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The Disability Cliff

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The Disability Cliff

We're pretty good about caring for our disabled citizens—as long as they're children. It's time to put equal thought into their adulthoods.

The “cliff” is something that all parents of teenagers with developmental disabilities worry about. The Census Bureau estimates that 1.7 million American children have intellectual or developmental disabilities. Unlike in past generations, these children often go to school alongside children without disabilities, taking classes that seek to prepare them for jobs in the competitive economy.

Yet once they age out of special education—usually at 22—many young adults with developmental disabilities find a reality that is very different from the one they had gotten used to. When they lose their federal entitlement to special education, they are thrown into an underfunded and uncoordinated system in which few services are available as a matter of right. They must now contend

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with services from a variety of providers, financed by a variety of agencies, most of which are not sufficiently funded to cover everyone, and many of which are far too bureaucratic and insufficiently focused on ensuring that their clients can spend meaningful days integrated in community life. They fall, in other words, off the cliff.

Young adults with intellectual disabilities for the most part now live in houses and apartments in the community, not in institutions as they did in years past—a measure of our progress. But far too many spend their days employed in sheltered workshops and activity centers that closely resemble the dayrooms of those old institutions. According to the Institute for Community Inclusion at the University of Massachusetts Boston, 80 percent of the 566,188 people served by state intellectual- and developmental-disabilities agencies in 2010 received services

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in sheltered workshops or segregated nonwork settings. Instead of productive, mainstream jobs with competitive wages, these individuals find that the only work options available to them are largely dead-end jobs that pay less—often far less—than the minimum wage. For some, the sheltered workshop is the best-case scenario—not because

they lack the skills to do better, but because our disability policies leave them with nothing even minimally productive to do all day.

We have largely achieved the goals of integration in terms of *where* people with intellectual and developmental disabilities live. But we have fallen far short of those goals in terms of *how* they live. To truly achieve the objectives to which our disability laws are formally committed, we must focus our attention on the cliff.

A fundamental change begins with integrating the various streams of funding for adults with disabilities. Congress should provide a federal entitlement to “supported employment services”—which provide ongoing supports, ranging from job coaches to modifications to work environments, to enable a recipient to obtain and keep a job in the competitive workforce—for all young adults with intellectual and developmental disabilities. That entitlement can be administered by the same public school system that provided services through age 21. And it can be paid for by Medicaid, with its substantial federal financial contribution.

Recent changes in the law have moved policy in the right direction by providing financial incentives and legal mandates for school systems and vocational rehabilitation agencies to begin to integrate their services. But these changes

have not moved nearly far or fast enough. Young adults with disabilities still must shuffle between multiple service systems, and they still often find that, at the precise moment they reach the age when they can benefit from supported employment services, those services stop being available. The costs—in lost human potential, in running expensive sheltered workshops, in dependency, and in the denial to people with disabilities of the opportunity to participate in meaningful, remunerative work—are enormous.

The Foundations of Disability Policy

Our current predicament is the legacy of three policy epochs: the aftermath of World War I; the Great Society of the mid-1960s; and the rights revolution of the 1970s. Each of those eras generated a particular set of laws and programs relating to disability. These laws and programs continue to play a central role in promoting—or failing to promote—employment opportunities for individuals with intellectual and developmental disabilities.

As medical knowledge has developed to enable more and more soldiers with serious injuries to survive their wounds, our nation's periodic wars have often served as catalysts for developments in disability policy. So it was with World War I. More than 200,000 American soldiers returned from that war with injuries. Congress responded by setting up the first national vocational rehabilitation program. That program aimed to prepare disabled veterans for gainful employment. Congress adopted a civilian counterpart to that program two years later to cover nonveterans disabled by industrial accidents.

The general vocational rehabilitation program continued to broaden its reach over the ensuing decades. During World War II, as the nation needed to mobilize new workers to staff war industries, vocational rehabilitation expanded to include individuals with developmental disabilities. And in the 1960s and '70s, the program expanded further. Today, vocational rehabilitation is an approximately \$4 billion-a-year cooperative program between the federal Department of Education and state agencies, with the federal government paying just over three-quarters of the cost and the states kicking in the rest and administering the program. In 2012, the vocational rehabilitation program served roughly 1.4 million individuals with disabilities, of whom just over 160,000 achieved the goal of competitive employment.

