type: none"> People with numerous social relationships have healthier outcomes and are less likely to be abused.
Work <ul style="list-style-type: none"> Working-age people with disabilities should be supported to pursue a working lifestyle. 	<ul style="list-style-type: none"> Work should not be optional for people who are capable of working and rely on public assistance. It should be presumed in all facets of public support structures that people with disabilities want to work. A well-compensated and well-trained workforce is critical to providing supports.

Core Values	Connecting, Guiding Principles
<p>Dignity of Risk</p> <ul style="list-style-type: none"> • Future systems of supports and service delivery should break away from cyclical paternalism and instead promote and respect the dignity of risk. 	<ul style="list-style-type: none"> • The nature of cognitive impairments associated with a DD/ID disability makes people living with DD/ID particularly vulnerable to the prejudices of external stakeholders and may affect the ability of these people to make informed choices based on personal desires as opposed to external influences and pressures. • Families (of biology or of choice) of adults living with ID/DD are an important component in considering supports.
<p>Equity</p> <ul style="list-style-type: none"> • All citizens with disabilities should receive public resources on the basis of the support they need to help them strive for and achieve personal objectives related to increasing their self-sufficiency, independence, and economic advancement. 	<ul style="list-style-type: none"> • Systems should focus scarce resources on assisting people with significant disabilities by producing outcomes related to inclusive education, integrated employment, and independent living in typical community settings.

Source: (2010). Collaboration to Promote Self-Determination.
<http://thecpsd.org/about/value-frame-work/>

2.4.1. Defining “Community” to Promote Inclusion and Full Participation

The Medicaid HCBS waiver program (also known as 1915(c) waivers) is one of the primary funding streams for long-term services and supports for citizens with ID/DD. Institutional settings have their own funding streams, and the misuse of HCBS waiver funds for institution-like settings in both residence and daily life restrict the choices available to individuals and families by forcing a choice heavily biased toward one or more institutional settings.

HCBS waiver funds are limited and are designed to ensure that citizens with disabilities have the supports they need to live and work in integrated settings. In April 2011, CMS published a Notice of Proposed Rulemaking (CMS-2296-P) clarifying the types of settings for which Medicaid HCBS waiver funding could be used. The proposed regulation was intended to establish minimum standards to ensure that HBCS are delivered in integrated community settings and that waiver funds are not spent in settings that are congregate in nature or have the characteristics of an institution.¹⁹ ADD has supported and should continue to support the efforts of CMS to move forward in implementing policy that will strengthen the integrity of the HCBS program by ensuring that funds are dedicated to getting people living, working, and fully participating in integrated settings.

The national self-advocacy movement has been particularly vocal about the importance of preserving HCBS waiver funding for community-based options. The 2011 report *Keeping the Promise – Self-Advocates Defining the Meaning of Community*²⁰ From the perspective of the national self-advocacy organizations that co-authored the publication (with ADD’s assistance), institutions are defined as those that—

- Include only people with disabilities.
- Include more than three people who have not chosen to live together.

- Do not permit people to lock their bedroom or bathroom doors.
- Enforce regimented meal and sleep times.
- Limit visitors, including who may visit and when they may do so.
- Restrict when an individual may enter or exit the home.
- Restrict people's religious practices or beliefs.
- Limit a person's ability to select or remove support staff.
- Restrict people's sexual preferences or activity.
- Require people to move if they want to make changes in the personnel providing their support or the nature of their support.
- Restrict access to the telephone or the Internet.
- Restrict access to broader community life and activities.

Community settings are defined in the report as having, at a minimum, the following characteristics:

- If people share a living arrangement, they have chosen to do so and chosen the people they will live with.
- Residents have lockable access to and egress from their own living area.
- Access to the greater community is easily facilitated on the basis of the person's preferences.
- People have the right to hire and fire their own staff.

- People may choose what, when, and where they eat, drink, and engage in social activities.
- People have access to affordable, accessible transportation to participate in the broader community, including attendance at places of worship, volunteerism, social and civic engagement, and natural support networks.

