From the Editors

In July 2015, we mark the 25th anniversary of the Americans with Disabilities Act (ADA). In talking with people about the difference this law has made in their lives, the lives of their loved ones, and our nation, one of the words we’ve heard most frequently is “promise.” The ADA is, for many, a promise our nation has made that Americans with disabilities will have the same opportunity as Americans without disabilities to experience freedom, dignity, meaning, and inclusion. It’s a promise that the full force of our system of government will be their ally and advocate as they seek to take a valued place in their communities. And it’s a promise that the law will go ahead of them and alongside them dismantling barriers to their full participation in their communities. Many of the people whose articles are in this Impact have found that the promise has changed their lives for the better.

But we’ve also heard authors in this issue talk about ways in which the promise, or the realization of the promise, is incomplete because it doesn’t yet include everyone. Specifically, we’ve heard about ways in which people with intellectual and developmental disabilities have often not reaped the full benefit of the ADA because the challenges and barriers they face are not yet fully addressed. From that perspective, the ADA has not done (and may not by itself be able to do) all that still needs to be done. So in this Impact, the ADA’s promise is seen as both having arrived, and still on the way. By sharing those different perspectives, we hope readers of this issue will both pause to celebrate the anniversary of this turning point in our nation’s journey, and then continue traveling toward that horizon of full inclusion we have yet to reach.

The ADA: Giving Everyone a Chance to Be Part of the Community

by Heidi Myhre

For disability rights activist and self-advocate Heidi Myhre, the Americans with Disabilities Act (ADA) is about making our communities, our world, a better place for everyone. In this February 2015, interview she reflects on the meaning of the ADA and where we go next. Video clips of Heidi discussing the ADA can be found at http://www.selfadvocacyonline.org/stories.

Q: When did you first hear about the Americans with Disabilities Act?
A: I learned about the ADA pretty close to when it got signed into law in Washington, DC. But actually I was already doing that kind of work not knowing that there was a law in motion. The word “ADA” wasn’t there, but we were fighting for the same things. We were fighting to have better education, we were fighting to have better homes, and better medical care. For me I was fighting to say that I have a real disability, and I deserve a real education, I deserve to live in an apartment, I deserve human services. So I was already fighting for it before it had the name ADA. But the Americans with Disabilities Act makes it so that some of the things I was fighting for are permanent. Like if I get a job, they have to follow certain rules; work fields have to accommodate to people with disabilities. I should be able to have an apartment or house that’s handicap accessible if I can afford it. I should be able to have transportation that I can get on.

[Myhre, continued on page 34]
The success of the Americans with Disabilities Act (ADA) is visible in many aspects of the lives of our children. As parents of children with disabilities who are now well into adulthood, we have sought continued acceptance of them and their inclusion into all aspects of community life. A major key to this has been the continual and consistent hard work and advocacy by the parents and families of people with disabilities, as well as people with disabilities themselves.

Signs of Progress

This, the 25th anniversary of the ADA, provides an opportunity to celebrate the accomplishments of these efforts. Our children, two born before passage of the ADA, and one in the same year, have grown up. One is 39 years old, one is 45, and the third is 25. They are benefiting from legal protections the law has provided, including protections to individuals with disabilities in employment, services and programs provided by State and local governments, public accommodations, telecommunications, and transportation. These protections, paired with the Individuals with Disabilities Education Act (IDEA), are extended to include the Individuals with Disabilities Edu

New Opportunities in Postsecondary Ed

In recent years, higher education has played an important part in providing programs addressing the needs of students with disabilities. Early on, demonstration projects were used to develop college curricula for students with disabilities on many campuses across the country. New opportunities for postsecondary education have opened up for students with intellectual disabilities in the past decade fueled by advocacy by students, parents, and professionals. During the consideration of the Higher Education Act Opportunity Act of 2008, advocates were successful in gaining bi-partisan, bi-cameral support to amend the bill to include provisions for students with intellectual disabilities. For the first time, students with intellectual disabilities became eligible for financial aid including grants and work study jobs (to learn more see http://www.thinkcollege.net/topics/opportunity-act). Transition and Post-secondary Programs for Students with Intellectual Disabilities (TPSID) were authorized to develop model inclusive programs and a National Coordinating Center (NCC) was authorized to evaluate the TPSIDs and provide technical assistance. One of the requirements for the NCC was to form a workgroup to develop model accreditation standards for such programs. In FY2010, appropriations began for the model programs and NCC and continued through FY2014.

Employment Challenges and Responses

While the ADA has provided protections for employees and job seekers with disabilities, it is discouraging that there has not been a significant increase in employment for individuals with disabilities since the ADA was signed by President George H.W. Bush in 1990. According to the National Organization on Disability National Survey, adults with disabilities are still almost three times less likely to be employed in full or part-time jobs as compared to people without disabilities, with only about one-fifth of adults with disabilities being employed (Kessler Foundation/NOD, 2010). In terms of diversity, the Bureau of
Labor Statistics reported in 2013 that the overall unemployment rate among people with disabilities was higher for African-Americans and Hispanics/Latinos with disabilities than for Whites with disabilities (Bureau of Labor Statistics, 2013).

In response to these circumstances, in the spring of 2014, the changes to the rules implementing Section 503 of the Rehabilitation Act announced by the U.S. Labor Department in 2013 took effect (for details, see http://www.dol.gov/ofccp/regs/compliance/section503.htm). Implementation of this reauthorization will likely have significant impact on employment for individuals with disabilities in terms of finally beginning to reverse the unemployment disparities.

Further, in July 2014, the Workforce Innovation and Opportunity Act (WIOA) – which reauthorizes and supersedes the Workforce Investment Act of 1998 and also amends the Adult Education and Family Literacy Act, the Wagner-Peyser Act, and the Rehabilitation Act Amendments of 1998 – was signed by President Obama. Many provisions under this new Act take effect on July 1, 2015. Youth/young adults with disabilities, their families, and the professionals who work with them will need information, training, and resources to help them understand these changes and optimally benefit from them (to learn more see http://www.dol.gov/wioa/pdf/WIOA-Factsheet.pdf).

Increased Family Support

Because of the ADAAA (Americans with Disabilities Act Amendments Act of 2008) the definition of “disabilities” was broadened to the maximum extent possible by the terms of the ADA. This amendment is not well known, but it prevents employers from discriminating against employees who have a relationship with someone who has a disability. Otherwise said, parents are protected from discrimination because they have a child or family member with a disability; this is in the language of the amendment that prohibits discrimination against “a qualified individual because of the known disability of an individual with whom the qualified individual is known to have a relationship or association” [42 U.S.C. sec 12112 (b)]. In addition, in 2013 new guidelines were issued by the Department of Labor to broaden the circumstances that allow parents to use the FMLA (Family Medical Leave Act) to care for their adult child with disabilities [42 U.S.C. sec 12102 (2)(A)-(B)]. It makes the age of the child irrelevant in relationship to the onset of the disability (see http://www.dol.gov/whd/fmla/AdultChildFAQs.htm).