The Great Society added another, perhaps unexpected, layer of policy response to disability. In 1965, Congress created Medicaid, a program in which the federal government pays most of the costs but that the states administer. Medicaid was designed to provide health insurance to poor Americans, and it still serves that role. But over time it has also become one of our nation's most

significant disability programs. In fact, individuals with disabilities and elderly persons account for two-thirds of the more than \$400 billion spent annually on Medicaid. More than nine million persons with disabilities receive Medicaid, and what they receive is not just medical care in the traditional sense. For example, the program has long required states to provide nursing-home and other institutional services to individuals who need them.

But by the 1980s, it had become clear that such institutions were often far more expensive—and far more restrictive of basic independence—than necessary for many individuals with disabilities. In 1981, Congress thus authorized states to obtain waivers from Medicaid rules to provide services to support individuals with disabilities in their own homes and communities. These waivers have provided a crucial alternative to institutionalization for individuals with developmental disabilities. States may provide a number of services under a Medicaid waiver, including prevocational services—providing general skills that contribute to employability—and supported employment services.

There's a catch. Medicaid, unlike vocational rehabilitation, is an entitlement program, meaning that every individual with a disability who meets the eligibility criteria is entitled to receive Medicaid services. Services provided under Medicaid waivers, however, are not entitlements. Thanks to Medicaid's institutional bias, an individual is entitled to be placed in a nursing home. But to receive waiver services, such as supported employment, that individual must wait until the state makes a slot available—and some of those waiting lists can be long.

Moreover, the employment services provided under these waivers are themselves tilted toward segregation. A state can provide both prevocational services and supported employment under a waiver. But prevocational services may be provided in a sheltered workshop or other segregated setting, and there is no time limit for them. As a result, individuals may spend their lives “preparing” for integrated jobs that they will never be presented with the opportunity to take—as is happening to hundreds of thousands of disabled adults now. And while current Medicaid policy prohibits providing supported employment services in a sheltered workshop—indisputably a good thing—it also disfavors using Medicaid to pay for supported employment where other federally funded programs might be available to pay for it.

The Rise of Disability Rights

The rights revolution of the 1970s brought the final layer of disability policy. In the past half-century, U.S. disability law has undergone a sea change. It has followed the path marked by the great constitutional scholar and disability-rights activist Jacobus tenBroek in a pair of 1966 articles in the *California Law Review*.

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In these articles, which created the field of disability law, tenBroek argued that laws covering disabled people had been marked, until very recently, by a policy of “custodialism.” That policy was “typically expressed in policies of segregation and shelter, of special treatment and separate institutions.” Children with significant disabilities received separate schooling, if they received schooling at all. As late as 1970, only a fifth of children with disabilities received public schooling; schools often simply excluded children with developmental disabilities as uneducable. As they grew to adulthood, individuals with developmental disabilities moved to state-run institutions that theoretically provided training and treatment, but in practice warehoused them.

But this system was already, by the mid-1960s, giving way to a policy of “integrationism,” one that “focuses attention upon the needs of the disabled as those of normal and ordinary people caught at a physical and social disadvantage.” Approving of that trend, tenBroek argued that disability law should be read as “entitling the disabled to full participation in the life of the community and encouraging and enabling them to do so.”

The American disability-rights movement made integrationism its main goal, and policy-makers listened. Where disability once triggered responses of care, custodialism, and paternalism, our laws and policies now aim at providing people with disabilities the supports to live as full and equal members of the community. Laws like the 1973 Rehabilitation Act, which prohibited disability discrimination by entities that receive federal funds, the 1975 Education for All Handicapped Children Act (more on this below), and the 1990 Americans with Disabilities Act (ADA) together worked a revolution—one that is the envy of activists with disabilities worldwide. As an American professor who specializes in disability law, I often have the opportunity to work with highly talented young lawyers with disabilities from around the world. These young lawyers consistently speak of the United States as a sort of disability Eden—a place where our buildings, spaces, and institutions are far more accessible than in their home countries, and where people with disabilities are visibly full participants in the life of the community. Although our nation has not yet reached the state of full equality for people with disabilities, we are far ahead of the rest of the world.