The report states:

We lose an important aspect of community life if we spend our time only around people with disabilities, in day habilitation centers, and are not able to be included in our broader communities.... We must have opportunities to work in jobs as part of the general work force, among people who do not have disabilities. Opportunities for earning wages and benefits should be the same as those of everyone else. CMS funding should be used for supported employment and not be used for sheltered workshops or settings paying sub-minimum wage to people with disabilities. CMS community funding should not be used for any segregated settings, including day habilitation centers. Anything that segregates us from our communities is not community.²¹

The definition of community has important public policy implications for the delivery of long-term supports and services for people with ID/DD. CMS should clarify that HCBS funds may not be used for congregate care settings, except where small groups of people with disabilities choose to live together and where the setting does not have the qualities of an institution. The rule should prohibit states from using HCBS waiver funds to provide services to people who are living in a setting in which they are required to receive and participate in services as a condition of continued tenancy. CMS should review state applications to ensure that these standards are met.





2.4.2. Realigning Public Resources to Prioritize Home and Community Based Services

Over the past several years, significant federal expenditures intended to help people with disabilities live and work independently in integrated community settings have achieved promising results. In 2009, federal and state investments in services for people with ID/DD totaled \$53.21 billion; 75.5 percent (\$40.2 billion) of these investments came from state and federal Medicaid contributions. Sixty-three percent of the funds came from HCBS waivers; 30 percent were dedicated to intermediate care facilities for people with intellectual disabilities; and 7 percent were directed toward other Medicaid-related services.²² However, despite the increased funding from HCBS waivers, many funds intended to help people with disabilities live, work, and engage in their communities continue to be misdirected to services that produce the opposite outcomes. As a result, thousands of people continue to receive services that are costly to the system, result in further segregation, impede individual progress, and create additional barriers to their successful participation in society at optimal levels of self-sufficiency. Table 4 shows the average cost per person according to the type of residential support received.

2.4.3. Transformational Change in the Context of Medicaid Reform

ADD has the opportunity to inform the ongoing work of CMS in defining and prioritizing waiver supports. The continued investment of federal funds in traditional, institutionally biased, and segregated facility-based models of service delivery for working-age adults with disabilities—including nursing home care and group residential housing, sheltered workshops, prevocational services, day treatment, and day habilitation—must be reexamined to determine whether they are producing the outcomes that Congress, the Administration, and the U.S. Supreme Court intend. So far, 14 states have closed all institutions within their jurisdiction.²³ NCD held its 2011 Living Forum in Portland, Oregon, to highlight the state's 20-year pathway to institutional closure. The forum identified three foundations for system change: (1) building values of community

**Table 4. Comparison of Costs of Institutional Versus
Community-Based Residential Services for
Working-Age Medicaid Beneficiaries with Significant Disabilities²⁴**

Type of Service	Cost per Person	People Served with \$5M
ICF/ID	\$128,275	39 
HCBS Residential	\$70,133	71 
Host/Foster Family	\$44,122	113 
Own Family	\$25,072	200 

Source: Presented by NASDDDS Executive Director Nancy Thaler in July 2011 during an NCD-hosted Congressional Briefing on the state of long-term supports and services for individuals with ID/DD in honor of the 12th anniversary of the Olmstead decision.

inclusion; (2) understanding influence and opportunities; and (3) developing long-term strategies for transitioning and sustaining people in community settings.²⁵

Federal spending and entitlement programs must be rebalanced and reinvested to create incentives for the use of evidence-based practices that result in living, working, and participating in the community as the norm, rather than the exception, for people with significant disabilities. Building the capacity of people with significant disabilities to be self-sufficient, taxpaying citizens who can contribute to their communities must be the expected outcome of public investments if we are to create an affordable and sustainable system of supports.

Medicaid eligibility requirements should be crafted to promote work, family, and savings. Current eligibility criteria set unrealistically low income and asset limits and penalize people who are married, which does not reflect the common American values that people should be encouraged to work to their optimal potential, build savings for their

future needs, and create and maintain strong familial structures. These issues arise not only in Medicaid but in other entitlement programs that people with disabilities rely on for survival, including Social Security, Temporary Assistance for Needy Families, and supplemental nutrition assistance programs. Until the eligibility structures of these programs are significantly overhauled and aligned, tremendous barriers will perpetuate cycles of poverty and dependence.

Data overwhelmingly demonstrates that where people live affects where they work, and where they work affects where they live. Medicaid reform must align public policy, regulations, incentives, and performance measurement, with the goal of helping people live, work, and participate in their communities.