Over the years there has been one message that has sustained and strengthened parents in the continuing need to advocate for their sons and daughters: “You are not alone.” The document, You Are Not Alone, was written years ago for parents of young children by Patty McGill Smith, and we now know the principles in it address the needs of parents and caregivers across the age range. Those principles include, but are not limited to, relying on positive sources in one’s life, taking one day at a time, avoiding feelings of intimidation, not being afraid to show one’s emotions, taking care of one’s self, keeping daily routines as normal as possible, remembering that this is your child, and recognizing that parents of children with disabilities (and people with disabilities in general) are not alone in their experiences (to learn more see the document on the opening page of the new Center for Parent Information and Resources Web site at www.parentcenterhub.org).

Today, there are so many resources on the Internet available for parents and family members. All they have to do is Google a subject matter pertaining to people with disabilities to find a long list of supportive information, and know that they are indeed not alone.

Greater Economic Security

In late 2014, the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014 (the ABLE Act, S. 313/H.R.647) passed the House and Senate with overwhelming bipartisan support in both houses. President Obama signed the new law on December 19, 2014. Its major focus is on the financial security of people with intellectual disabilities. Under the ABLE Act, people with disabilities would be able to save up to $14,000 annually in special accounts that could be established at any financial institution. Individuals could accrue up to $100,000 in savings without risking eligibility for government benefits like Social Security. And Medicaid coverage could be retained no matter how much money is deposited. Money set aside in the proposed ABLE accounts could be used to pay for education, health care, transportation, housing, and other expenses. What’s more, interest earned on savings within the accounts, which are modeled off of the popular 529 college savings plans, would be tax-free (for details see http://www.autismspeaks.org/advocacy/advocacy-news/able-act-law-2015-what-you-need-know).

Conclusion

We will always be parents of children and adults with disabilities. Our two primary goals for them will always stay the same: (1) acceptance by other people and (2) inclusion into community life. While it would seem that these two goals have been made more attainable by the ADA and other legislation over the years, in reality they cannot be reached without the continued persistence and hard work of families of persons with disabilities and by self-advocates.

References


Patty McGill Smith is the retired Executive Director of the National Parent Network on Disabilities. She lives in Kansas City and may be reached at pmcglsmith@aol.com. Anne Lauritzen is retired from many years of advocacy work. She lives in Lincoln, Nebraska, and may be reached at alauritzen@aol.com. Mark A. Smith is Resource Family Support Coordinator, Nebraska Center on Disabilities, University of Nebraska, Omaha. He may be reached at msmitha@unmc.edu.
“We Were Fighters”:
An Interview with Connie Martinez

by Connie Martinez with Charlene Jones

In 1988-89, Connie Martinez was a member of the Task Force on the Rights and Empowerment of Americans with Disabilities. The Task Force, established by Rep. Major R. Owens, was described in this way in its 1989 report to Congress: “composed of 35 distinguished representatives of every major segment of the nation’s 43 million American citizens with disabilities, the Task Force is mandated to collect information and to make recommendations which will assist the Congress as it considers the Americans with Disabilities Act.” In Fall 2014, Connie spoke with Charlene Jones about her experience with the task force, and the ADA’s impact on people’s lives. These are her reflections, as adapted from their conversation.

Charlene: Why was it important to you to be part of the task force?

Connie: To be a voice for people who cannot speak for themselves. Many years ago (I won’t say how many!), I went to a program that was supposed to be a school, but was like a workshop where they treated people with disabilities like children. I left when I knew they were not going to teach me anything but sweep the floors. They hurt people, and I decided to stand up for them. I got into independent living and People First. I spoke out, gave speeches. When people heard me, I was asked to be on the State Council on Developmental Disabilities in Sacramento, California, and began to travel around the country, Canada, and later Japan so more people with disabilities and parents would have hope and be independent.

Charlene: What did you do as a task force member?

Connie: I don’t remember, but it was important that other people saw me there, that they understood just because I do not read, didn’t mean I could not understand what prejudice is and when people judge other people. We helped people understand that when we, as People First members, traveled around and talked to other people with disabilities about their lives and dreams. They were afraid to talk for themselves because people around them were “keepers,” not teachers. We helped write a book about it, [Surviving the System, Mental Retardation and the Retarding Environment] and we were fighters.

Charlene: What kinds of changes did you hope the ADA would make in people’s lives?

Connie: That it would change the prejudice, help more people have lives like other people, with relationships and jobs, and to be a part of the community. I live in my own place, have for a long time, and I am involved with my church, not with People First anymore, but interested in other things I want to do. I still fight for rights of people, not just people with disabilities.

Charlene: How did you feel when the ADA was signed into law?

Connie: When I heard, and we talked about what it means, there were tears. It gave dignity to our lives; it gave hope for a better life because it opened many doors. Life with choices, to live and love like we want to, like other people without disabilities.

Charlene: In what ways have your hopes about the ADA come true in the past 25 years?

Connie Martinez (center), as co-founder of Capitol People First in California, traveled with People First advisor Barbara Blease (right) to Japan in 1990 to support growth of the self-advocacy movement there.

Today, Connie lives the life of her choosing, and continues to support the rights of all people.
Connie: More people are in independent living, living like they want to. They are involved and voting, too. People who in the past were called “retarded” show that they care about issues, and understand and really vote. Not just pretend voting like they did at the workshop a long time ago, but voting on important things.
Charlene: Do people with disabilities still face barriers to living the kinds of lives they want?
Connie: Sometimes people are still treated like I was treated in the past. Not all attitudes have changed, with people still treated like second-class citizens. Help and programs [services and supports] are not always good in other parts of the state and country. They don’t help people grow.
Charlene: How do you think the U.S. can continue to make things better for people with disabilities?
Connie: If we stop, nothing more will change. We have to work together, not just with people with disabilities, but work with other groups to fight prejudice and have more rights for more people.

We must show and teach other people to take over now and be good leaders.

Connie Martinez lives in Sacramento. Charlene Jones, a Consultant and Project Coordinator from Sacramento, has been a colleague of Connie, and advisor/facilitator to California self-advocacy organizations and committees, for over 20 years. To learn more about the Task Force on the Rights and Empowerment of Americans with Disabilities, see the Executive Summary of its 1989 report available online at http://digitalcollections.library.cmu.edu/awweb/awarchive?type=file&item=418356.

Why the Americans with Disabilities Act is Important to Me
by John Smith

John Smith is a long-time champion of the self-advocacy movement, and a Coordinator at the Institute on Community Integration. In this February 2015 interview, he shared some of his thoughts about the Americans with Disabilities Act (ADA) and its importance in his life. Video clips of the interview are online at http://www.selfadvocacyonline.org/stories.