Our disability-law revolution has been especially dramatic in the area of education. In the middle of the twentieth century, our nation’s dominant approach to intellectual and developmental disabilities reflected a particularly virulent form of custodialism. Doctors typically advised parents to institutionalize children with these disabilities for life, beginning at a very young age. Parents who wished to reject that advice often found that they had no real alternative, because local school districts refused to allow their children even to attend school. And the

institutions that the state made available often housed individuals in wretched conditions. New York City's notorious Willowbrook State School was one well-known example: After visiting Willowbrook in 1965, then-Senator Robert F. Kennedy described the facility as bordering on a "snakepit," and as "less comfortable and cheerful than the cages in which we put animals in a zoo."

But in 1975, a coalition of civil rights advocates, parents, teachers, and disability professionals pressed Congress to enact the Education for All Handicapped Children Act—now known as the Individuals with Disabilities Education Act (IDEA)—a landmark in disability policy. It guaranteed a free appropriate public education to each and every child with a disability from age five onward (and from age three onward in states that provide public preschool), in the "least restrictive environment," defined as an environment that permits an individual with a disability to be unrestrained, and to be integrated with the mainstream school population as much as possible. Children with intellectual and developmental disabilities—even very significant ones—now go to school in integrated settings. School districts may no longer reject disabled children as uneducable. Moreover, services under the statute, unlike under Medicaid waivers and vocational rehabilitation, are an entitlement.

Life after the Cliff

The IDEA has been, in the main, a dramatic success. For nearly 40 years, we have succeeded in preparing children with even the most severe disabilities for lives that are fully integrated in the community. But it's that very success that creates the cliff that haunts all parents of teenagers with intellectual and developmental disabilities.

IDEA services end at age 22. At that point, a young adult with a disability must turn to vocational rehabilitation or Medicaid waivers to obtain employment supports. But those services, unlike IDEA services, are not entitlements. And unlike IDEA services, they are not administered by the familiar public school system but instead by distinct state bureaucracies: the state Medicaid department (which often provides services through a separate state developmental-disabilities agency) and the state vocational rehabilitation service. Moreover, these state bureaucracies don't deliver the services directly. Rather, they contract with an array of service providers (which may be units of local government, nonprofit groups, or even for-profit corporations) to deliver them.

For example, until the school year in which he turns 21, a young man with an intellectual disability in New York City is entitled to receive services from the New York City Department of Education, an entity he and his parents have been dealing with for most of his life. But if he wants supported employment

services when that school year ends, he will likely apply to the state vocational rehabilitation agency, known as ACCES-VR. When he applies to ACCES-VR, a counselor will conduct a comprehensive assessment of his rehabilitation needs. If the counselor determines that he has a “Most Significant Disability,” and there is funding available, ACCES-VR will refer him to a supported employment provider. Because of the limited funds available for vocational rehabilitation services, federal law requires state vocational rehabilitation agencies to establish an order of priority for receiving services, under which individuals with the most significant disabilities receive services first. When an individual with a developmental disability scores too high on a test of social and behavioral skills, ACCES-VR will not refer that individual for supported employment—even if he needs supports to obtain and retain a job. If he is lucky enough to steer between the Scylla of being too significantly affected by a disability to benefit from supported employment and the Charibdis of being insufficiently affected to qualify for these services, our young man will be referred to a local provider, like the Queens Centers for Progress, a nonprofit organization in Jamaica, Queens. That provider will be the one that employs his job coach.

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If our young man is denied ACCES-VR services, he may seek to receive supported employment through a Medicaid waiver. Although New York generally administers Medicaid through its Department of Health, it administers Medicaid services for people with developmental disabilities through the Office for People With Developmental Disabilities. To obtain Medicaid-financed services, our young man would have to contact his regional Developmental Disabilities Services Office, which would then refer him (perhaps after a wait) to its own contracted supported employment provider—which might, or might not, be the same nonprofit entity that would provide services under the ACCES-VR program.