Recommendations

To fully realize the principles of the DD Act, NCD recommends that any Medicaid reform proposal should embody a central focus on system change that includes the following guiding principles:

- An emphasis on person-centered practices in all Medicaid services and the provision of guidance and technical assistance to state Medicaid agencies and their state operational counterparts to help them adopt such practices.
- A primary focus on Employment First and on using public funds to get people working and living in the community.
- Stronger accountability through improved consumer-outcome-based performance measures for states administering the Medicaid program.
- Criteria for state Medicaid plans to ensure compliance with Title II of ADA and the *Olmstead* decision: the “most integrated setting” in long-term services and support in living and day/employment supports.

- An overhaul of current eligibility requirements related to asset and income limits, as well as criteria that create unfair barriers for married people.
- The use of Medicaid HCBS waivers or state plan services for the purchase of benefit planning services.
- Better coordination within and among systems, linking objectives, investments, planning, and outcomes across systems (e.g., education, aging networks, vocational rehabilitation, and general workforce development).
- Statutory authority and a stronger leadership role for CMS in establishing fee structures and reimbursement rates to ensure financial incentives that promote community-based outcomes, including the provision of individualized supports and natural supports.
- Greater flexibility to states through the coordination and sharing of resources across systems by planning, braiding, and blending strategies for multiple funding streams.
- Control, when desired, over planning processes, service options, and resources for and by individuals and families.
- Significant transparency in the dissemination of information to individuals and families to ensure easier navigation through various systems and support options focused on promoting each person's optimal independence and self-sufficiency.
- Recognition that Medicaid services should increase individual self-sufficiency, even though a majority of recipients will still require a certain level of long-term supports throughout the lifespan that are not available through private health insurance or the health exchanges to be established by 2014 under the Affordable Care Act.

- A broader focus on the role of families and extended families as caregivers, when necessary and appropriate, to ensure that supports for caregivers are in place.
- Attention to programs for dually eligible persons to ensure that working-age adults with disabilities continue to receive the supports necessary to sustain a fully integrated life in the community.

Again, ADD can play an important leadership role in establishing a framework of guiding principles for the upcoming Medicaid debate. For example, on September 12, 2011, CMS released guidance on the Balancing Incentive Initiative, authorized by Section 10202 of the Affordable Care Act, which allows CMS to award additional federal funds to states to provide financial incentives to increase access to noninstitutionally based long-term services and supports (LTSS). ADD could have played an important role in the development of criteria for the Balancing Incentive Initiative, which provides an enhanced Federal Medical Assistance Percentage (FMAP) rate to states that focus more of their federal resources on home- and community-based options.²⁶

In addition to key structural reforms that result in a greater emphasis on the prioritization of HCBS, states that want to take advantage of the enhanced FMAP rate must agree to two additional requirements. First, they must agree to provide services to eligible beneficiaries regardless of how people enter the program (i.e., no preference is allowed for a single point of entry). Second, states will no longer be allowed to enter into contracts with one entity to provide both case management and the services people with ID/DD can receive using waiver dollars.

SECTION 3. Conclusion: Transformation in the Midst of Fiscal Crisis

Given the current economic crisis, a transformation is required across systems of policy, practice, and funding toward a more progressive approach to serving people with the greatest need; this approach must focus on promoting optimal self-sufficiency and independence. The public systems on which the majority of the ID/DD population relies throughout their lifespan have not been significantly modernized since their inception more than 45 years ago. Thus, public policy remains entrenched in the 1960s-era all-or-nothing approach to serving people with disabilities, in which a person must demonstrate inability to be productive to be deemed eligible for critically important supports. Federal policy and programs have not kept pace with evidence-based best practices or with the evolving desires of self-advocates and families. Existing systemic impediments must be addressed holistically and comprehensively to allow citizens with ID/DD to work, save, and financially contribute as taxpayers to society, and to ensure that they also continue to receive the support necessary to thrive, enjoy optimal health, and become as independent as possible.

The current structure of publicly funded supports for citizens with ID/DD will continue to face scrutiny in the years to come; this structure should be carefully modernized in a way that helps people reach their optimal levels of self-sufficiency while acknowledging that many of them will require some level of supports throughout their lifespan.