Q: What difference has the ADA made in your life?
A: The ADA gives assurances, gives me assurances, that when I go out to a restaurant I’ll be able to get in the door. It gives me assurances that when I go out to a job interview that I’ll have a shot at being considered. It also means that once I get that job I have a right to ask for the things that I need to succeed. The ADA also helps me notice when I’m being discriminated against – we’re not there yet (meaning, the ADA has not ended disability discrimination). But because of the ADA, discrimination based on disability status now sticks out like a sore thumb. The lack of a wheelchair ramp in a public place now sticks out like a sore thumb. If I apply for a job and if I get asked about my disability in inappropriate ways, it now sticks out like a sore thumb. I have a right, because of the ADA, to say something or to step back again and say, “You know what? I’m out of here.” So the ADA has made me aware, our communities aware, and our nation aware that people with disabilities belong, they have rights.

Q: The ADA was passed 25 years ago. Is it still important today?
A: The ADA is still really important. We’re going to need it in the future because the world’s changing all the time and people with disabilities continue to face discrimination in ways that the folks who wrote the ADA, and advocated for the ADA, couldn’t imagine. I know that I, as a person with a disability, am going to want to go on and keep adventuring and trying all kinds of new stuff, new kinds of adventures, and I’m going to need the ADA there to protect me as I go on and do the things that everyone else does. As an example, the ADA was passed in 1990, and in 1990 I had never been on the Internet. I didn’t own a computer, so I couldn’t have cared less about the ADA talking about computer access. But today it’s absolutely critical that people with disabilities are accommodated and are able to have full access to that. I have no idea what the future holds and what the opportunities are going to be 25 years from now, and that’s exactly why we need the ADA and its broad, but beautiful, language that says people with disabilities are part of a community, and have a right to everything the community has to offer.

Q: Anything else you’d like to add?
A: The ADA is a civil rights act, and I like the fact that it’s modeled after the Civil Rights Act of 1964, which banned discrimination based on race. I like the idea that the ADA bonds people with disabilities together with all those other groups of people who face discrimination. And I like the idea that the ADA is about all people with disabilities. The ADA was passed because the entire disability coalition had to come together and fight together to get it passed. That was a new thing for people with physical disabilities to sit down with folks with intellectual disabilities, and people who had mental health disabilities, and say: “You know, we’re all in this together. We’ve got to fight together. And we’ve got to fight for each other.” I think it’s cool the ADA is about everyone.

John Smith may be reached at smith144@umn.edu or 612/624-0219.
Promises Kept, Promises Broken, Promises Deferred: The Americans with Disabilities Act

by Robert D. Dinerstein

Twenty-five years ago this coming July, Congress, by wide margins, passed the landmark Americans with Disabilities Act of 1990 (ADA). Congress stated its purpose, in part, as:

(1) To provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
(2) To provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
(3) To ensure that the Federal Government plays a central role in enforcing the standards Established in this Act on behalf of individuals with disabilities . . . (ADA §12101(b)).

Buttressed by a set of robust findings that emphasized the pervasive nature of discrimination against people with disabilities in “such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services,” the ADA purported to address discrimination in virtually all areas of the lives of people with disabilities (ADA, §12101(a)(3)).

Has this ringing mandate been met for people with intellectual and developmental disabilities? The answer must be: Yes, No, and To Be Determined. Or, if one prefers, promises kept, promises broken, and promises deferred.

Promises Kept

The ADA has served an important symbolic function in raising the consciousness of the broader society regarding the rights of people with disabilities. Though one could argue that this consciousness-raising relates more to people with physical disabilities than mental disabilities, as reflected in the ubiquitous figure of the person in a wheelchair, it is undeniably true that many people without disabilities have a greater appreciation for the contributions to society that people with IDD make and the discrimination that they have experienced. This symbolic function is not to be gainsaid, even if it is difficult to quantify. Ironically, the very success of the ADA has been used by some politicians to argue against ratification of the United Nations Convention on the Rights of Persons with Disabilities as unnecessary because “we already have the ADA.” The ADA is now part of the public rights discourse in the same way that the Civil Rights Act of 1964 and Title IX of the Education Amendments of 1972 are for racial minorities and women (Engel & Munger, 2003).

The ADA is more than a symbol, however. Critical cases such as the Supreme Court case of Olmstead v. L.C. have been instrumental (eventually, at least) in encouraging the trend of deinstitutionalizing people with IDD and keeping them out of institutions altogether. Other cases, though not specifically about people with IDD, have increased access to public accommodations by people with disabilities (Bragdon v. Abbott – people who are HIV+), limited the reach of the “fundamental alteration” defense by places of public accommodation (PGA v. Martin), and recognized that Title II of the ADA is a legitimate exercise of congressional power when addressing fundamental issues such as access to courts (Tennessee v. Lane). Many lower-court cases have addressed important issues such as access to the Internet, the viability of sheltered workshops, disability-based harassment, and other matters. And in addition to court cases, the Federal Government, primarily the U.S. Department of Justice, Civil Rights Division, has been active in promulgating regulations and bringing (and often settling) major litigation that has vindicated the rights of people with disabilities.

Promises Broken

But in other respects the ADA has not delivered on its promise. Supreme Court decisions that severely constricted the interpretation of the statute – Sutton v. United Airlines and its two companion cases, as well as Toyota Manufacturing Co. of Kentucky, Inc. v. Williams, and Board of Trustees v. Garrett, to name several – limited the reach of the ADA, especially in the employment area. The Sutton trilogy and Toyota case established an insidious environment in which individuals with disabilities, including people with IDD, could not meet the threshold definition of being a qualified individual with a disability – that is, an individual with a physical or mental impairment that substantially limited a major life activity – and hence could not even raise a claim of substantive discrimination, let alone prevail. For those who could overcome this hurdle, the difficulty of demonstrating a level of impairment that would rise to the level of seriousness that the Supreme Court required while then proving that the individual could perform the essential functions of the job, with or without reasonable accommodations, created a Catch-22 situation that made it difficult to demonstrate substantive
discrimination. In Garrett, the Supreme Court used its 1985 equal protection decision in City of Cleburne, Texas v. Cleburne Living Center, Inc., (in which the Court concluded that classifications based on intellectual disability were not entitled to heightened review, but only rational basis review) to rule that Title I of the ADA was unconstitutional on grounds of sovereign immunity insofar as it purported to authorize private damage actions against State employers because it did not clearly demonstrate that the provisions of the ADA, or the legislative history underlying it, attacked irrational State employment discrimination. The result was that the ADA wound up providing a lot less protection for people with disabilities than people with disabilities, advocates, academics, and even individual Senators and Congress members themselves, expected.