The details will change in different states, though the overall story is the same across the nation. But our hypothetical New Yorker is one of the lucky ones—those who receive supported employment are a privileged few. Hundreds of thousands of individuals with developmental disabilities, if they get to work at all, must content themselves with a dead-end job in a sheltered workshop. Such workshops tend to be operated by state and local government entities and nonprofit agencies. But nonprofit doesn’t mean nonlucrative. Disability-rights activists from the National Federation of the Blind and elsewhere have recently

focused attention on Goodwill, which operates sheltered workshops across the country. Pursuant to a loophole in the Fair Labor Standards Act, the workers at these facilities often make well below minimum wage, but many of Goodwill's executives make hundreds of thousands of dollars a year. These workshops are financed by state Medicaid or vocational rehabilitation funds, as well as by the money they receive from selling goods they produce.

As a scholar and an advocate, I have toured today's sheltered workshops. Unlike in the case of the old institutions, nobody is likely to describe them as snakepits. But tenBroek's description from 1962 remains apt: "[A] vague combination of the workhouse, the almshouse, the factory, and the asylum, carefully segregated from normal competitive society and administered by a custodial staff armed with sweeping discretionary authority," sheltered workshops tend "to become terminal places of employment in which so-called unemployables may find a drudge's niche at the workbench."

As the National Disability Rights Network (NDRN) put it in 2011, sheltered workshops "purport to offer pre-employment and pre-vocational skills," but often simply "prepare people with disabilities for long term sheltered employment." Workshops often fail to employ state-of-the-art production techniques, so even those clients who excel in their jobs do not learn how to work in the outside marketplace. At a workshop I visited several months ago, men and women with developmental disabilities spent their days using a simple hand-operated lever to place half-inch rubber rings around pieces of metal that resembled chess pieces. Clients got paid a small amount for each ring they placed on a piece. Some looked almost like human machines, quickly placing the ring on the metal, pulling the lever, and putting the assembled piece in the box, one after another. But these clients were not learning skills that would enable them to do a production-and-assembly job outside of the workshop, which typically requires far more than pulling a single lever over and over.

As I talked to the clients, I found that a number had job-related skills that were readily evident even to the non-expert, including interpersonal, communication, and artistic talents. But the workshop was not helping them find a job that matched those skills. That is all too common. The NDRN's report described the case in another state of an autistic man named Andy. As of 2011, Andy had worked in a sheltered workshop for 15 years. Outside of the workshop, Andy handled much of life independently or with limited support from others. He had taught himself five languages and enjoyed building computers out of old parts. But the sheltered workshop did not put him in a job that fit any of these skills or interests. Instead, his job at the workshop was to feed paper into a shredder, over and over. "So Andy is only able to fulfill his potential in his free time," the

NDRN report noted archly, “by putting computers together while reading a manual in Chinese.” Although Andy’s case is an extreme one, it illustrates the far more general problem highlighted by that report: “[Y]oung people with disabilities who want to transition into traditional work . . . instead wind up trapped in a sheltered workshop with little chance for something different.”

The Beginnings of Reform

These problems are well known among disability-policy experts. And through the years policy-makers have made a number of efforts to address them. These efforts have helped at the margins, but they have not taken on the fundamental issues.

Over the decades, the federal government has substantially increased its investment in supported employment for individuals with developmental disabilities. Supported employment provides job coaches and other ongoing, individualized supports to enable them to work in productive, integrated jobs for competitive wages. As I have explained, Medicaid waiver programs sometimes pay for supported employment, as do vocational rehabilitation programs. A major study published in summer 2014 found that supported employment consistently leads to employment for at least half of young adults with intellectual and developmental disabilities who receive it—and that it substantially increases employment rates over alternative approaches. But it also found that large percentages of young adults with those disabilities—particularly high-school dropouts and those with cerebral palsy or traumatic brain injury—are never offered supported employment services. And the study’s authors singled out the lack of “entitlement to services after age 21” as a particular problem: “For those with severe disabilities who require support after the 90-day closure period [for vocational rehabilitation services], it is often excessively difficult for them to obtain the long-term support they need.” In short, although we know that supported employment works for large numbers of young adults with developmental disabilities, we have not succeeded in extending that policy to all of the individuals who could benefit from it.