We must identify and eliminate the systemic impediments in our current public infrastructure that discourage and even prevent citizens with ID/DD from enjoying the same opportunities as those without disabilities to go to school, work, earn a livable wage, live independently, and engage meaningfully in their communities. Promoting citizenship and self-sufficiency is at the core of our nation's social fabric, and federal policies or systems that perpetuate the discrimination, segregation, or diminution of citizens with ID/DD are financially unsustainable and morally contradictory to the rights

outlined in the DD Act and the ADA. Various pockets of the country have made progress in moving beyond the old models of segregation and cyclical dependency toward optimal self-sufficiency and advancement of citizens with ID/DD. This progress must be brought to a national scale.

The aims of the DD Act can be fully realized only if the Federal Government makes a firm commitment to realigning public policy, funding streams, and goals across federal systems to focus on achieving the highest expectations of and for citizens with ID/DD.

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Endnotes

¹ National Council on Disability, *Rising Expectations: The DD Act Revisited*, 2011 (<http://www.ncd.gov/publications/2011/Feb142011>).

² Developmental Disabilities Assistance and Bill of Rights Act of 1963 (reauthorized as P.L. 106-402). http://www.mnddc.org/dd_act/documents/63-MHH-CIF.pdf

³ Most community-based participatory research (CBPR) projects involve local communities defined by race, ethnicity, geography, or occupation. Autistic self-advocates, a geographically dispersed community defined by disability, face issues in research similar to those experienced by more traditional minorities. Nicolaidis et al. sought to build an academic-community partnership that uses CBPR to improve the lives of people on the autistic spectrum. Through the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), the research team conducted several studies on the health care experiences and well-being of autistic adults. They identified a number of strategies that integrate technology and process to successfully equalize power and accommodate diverse communication and collaboration needs. Nicolaidis et al. concluded that CBPR can be conducted successfully with autistic self-advocates. <http://aaspire.org/?p=publications>

⁴ National Early Childhood Technical Assistance Center, “Annual Appropriations and Number of Children Served Under Part C of IDEA,” 2011 (<http://www.nectac.org/partc/partcdata.asp>); M. Greer, A. Taylor, and S. D. Mackey Andrews, FPG Child Development Institute, National Early Childhood Technical Assistance Center (NECTAC), University of North Carolina, *A Framework for Developing and Sustaining a Part C Finance System*, NECTAC Note No.23, 2007. This paper is based on a presentation of the same name given at the November 2003 Office of Special Education Programs National Early Childhood Conference in Washington, DC (<http://www.nectac.org/~pdfs/pubs/nnotes23.pdf>).

⁵ Ibid. NECTAC, funded through the Department of Education’s Office of Special Education Programs (OSEP), has prepared a chart that outlines federal appropriations compared with number of children served from FY1987 through FY2011 (<http://www.nectac.org/partc/partcdata.asp>). The chart shows that while the number of children deemed eligible for Part C early intervention services grew from 274,747 in FY2004 to 342,821 in FY2011, the annual federal appropriations for Part C services declined from \$444.4 million in FY2005 to \$438.5 million in FY2011.

⁶ Data obtained from the Centers for Disease Control, 2011 (www.cdc.gov).

⁷ The information was summarized in an executive summary developed by the National Association of State Directors of Special Education, the entity responsible for organizing the OSEP meeting on the State Performance Plan/Annual Performance Report process within IDEA accountability system during the summer of 2011 (Alexandria, VA, May 11–

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¹¹ Data shared by NASDDDS Executive Director Nancy Thaler in July 2011 during an NCD-hosted congressional briefing on the state of long-term supports and services for people with ID/DD in honor of the 12th anniversary of the *Olmstead* decision. Data originated from J. Butterworth, A. Cohen Hall, F. A. Smith, A. Migliore, and J. A. Winsor, *The National Report on Employment Services and Outcomes*, Institute for Community Inclusion, University of Massachusetts, Boston, 2011, p 19. http://www.communityinclusion.org/pdf/statedata2010_finaldraft.pdf

¹² Bill Kiernan, director of the Institute for Community Inclusion (UCI) at the University of Massachusetts, and Chas Moseley, deputy executive director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), developed a policy paper on Employment First strategies and experiences of states that participated in the State Employment Leadership Network (SELN) in 2009. SELN is a national collaborative of ICI and NASDDDS to provide technical assistance to states, focusing on systems change to improve employment outcomes of citizens with ID/DD. In 2001, 26 states were members of SELN. More information can be found at www.seln.org.

¹³ Kiernan and Moseley, Employment First policy paper, 2009.