A 2007 case from the U.S. Court of Appeals for the Eleventh Circuit regarding a person with an intellectual disability, Littleton v. Wal-Mart, reflected the absurdity of the jurisprudence in this area. In that case, the appellate court affirmed a lower-court order granting summary judgment to Wal-Mart, concluding that Littleton had not demonstrated that his intellectual disability constituted a mental impairment that substantially limited a major life activity. Littleton argued that his intellectual disability substantially limited him in such major life activities as learning, thinking, communicating, and social interaction (as well as working). In rejecting his argument, the court determined that Littleton’s abilities to drive a car, to be interviewed alone for a job, and to interact verbally with co-workers negated a finding that he was substantially limited in any of these life activities. By definition, anyone with an intellectual disability, even in its mildest form, is within the bottom 3% of the population in terms of intellectual functioning. The court’s lack of understanding about what people with intellectual disabilities can do led it to conclude that the above abilities were inconsistent with a determination that Littleton’s ability to think and learn was substantially limited. The court’s conclusion that “we do not doubt that Littleton has certain limitations because of his mental retardation” seems damning with faint praise.

The Supreme Court’s only ADA case dealing with people with IDD was Olmstead. But other cases presented interpretations of the statute that could bode ill for people with IDD. For example, in Chevron USA, Inc. v. Echazabal, the Court held that the statutory defense of “direct threat to others” did not preclude an employer from arguing that an employee should be fired because, in its judgment, exposure to toxins would constitute a “direct threat to self.” This paternalistic judgment was precisely the kind of judgment that Congress had in mind when it noted that “individuals with disabilities continually encounter various forms of discrimination, including . . . overprotective rules and policies” (ADA, 42 USC §12101 (a)(5)). In U.S. Airways, Inc. v. Barnett, the Court, in a somewhat fractured opinion, held that the existence of an employer’s seniority system would in most cases trump the ADA requirement that a worker with a disability be assigned to a vacant position as a reasonable accommodation if the worker no longer could perform his or her original job with or without an accommodation. These cases, and those mentioned earlier, create particular barriers for employment of people with disabilities, including those with IDD.

**Promises Deferred**

In the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), Congress attempted to right the ship of ADA interpretation and return Title I of the ADA to its original meaning. It specifically overruled the Sutton and Toyota cases as having been unfaithful to congressional intent in the original ADA by having established a too-demanding test for the threshold determination of disability. Among other things, the ADAAA makes it clear that the Court and the Equal Employment Opportunity Commission (EEOC) had adopted a too-stringent interpretation of “substantial limitation,” adding that the threshold determination of disability should no longer be a demanding one. The ADAAA defines major life activities in the statute itself; adds operation of a major bodily function to the list of major life activities; clarifies that the limitation imposed by the physical or mental impairment should be assessed without consideration of so-called mitigating measures that might ameliorate the effects of the condition; and reinvigorates the definitional prong of “regarded as” having a disability by removing any requirement that the impairment that forms the basis of the perceived disability actually limit a major life activity. Although it is still relatively early, for the most part it appears that lower courts are heeding the ADAAA statutory language and reaching the merits of employment discrimination claims. Case results are mixed, as one would expect, but at least courts are adjudicating claims on their substantive merits.

The deferred promise of the ADA is not merely the result of it being too early to determine if the ADAAA will be effective. In other respects, the promise may be deferred – or at least redefined – not because of what the ADA or ADAAA purport to do, but because some of the expectations that some had for the ADA may not have been reasonable. That is, although many have expressed disappointment that the level of employment of people with disabilities has not increased significantly since the enactment of the ADA – and according to some, has actually decreased – it hardly seems reasonable to blame this fact on the ADA. The reasons for un- and under-employment of people with disabilities (especially, people with IDD) are complex and multi-factored. Over-use of sheltered workshops, educational shortfalls, transportation difficulties, and under-funded supported employment programs are just some of the reasons that unemployment has remained high. Moreover, discrimination, especially in hiring, is increasingly difficult to prove, whether it is based on disability, race or gender. But at least plaintiffs can now have their day in court.

[Dinerstein, continued on page 35]
In 1990, the Americans with Disabilities Act (ADA) was enacted to break down barriers to employment, transportation, public accommodations, public services, and telecommunications for individuals with disabilities. Its enactment illustrates our nation’s obligation and commitment to reject discrimination based on disability, and to support participatory community lives for all individuals. In this article, we describe two national research efforts – the National Core Indicators and the Personal Outcome Measures® – and what their data tell us about the performance of service systems and the outcomes they generate for people with intellectual and developmental disabilities (IDD) in employment, choice and rights, and community participation. It tells us where we’re at 25 years after passage of the ADA.

The National Core Indicators Program

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to evaluate their performance using a common nationally validated set of measures. The effort began in 1997 and is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). NCI includes a set of more than 100 standard performance measures (or “indicators”) in areas such as: employment, rights, service planning, community inclusion, choice, health, and safety. NCI uses four main surveys to collect this information – an in-person Adult Consumer Survey as well as three mail-out surveys to families. Currently, there are 42 states (including the District of Columbia), and 22 sub-state entities participating in NCI. The information presented here reflects data from the 2012-13 Adult Consumer Survey data collection cycle.

The Personal Outcomes Measures®

In 1993, the Council on Quality and Leadership (CQL) introduced the Personal Outcome Measures® (POM) that includes 21 outcomes grouped in three factors: (1) My Self – personal, physical, and environmental outcomes; (2) My World – connectedness and life in the community; and (3) My Dreams – discovery, choice, and self-determination. The POM is a valid and reliable tool that can be incorporated in human services systems for people of all ages receiving mental health, aging, and/or IDD services. It focuses on the choices and control people have in their lives. It is an instrument for evaluating quality of life for people, and the degree to which organizations individualize supports to facilitate outcomes. The data included here are drawn from interviews conducted with individuals receiving IDD services from organizations (or funded through State agencies) participating in CQL’s accreditation processes in 2013. A total of 350 agencies are currently CQL accredited.

Employment

In 1990, the ADA recognized the importance of employment not just for its economic benefits, but as a central component of living an engaged life. Today, employment remains a central issue for individuals with IDD. Recent data illustrate that people with IDD are underemployed, and lack the vocational choices and benefits afforded to others. NCI data from 2012-13 show that employment rates for people with IDD remain stagnant at around 15%, and of those employed, only 3% work an average of 35 hours or more per week. Only one-quarter receive paid vacation or sick time. Data collected by POM indicate that in 2013, only 43% of participants identified as having a choice of where they work, with only 34% of those having supports to make the choice.

For people with IDD, making sure an integrated employment goal is in their service plan is an important step to finding employment. NCI data show two and a half times as many people who had a job in the community had an integrated employment goal in their service plan.