Two major recent initiatives promise to provide supported employment opportunities to more young adults with intellectual and developmental disabilities. I played a role in the first of these initiatives when I served in the Justice Department in the first years of the Obama Administration. That was the effort by the department’s Civil Rights Division to use the Americans with Disabilities Act to reorient states’ disability-services systems toward integrationism. As interpreted in the Supreme Court’s landmark 1999 decision in *Olmstead v. L.C.*, the ADA requires states to provide services to individuals with disabilities in

the most integrated setting appropriate. The Justice Department has relied on *Olmstead* to negotiate settlements with eight states, requiring them to provide an array of services to enable individuals with, among other things, intellectual and developmental disabilities to live full lives in the community.

Much of the Justice Department's *Olmstead* enforcement has focused on questions of *where* people with disabilities have the opportunity to live—in institutions or in their own homes and apartments scattered throughout the community. But the department has also relied on *Olmstead* to press states to expand integrated opportunities for employment. Consent decrees with Rhode Island, Virginia, New Hampshire, and Delaware explicitly require those states to provide new supported employment slots for individuals with intellectual disabilities and/or mental illness. A landmark consent decree the Justice Department entered

into with Rhode Island in April 2014 requires the state to provide supported employment services to 3,250 individuals with intellectual and developmental disabilities over ten years. And the department has joined a private *Olmstead* lawsuit against Oregon that challenges that state's heavy reliance on sheltered workshops to serve people

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with intellectual and developmental disabilities.

The Department of Justice's enforcement efforts are likely to accelerate the other major initiative that has helped to increase access to supported employment: the rapid spread of Employment First policies across the states. As the name implies, under an Employment First policy a state commits to making integrated, competitive employment its first option for individuals served by its disability system. Rather than sending individuals to sheltered workshops until they are deemed ready for competitive work—a result that often never arrives—an effective Employment First policy says that the state should match people with disabilities with competitive jobs, place them in those jobs, and give them the supports they need to succeed. Tennessee adopted the first statewide Employment First policy in 2003; today, less than a dozen years later, 32 states have adopted them. While largely abstract statements rather than concrete commitments, these policies serve as a guidepost that should promote efforts by states to expand supported employment services.

But these initiatives still do not directly address the problem of fragmented, uncoordinated service systems. Over the past 20 years, Congress has increasingly attended to that problem. The IDEA has long required that individual

education plans (IEPs) for teenagers with disabilities describe the transition services those students will require as they prepare to leave the school system. When Congress reauthorized the IDEA in 2004, it directed that each IEP for a student age 16 and above must include particular transition goals tied to the student's strengths and interests, and that it must also describe the transition services that will help him or her achieve those goals. Since 1998, the Rehabilitation Act has required that state vocational rehabilitation agencies consult with state education agencies to facilitate successful transitions.

In summer 2014, in a rare break from the partisan polarization that has characterized that body, Congress strengthened these requirements. The Workforce Innovation and Opportunity Act, passed on a bipartisan basis and signed by President Obama in July, requires state vocational rehabilitation agencies to spend 15 percent of their funds on the school-to-work transition for young adults with disabilities.

All of these initiatives will help. But the cliff remains. When they turn 22, young adults with intellectual and developmental disabilities are thrown out of the one system that guarantees services and that has prepared them to live and work in an integrated environment. Expanded supported employment and better transition services can provide some of these young adults a parachute or a hang glider, but the cliff will remain a source of fear and peril for far too many. The only way to truly solve the problem is to eliminate the cliff—to give young adults with intellectual and developmental disabilities an entitlement to supported employment as they age out of IDEA services, and to administer that entitlement through the agencies that are already familiar to them.