¹⁴ For more information on the ADD's Partnerships in Employment Systems Change grants, go to <http://www.acf.hhs.gov/programs/add/grantsandfunding.html>.

¹⁵ The Department of Labor's Office on Disability Employment Policy (ODEP) has developed a series of educational materials and toolkits for practitioners on customized employment strategies and approaching the process of discovery. For additional information, go to <http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/deliverables/index.htm>.

¹⁶ Policy brief, *Taking a Hard Look at Medicaid and the Economic Well-Being of Americans with Disabilities: Recommendations to Reform and Improve Economic Outcomes for Citizens with Disabilities*, 2011. The following national organizations endorsed the recommendations outlined in the policy brief: American Association of People with Disabilities; APSE; Autistic Self-Advocacy Network; Autism Society of America; Center for Self-Determination; National Association of State Directors of Developmental Disabilities Services; National Council on Independent Living; National Disability Institute; National Down Syndrome Congress; National Down Syndrome Society; National Organization of Nurses with Disabilities; TASH; World Institute on Disability. The policy brief can be downloaded at <http://TheCPSD.org>.

¹⁷ Developed by Annette Shea, Money Follows the Person (MFP) project officer, Disabled and Elderly Health Programs Group, Division of Community Systems Transformation, CMS, in February 2011 and disseminated to state Medicaid Infrastructure Grant (MIG) and MFP directors at the MIG conference in May 2011 as a tool to help state MFP programs think about how to use MFP funds to provide integrated employment supports for citizens with ID/DD.

¹⁸ The Collaboration to Promote Self Determination is a network of national disability organizations created in 2007 that advocates for high-impact public policy reform aimed at optimizing the economic advancement of citizens with ID/DD (<http://TheCPSD.org>).

¹⁹ “Medicaid Program: Home- and Community-Based Services (HCBS) Waiver, Notice of Proposed Rulemaking,” 76 *Federal Register* 73 (April 15, 2011, p. 21311). This CMS notice (CMS-2296-P) clarified the kinds of settings for which HCBS waiver funding could be used. The proposed regulation stated that an HCBS setting “must be integrated in the community; must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care; must not be located in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual’s diagnosis or disability, as determined by the Secretary...[and] must not have qualities of an institution, as determined by the Secretary. Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual’s ability to engage freely in the community.” <http://www.gpo.gov/fdsys/pkg/FR-2011-04-15/pdf/2011-9116.pdf>

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²¹ Ibid.

²² Braddock et al, Coleman Institute and Department of Psychiatry, University of Colorado, 2011. Data from the 2010 State of the States in Developmental Disabilities, a national data collection initiative managed by the Coleman Institute and funded by ADD and NIDRR. <http://sos.arielmis.net/index.php/publications/books>

²³ To date, the following states have closed all intermediate care facilities for the mentally retarded: District of Columbia (1991), New Hampshire (1991), Vermont (1993), Rhode Island (1994), Alaska (1997), New Mexico (1997), West Virginia (1998), Hawaii (1999), Maine (1999), Minnesota (2000), Indiana (2007), Michigan (2009), Oregon (2009), and Alabama (2012).

²⁴ Presented by N. Thaler at NCD Congressional briefing, 2011.

²⁵ For a summary of the 2011 Living Forum hosted by NCD in Portland, Oregon, May 6–7, 2011, http://www.ncd.gov/events/RegionalForums/Living_Forums.

²⁶ On September 12, 2011, CMS released guidance on the Balancing Incentive Program: <https://www.cms.gov/CMCSBulletins/downloads/cib-9-20-11.pdf>. Total funding is not to exceed \$3 billion in federal matching payments. Once CMS approves a state's application, the funding is available beginning October 1, 2011, and ending September 30, 2015, or whenever the \$3 billion has been expended. Effective October 1, 2011, the Balancing Incentive Initiative began offering a targeted increase in the FMAP to states that undertake certain structural reforms to increase access to noninstitutional LTSS. The increased matching payments are tied to the percentage of a state's noninstitutional LTSS spending, with lower FMAP increases going to states that need to make fewer reforms. States in which 25–50 percent of total expenditures for LTSS are directed toward noninstitutionally based supports are eligible for a 2 percent enhanced FMAP. States in which less than 25 percent of total expenditures for Medicaid LTSS are for noninstitutionally based LTSS are eligible for a 5 percent enhancement.