Outcomes in a number of domains in both NCI and CQL show significant differences for those who are employed compared to those who are not. Those employed reported higher rates of satisfaction and respect, more expanded and interactive relationships, more autonomy, higher rates of both choosing and realizing personal goals, and greater

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*Figure 1: Right to Choose Where to Live*

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<th>Outcome</th>
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<th>POM</th>
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<td>Wanting to live somewhere else</td>
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<td>53%</td>
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<td>Feeling ahead at home</td>
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<tr>
<td>Talking with neighbors</td>
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<td>Performing different social roles</td>
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<td>Living in community</td>
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<td>Having input in deciding where to live</td>
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participation in volunteering and community activities. Further, those who were employed cited fewer instances of feeling afraid in their homes and were less likely to feel lonely. As suggested by the ADA, these outcomes show that the benefits of being employed extend far beyond economic self-sufficiency to the ability to lead a more fulfilling life.

Choice and Rights

NCI Adult Consumer Survey data over several years indicate that the overall rates of choice and decision-making related to where people live, work, and what they do during the day differ greatly by residence type, with those who live in their own home reporting the greatest amount of choice compared to those living in an institution, community residence, family home or foster care. Those who reported having some input in choices, such as where and with whom they live, their daily schedule, and how they spend their free time, tended to show higher rates of satisfaction with where they live and what they do during the day. CQL POM data indicate that 70% of interviewees say they exercise their rights. Figure 1 illustrates the impact of being able to decide where one lives, and Figure 2 the impact of being able to exercise one’s rights on outcomes such as participating in the community or feeling respected.

Community Inclusion

The ADA insists that community participation is a right for ALL citizens. In general, CQL and NCI data reveal that most people receiving services take part in community activities. CQL’s most recent data indicate that individuals participating in the community are more connected to natural support networks, perform different social roles within their communities, have friends, and have higher rates of intimate relationships. NCI data indicate that nearly all respondents went shopping, ran errands, went out to eat, or attended religious services in the past month; most reported doing each of these activities 3-4 times per month. Having access to transportation is key to an individual’s ability to access the community. Not surprisingly, those who report always being able to get to places where they want to go report going out in the community at higher rates and more frequently throughout the month.

NCI data reveal that individuals who use aids to move or are non-ambulatory are less likely to access transportation at any time and to engage in community activities. While 89% of those who were fully ambulatory reported going out to eat in the past month, 80% of those needing some support did so; similar findings were true for going out shopping, on errands, for entertainment, to religious practice, and for exercise. These findings exemplify that though most people have basic access to community activities, there are still barriers, particularly for those who require more assistance.

Concluding Remarks

Twenty-five years after enactment of the ADA, the correlation between employment, choice, rights, public access and community participation remain evident for people with IDD. Positive outcomes in one area influence positive outcomes in others. Data from 2013 illustrate that those leading lives with more choice, control, and public access are achieving more self-defined personal outcomes. The ADA, in combination with other national efforts (e.g., Employment First Initiatives, advocacy initiatives, HCBS waiver reforms, self-determination movement), has led to great system reforms and achievement of personal outcomes. Yet, much work remains. While data illustrate high percentages of individuals with IDD participating in community life, employment statistics for people with IDD remain depressingly low, and choice and control are still not present for a significant portion of the population.

The NCI and CQL assessment initiatives serve an important role in providing reliable and valid data to monitor and evaluate the outcomes as well as experiences of people with disabilities in U.S. society. The findings provide systematic evidence about the way ADA has been followed and implemented over time to improve the lives of persons with disabilities. This should suggest to policymakers, advocates, and others that while progress has been made, there is still a long way to go before people with IDD enjoy all of the promises of the ADA.

Notes

2 Additional information on the Personal Outcome Measures® and its data is at http://www.c-q-l.org.

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In 1990, we were slow to understand the violations of the ADA by congregate and institutional disability programs. Now we may be facing major program realignments just as remarkable as the initial effort to close state institutions.

I remember the joy and excitement felt throughout the disability community in 1990 when then-President George H.W. Bush signed the Americans with Disabilities Act. At that time, my main introduction to the disability community was through my brother, Steve, who was 33 years of age – three years my junior – and living in a state institution in Kansas for people with intellectual and developmental disabilities. His life’s journey had been one of federal- and State-enabled neglect, with even an occasional State-sanctioned tolerance of abuse.

Steve had been one of millions of people with intellectual and developmental disabilities (IDD) excluded from educational services during his childhood when the Education of All Handicapped Children Act (PL 94-142), or the Individuals with Disabilities Education Act (IDEA), or the Americans with Disabilities Act (ADA) were years away from enactment. So Steve’s life was centered on receiving either the minimum or nothing from our local school district or the State of Kansas.

That’s not to say Steve had no services. In 1966, at age 9, he was admitted to Parsons State “School” and Training Center for 11 years, then discharged to a community program known as the Johnson County Mental Retardation Center (now called Developmental Services), then discharged because of the challenges of his behavior related to autism, then returned to the locked environment of another State institution in 1983.

For many families like mine, siblings of people with disabilities migrated into positions as disability advocates or professionals, or just plain hell raisers. I took a different route and became an advocate who ran for my state’s House of Representatives, shockingly winning by defeating an incumbent Representative. That led me to a life of activism, including being a service provider, a state protection and advocacy director, a disability advisor to both Presidents Clinton and Obama, and a disability provider trade association leader.

I am ashamed when I think of how the advocacy and service communities viewed success before the passage of the ADA. In the past, disability advocates often celebrated when state leaders gave meager hints of support, including less-than-quality services and supports or institutional programs that more closely resembled the “three hots and a cot” mentality of the corrections system than what we knew our loved ones needed or deserved. Without the force of law, people with IDD were targeted beneficiaries of paternalism by elected and appointed officials who provided not much more than the bare minimum to survive. People with IDD were often limited to getting services in locked wards, isolated State institutions in rural communities, segregated classrooms or programs with minimal expectations (if any) for the participants.

Self-advocacy in the developmental disabilities community in the 1970s and 1980s was merely in its infancy, while in the physical disability community the Independent Living movement was growing in both sound and influence. Those voices grew louder each day over the vast waste of human potential resulting from ignoring people with disabilities as a potential labor force. Through the efficacy of the greater disability community, and tremendous bi-partisan Congressional allies like Senators Bob Dole, Tom Harkin, Ted Kennedy, Lowell Weicker and Representative Tony Coelho, doubts of extending civil rights protections to people with disabilities began to fall by the wayside, and a working majority developed in Congress to send the Americans with Disabilities Act to the welcoming desk of President Bush, where he joyfully signed the ADA on July 26, 1990 on the White House South Lawn.

As enacted in 1990, the scope of the ADA was breathtaking. After decades of advocacy, the new law prohibited discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities. The immediate impact of the new law was first acutely felt by individuals with physical disabilities. For people with IDD the impact of the ADA was more gradual, incremental, and often more symbolic than substantive, until later court cases proved pivotal in expanding the impact of the Act.