Renewing Our Promise

The word “entitlement” sets off alarm bells in Washington. It calls forth images of uncontrollable costs and ballooning budgets. But it makes no sense to spend two decades preparing children with intellectual disabilities for independent, integrated lives in the community and then, just at the moment that they are in a position to begin those lives, take away from them the services that will make that outcome possible. And evidence suggests that concerns about the cost of supported employment are misplaced. Susan Stefan, a leading mental disability litigator and scholar, explains that “supported employment is cost-intensive at the front end: when the client is being interviewed as to his or her desires and preferences, the job is being located, and support is being initially provided” but that supports, and therefore costs, “decline over time as the client becomes familiar with the job.” According to Stefan’s analysis, supported employment programs “provide a net benefit to the taxpayer through the

taxes paid by disabled individuals in competitive employment beginning in the fourth year of the supported employment program.” The costs of a sheltered workshop, by contrast, do not decline over time.

Increased tax revenues are not the only fiscal benefit to wider implementation of supported employment. Adults with disabilities who cannot work receive significant cash benefits through the Social Security system. For each individual who moves into competitive work through supported employment, the federal government will save thousands of dollars in Social Security Disability Insurance and Supplemental Security Income payments per year. And evidence shows that Medicaid costs decline—by up to \$15,000 per person per year—when individuals with significant disabilities move into competitive work. Pundits and policy-makers are increasingly focused on the costs of Social Security’s disability programs and of Medicaid. A commitment to supported employment—even with its up-front price tag—can directly address these concerns.

But which of the many service systems should administer a new entitlement to supported employment? In principle, any of the existing systems—the educational agencies that administer the IDEA, vocational rehabilitation systems, or state Medicaid or developmental-disabilities departments—could be satisfactory. Any move to guarantee supported employment to young adults with developmental disabilities should allow for state experimentation. As a first principle, however, there is important value in continuity. Even when the law grants an entitlement to particular services, individuals risk falling through the administrative cracks when they must travel across multiple bureaucracies to receive what the law guarantees them.

For that reason, the new supported employment entitlement should be administered, at least as a default position, by the state educational agency that runs IDEA services. By the time they reach adulthood, individuals with disabilities (not to mention their parents) have been dealing with the state educational agency for nearly two decades. The state educational agency is familiar, and it is the part of the disability-services system that—notwithstanding real problems—tends to work the best at promoting the opportunity to live an independent, integrated life. Many recent policy initiatives focus on smoothing the handoff from the education agency to vocational rehabilitation. But a better policy would ensure that young adults with disabilities are not handed off at all.

State education agencies will likely resist a mandate that they provide supported employment services. Although some of the financial benefits of supported employment accrue to the state, few of those benefits will accrue directly to the state education agency. Rather, they will flow largely to the state Medicaid and vocational rehabilitation agencies, as well as the state’s general revenue

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stream. And many of the financial benefits (lower spending on Social Security disability programs, increased federal tax revenue from new workers) will go to the federal government. Accordingly, state education officials may feel that they are being forced to drain resources from valuable school programs in order to improve the finances of other state and federal accounts.

There is an obvious solution to this problem: Have the federal government reimburse (a large fraction of) the cost of the new supported employment mandate. Congress could make the mandate a part of the IDEA. But that would still likely undercompensate the states. The federal government pays less than 20 percent of the cost of services under the IDEA, with the states responsible for the rest. A better answer would be to pay for the mandate by making it an entitlement under Medicaid. Depending on the state, the federal government pays between 50 percent and 75 percent of the costs of Medicaid. And it is state Medicaid agencies that stand the most to gain from an expansion of supported employment. They are typically the ones paying today for sheltered workshops and other prevocational services that supported employment will supplant.

Under the new entitlement, a state education agency would be required to provide the supported employment services to each young adult client with a developmental disability. It would then bill the state Medicaid agency for the service, which would be paid for at the state's normal state-federal match rate. This is hardly the simplest administrative structure, but it is much simpler than what we have today. And it has the advantages of properly aligning agency incentives and of keeping the bureaucratic complexities in the back office, while presenting a simple service delivery face to young adults with disabilities and their families.

The cliff is a human tragedy and a fiscal drag. More importantly, it represents this nation's betrayal of its promise of integration. Children and young adults with intellectual disabilities spend the first two decades of their lives preparing to be full members of the community. We should not break that promise just as it is about to be achieved. A guarantee of supported employment services would help to keep that promise. ■