Services and supports for people with IDD after the ADA didn’t look too different than services before passage. In the early 1990s, institutions continued to draw down more and more fiscal resources for fewer and fewer people, while thousands needing community residential, employment or family support services were relegated to ever-growing State waiting lists. The objectives of many programs continued to be focused on meeting the minimum needs of people with IDD, focusing on their DISability and not on their abilities. Thus programs, including residential, day services, employment, and even recreational services continued to feature separation and segregation from the
general community and continued low expectations of their participants.

Through the years, pressure from self-advocates and advocates, critical court decisions such as *Olmstead* and others, plus the actions of the U.S. Department of Justice intervening in local communities have led to a greater understanding of the full potential of the ADA. That knowledge has helped transform the face of supports and services for people with IDD.

Especially since *Olmstead* we have seen community residential provider programs be transformed from a money chase to see which State or federal spigot could be tapped, to a better-defined system that has moved away from institutions, embraced community residences, envisioned independent living, offered alternatives such as Shared Living and Adult Foster Care, and given greater control to self-advocates through self-directed services. The face of supports and services for people with IDD.

With the recent approval of the CMS Home and Community Based Services (HCBS) Final Rule on Community Living*, the provider and service sector will once again see a transformation in program design and a shift of power towards the individual receiving services and away from the design of service systems. Immediate changes will be felt by increased privacy, individual control over who comes and goes within individual homes, and how one’s time is spent. Further CMS actions inspired by the ADA will likely result in a reshaping of day and employment programs, including the eventual elimination of sheltered workshops, the elevation of individual salaries of people with disabilities as they earn real and competitive wages, an expansion of supported employment, and a creative journey into social enterprises.

The changes that will be brought about by the CMS Final Rule on Community Living are directly tied to our growing and evolving understanding of the ADA, and the implications of Title II prohibiting state and local entities from discriminating against individuals in the delivery of services, programs, and other activities provided by state, local or federal government. In 1990, we were slow to understand the violations of the ADA by congregate and institutional disability programs. But now, with greater understanding and clarification from CMS and the courts, we may be facing major program realignments just as remarkable as the initial effort to close State institutions. How these changes will continue to impact local community programs remains to be seen as States scramble in the next few months to respond to CMS by developing their individual State transition plans that are expected to build greater community inclusion as a basis for continuing to receive HCBS funding of residential and employment programs.

For people like my brother Steve, it’s been a long journey from an era of no laws supporting education or services for people with disabilities beyond institutional confinement. With the 25th anniversary of the ADA approaching, Steve now lives in his local community

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*Note: See the Medicaid.gov Web page, Home and Community Based Services, for more information on the final rule (http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html).

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For people like my brother Steve, it’s been a long journey from an era of no laws supporting education or services for people with disabilities beyond institutional confinement.

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*For people like my brother Steve, it’s been a long journey from an era of no laws supporting education or services for people with disabilities beyond institutional confinement.*
The Role of the U.S. Department of Justice in Enforcing the ADA’s Integration Mandate

by Dan Berland and Nancy Thaler

It is easy to forget that, when the Americans with Disabilities Act (ADA) became law in 1990, its profound implications for State intellectual and developmental disability (IDD) service systems were not immediately recognized. In most quarters, the ADA was regarded as an important anti-discrimination law whose most significant provisions dealt with accessibility of public spaces and accommodations in the workplace. Although the Department of Justice (DOJ) had, as part of implementing the ADA, issued an “integration regulation” requiring public entities to administer programs “in the most integrated setting appropriate to the needs of qualified individuals with disabilities,” it was not until almost 10 years after the law’s passage, that the full scope of the law’s integration mandate began to be generally understood. That shift came about when the Supreme Court ruled in Olmstead v. L.C. that “unjustified isolation” of a person with a disability is a form of discrimination under Title II of the ADA. Today, that integration mandate is front and center in the consciousness of State directors of IDD services, and informs key decisions about the direction of the systems they oversee. While it was the Olmstead decision that first made the ADA’s integration mandate explicit to States, the Olmstead enforcement actions of the DOJ have defined the contours of States’ Olmstead obligations.

Even before the Olmstead decision, many States were on a deinstitutionalization trajectory, as demonstrated by the following data (Prouty & Lakin, 2001):

- In 1977, 83.7% of the estimated population of persons with IDD receiving residential services lived in residences of 16 or more people. But by 2000, the year federal Olmstead implementation began, an estimated 77.2% lived in community settings of 15 or fewer people, and 63.1% lived in settings with six or fewer people.
- Between 1980 and 2000, large State IDD facilities’ average daily populations decreased by 63.7%. In 41 states, a majority of persons with IDD received residential services in settings of six or fewer residents as of 2000.
- Between 1993 and 2000 the estimated number of people with IDD living in their own homes nationally increased by 115.8%.
- In 2000, an estimated 146,612 individuals (39%) receiving publicly-funded services lived in homes of three or fewer residents – this represented a more than nine-fold increase over the number of individuals in similar settings in 1982.

For those States that were already on this path, the Olmstead decision bolstered their efforts and reinforced that they were moving in the right direction. In 2009, DOJ’s Civil Rights Division launched an aggressive effort to enforce Olmstead. Over the next several years, the division was involved in more than 40 matters in 25 states. Through a series of system-wide settlement agreements, DOJ has expanded the understanding of Olmstead obligations from getting people out of institutions to assisting people to engage in community life. A settlement agreement with the state of Georgia in 2010, U.S. v. Georgia, was a landmark moment: Georgia not only committed to cease all admissions of individuals with developmental disabilities to their State hospitals by July 1, 2011, and transition all individuals with developmental disabilities in the State hospitals to the most integrated setting appropriate to their needs by July 1, 2015, but also negotiated with DOJ specific requirements regarding how they would serve these individuals in the community (U.S. v. Georgia, 2010). Georgia agreed to serve individuals “in their own home or their family’s home consistent with each individual’s informed choice,” rather than “a host home or a congregate community living setting” (U.S. v. Georgia, 2010, pp. 7-8). The settlement agreement stipulates that host home settings will not serve more than two individuals, and any congregate community living settings no more than four. The agreement also requires that Georgia provide “family supports,” defined as “an array of goods and services aimed at providing families with the highly individualized support needed to prevent institutionalization and continue to care for a family member with developmental disabilities at home” to some 2,350 individuals (U.S. v. Georgia, 2010, p. 4). The Georgia settlement is the first high profile instance in which DOJ used its authority under the ADA not just to facilitate deinstitutionalization, but to enforce the idea that publicly-funded community services must maximize integration, and to negotiate specific elements of a State’s service system in order to achieve that goal.

The message of the Georgia settlement was not lost on States and stakeholders. Cases like the one in Georgia...
have introduced a new federal policy consideration into state-level decisions about services and supports for individuals with IDD. Before the Georgia settlement, the prevailing question about federal regulation that figured into such decisions was, “Does it conform to Medicaid rules?” DOJ’s recent activity has made the question, “Does it conform to Olmstead obligations?” an equal consideration. It is the Olmstead integration mandate and DOJ’s enforcement activities that States have often referenced, for example, when they have declined to fund a new wave of proposed congregate living facilities, often referred to as “farms” or “villages,” for specific disability groups.

The January 2012 settlement agreement in U.S. v. Virginia signaled a further expansion of DOJ’s focus, concentrating not just on individuals currently residing in institutions, but also on preventing “the unnecessary institutionalization of individuals with developmental disabilities who are living in the community, including thousands of individuals on waitlists for community-based services” (U.S. Department of Justice, 2015). The Commonwealth agreed to add approximately 4,200 people from waitlists and institutional settings to their HCBS waiver programs over a 10-year period. An additional 1,000 individuals on waitlists for community services will receive family supports to assist with providing care in their family home or their own home. The agreement also requires Virginia to “create an $800,000 fund for housing assistance to facilitate opportunities for independent living for people with developmental disabilities,” and, importantly, to develop and implement an Employment First policy to “prioritize and expand meaningful work opportunities for individuals with developmental disabilities” (U.S. Department of Justice, 2015). The inclusion of the Employment First provision in the Virginia settlement was an early and clear signal that DOJ’s approach to enforcing Olmstead would increasingly focus on employment, and, more broadly, factors beyond residence, as significant indicators of integration. Just three months later, DOJ intervened in a pending class action lawsuit against the State of Oregon in which it argued that Title II of the ADA and the integration regulation “apply to all services, programs, and activities of a public entity, including segregated, non-residential employment settings such as sheltered workshops” (Lane v. Kitzhaber, 2012, p. 3). This action represented perhaps the most dramatic expansion of DOJ’s enforcement policy yet, broadening department activity beyond consideration of where people live to concerns about how people spend their days. This development reached full fruition in 2013 and 2014 with two major actions in Rhode Island. In 2013, DOJ, Rhode Island, and the city of Providence entered into a settlement agreement specifically focused on 200 Rhode Islanders with IDD who had received services from a particular segregated sheltered workshop and day activity service provider (U.S. v. Rhode Island and City of Providence, 2013). In 2014, DOJ and Rhode Island followed this groundbreaking agreement by entering into the first statewide agreement, in this case a consent decree, citing the Olmstead mandate to prevent individuals with disabilities from being unnecessarily segregated in sheltered workshops and facility-based day programs (U.S. v. Rhode Island, 2014). The milestone agreement is the first to focus entirely on the extent to which a State’s day activity service system includes segregated settings, such as sheltered workshops and facility-based day programs, that have the effect of reducing access to alternatives like supported employment and integrated day services.

Since redoubling its Olmstead enforcement work in 2009, DOJ has taken a series of actions demonstrating a vision of the integration required by Title II of the ADA that extends far beyond the simple question of whether an individual lives in an institutional setting. In Georgia, DOJ sent a strong message that fulfilling a state’s Olmstead obligations includes designing a service system that truly offers individuals the supports they need to successfully live in their communities. The action in Virginia established that Title II gave DOJ the authority to intervene not just to move people out of institutions, but to ensure that a State’s community service system was robust enough to prevent institutionalization in the first place. In Oregon and Rhode Island, DOJ made it clear that the Olmstead mandate applies not just to services that allow an individual to live in their community, but to the entire range of day services States provide to individuals with IDD and others. These expansive Olmstead implementation efforts have had a profound impact on State service systems for individuals with IDD. DOJ’s vigorous pursuit of true integration has ensured that as State officials, individuals with IDD and their families, providers, and other stakeholders work together to determine policy directions for their state, they must take into account the Olmstead implications of decisions regarding not just institutional admissions, but sheltered workshops, congregate day programs, and the very character of the supports they offer to ensure that people with IDD have the opportunity to exercise their civil right to participate fully in their communities.

References

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In this February 2015 interview, Carol Ely, a Community Program Specialist at the Institute on Community Integration, talked about some of the ways that the Americans with Disabilities Act (ADA) has made a difference in her life. Video clips of the interview are online at http://www.selfadvocacyonline.org/stories.

Q: What difference has the ADA made in your life?

A: I think one of the biggest differences the ADA has made for me as a person who uses a wheelchair is that it’s quite a bit easier to get around than it used to be in terms of being able to ride independently on the sidewalk, get down the curbs, get across the street. It’s also expanded the options that people with disabilities have when it comes to using methods of transportation. Now as well as having Metro Mobility [a local shared-ride paratransit provider] we can also use the transit buses along with people who do not have disabilities, and we can take the light rail. So it’s expanded horizons in a lot of ways so we can get out and do more things than used to be the case.

Q: Has it made a difference for you in terms of being able to work, to have a job?

A: Every job I’ve gotten so far I’ve gotten on my own. That does not mean it has not been a challenge. There have been a couple times in years past when I felt like the minute I came into the room, even though the interviewer didn’t say anything, I had the gut feeling that the first thing the person was looking at was not me but my wheelchair. Yes, the ADA has helped because legally you cannot not give me a job simply on the basis that I have a disability.

I happen to know a young lady in her 20s who is a college graduate and who has been having an extremely difficult time getting a job. I’m on the Employment Learning Committee with her and she’s a bright young lady who has a job, but it’s not one she wants so she’s looking for a new job. She’s said that when she goes into interviews – she also has Cerebral Palsy, as I do, but it’s a bit milder than mine so she uses a walker – she says that when she goes into an interview the first thing that she notices is that the interviewer’s eyes go down to her walker rather than looking straight at her. And she says, “The minute that I go into a room to get interviewed they don’t notice me first, or my qualifications, they notice my walker first.”

I do remember a job that I was interviewing for a number of years ago where during the interview the person who was the executive director just came out and said, “Well, how do I know that you’ll be reliable just in terms of getting to work, because I’ve heard about Metro Mobility. So how do I know you’re even going to come to work, or that you’re going to even want to come to work?” I explained that I can’t guarantee you I’ll always be on time, but I will do whatever I can to schedule rides in such a way that if they are late I’ve got a little wiggle room. She asked me about my general health. Because I have a disability she assumed I have a lot of health problems and that it would mean I’m not at work. I said that my health is as good as anyone else’s and that’s really not an issue. I said that in terms of wanting to go to work, I’ve been out of college since I was 25 (and I interviewed for that job when I was 34), so yes, I do want to come to work. I had gotten tired of okay, now you’ve got a job, but then in the next few days or months they run out of funding and you’re unemployed. I had one period when I was unemployed for two years, and it wasn’t for lack of looking.

Q: You mentioned education. Has the ADA played a role in you getting your college education, or in your work on a university campus today?

A: My mother has been the reason I got my education. Seriously, I wasn’t given a choice. I didn’t have a parent who said, “Well, you have a disability so you don’t have to do it.” I had a mother who said, “Yes, you do have a disability, but we’re going to figure out ways you’re going to do as much as you can do, and I expect you to get the best grades possible. If you don’t, we’ll take away the phone, and the TV...in other words, we’ll take away all the things you love the most.”

In terms of the ADA, when I started school here at the University of Minnesota that was before they had even passed the ADA. But there still was Disability Services, so I still did have the opportunity to say that I have a class in a building that’s not accessible, and I need to be in an accessible building. So they’d have to move the whole class. I have to admit that probably because I was youthful at the time it kind of made me feel powerful that I could make somebody move a whole class just for me. The same with curb cuts. A lot of times, even now, they’ll shovel snow and put it in front of curb cuts, and it was even worse when I was here as an undergraduate. So I’d go inside and call around until I found who shoveled the snow and get them to move the snow. I remember one winter when I
was living in the dorm there was literally too much snow for me to go to my final exams. So they arranged for a proctor to come to my dorm room, and that’s how I took my finals. So they did make accommodations even before the ADA.

Q: Is the ADA still important today?

A: I think the ADA is still important today for a lot of reasons. One is that the unemployment rate for people with disabilities is still double that of persons without disabilities. So even though there’s a law that says if you can perform the essential qualifications of a job you should be able to get that job whether or not you have a disability, I think there’s still hesitation on the part of a lot of employers to hire people with disabilities because they think that they’re going to have to make accommodations that are very expensive, or that they’re going to somehow have to totally alter the job, or any number of things. So yes, I do think there’s a huge need still for the ADA.

In terms of affordable housing, for the most part people with disabilities live at or below the poverty level. There’s a whole problem with getting housing that is affordable and in a place where you can feel relatively safe. I still don’t think that people with disabilities often have the choice to live in the situation they want. They find themselves living in, say, a group home when they’d rather have supports and live in their own home, for example. I think for those and many other reasons the ADA will be needed far into the future.

The other thing we still need to work on is that there’s still often an attitude that people have about people with disabilities and a lot of assumptions that are automatically made before somebody even talks to you if they see you in a wheelchair, or using a walker, or something like that.

Was there anything else you’d like to say about the ADA?

A: I think the thing that I want to see more than anything else is that home and community-based services become better in terms of having more qualified people to provide in-home services so that more people have an opportunity to get out there and get jobs. You need services in your home in order to get out to do anything. If you don’t have good, reliable people who know what they’re doing then you can’t even attempt to get out there to see what you can do in terms of employment. So I want to see that get a lot better for people with disabilities. If you’ve got a job but you don’t have anybody to help you get ready for that job, if that’s what you need for your disability, then it’s all for naught. It’s another person with a disability living below the poverty level.

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Resources on the Americans with Disabilities Act

The following resources from around the country may be of interest to readers of this Impact:

• ADA Legacy Project (http://www.adalegacy.com/ada25). The mission of the ADA Legacy Project is to honor the contributions of people with disabilities and their allies by preserving the history of the disability rights movement, celebrating its milestones, and educating the public and future generations of advocates. On its ADA at 25 Web site are extensive resources, including schedules of ADA 25th anniversary events nationwide, anniversary toolkit, and information about the nationwide ADA Legacy Bus Tour.

• Moments in Disability History (http://mn.gov/mnddc/ada-legacy/index.html). This contribution to the nationwide ADA Legacy project draws on the Moments in Disability History compiled by the Minnesota Governor’s Council on Developmental Disabilities. They are moments that capture the historical events and key leaders in the disability rights movement whose common vision, persistence, and passion to be included in the broader civil rights movement culminated in the signing of the ADA. The “moments” include a wide range of audio and video clips, historical documents, images, and slides from over a span of decades. They are the “moments” every self-advocate, parent and professional advocate should know and be literate about in order to create future policy.

• Self-Advocacy Online (http://www.selfadvocacyonline.org/stories). The “Stories from Self-Advocates” section of this Web site includes over 40 short video interviews with self-advocates who share their thoughts on the ADA. The site is designed especially for use by self-advocates and their allies, and is operated by the Research and Training Center on Community Living at the Institute on Community Integration, University of Minnesota.

• ADA Signing Ceremony Video (http://www ada.gov/videogallery.htm#ADAsigning990). This video documents the speech by President George H. W. Bush when he signed the Americans with Disabilities Act (ADA) into law on July 26, 1990. In the video, he speaks to a huge audience gathered on the south lawn of the White House. This 22-minute film, provided to the U.S. Department of Justice, Civil Rights Division, by the George Bush Presidential Library, is being re-released on the department’s ADA.gov Web site to increase awareness of the ADA.

• Generation ADA: Disabled Girls Talk Podcast (http://disabledgirlstalk.tumblr.com/). Maddy Ruvo, 21, and Emily Ladau, 23, launched the Disabled Girls Talk podcast in 2014 as an ongoing discussion about coming of age with a disability. Their first episode focuses on the ADA, including what it means to them as part of the generation reaching adulthood after its passage.
How ADA Litigation Has Supported the Rights of People with Intellectual/Developmental Disabilities

by Bud Rosenfield

The opening provisions of the Americans with Disabilities Act (ADA) note bluntly that “society has tended to isolate and segregate individuals with disabilities” and that “discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services” (ADA, 1990). With comprehensive prohibitions on disability discrimination and requirements for reasonable accommodation, some of the ADA’s positive impacts are clear. Buildings commonly have ramps and push-button door openers. Stadiums and movie theaters routinely offer closed captioning. But for people with intellectual and developmental disabilities (IDD), it is fair to ask the question: Has this landmark civil rights law lived up to its promise?

A review of cases involving persons with IDD can provide only a snapshot of the overall legal landscape. But the big picture of the past 25 years shows that the ADA has been an integral tool in shaping society’s understanding of what inclusion means and requires, and in helping people with IDD enforce their rights and achieve more meaningful connections to their communities.

The Early Years

In 1996, six years after the ADA was signed into law, the United Cerebral Palsy Association conducted a survey regarding the effect of the ADA on the lives of people with disabilities (United Cerebral Palsy Associations, Inc., 1996). The survey found that the ADA had made a great difference, prompting better access to buildings, greater access to transportation, and fuller inclusion in the community. Respondents described significant improvements in access to public accommodations. Most found local businesses, as well as government buildings and other public facilities, to be more accessible.

Still, mere passage of the ADA did not eliminate discrimination or problems with access to facilities and services. Given a new, broader right to seek relief for discrimination and the denial of reasonable accommodations, people with IDD used the ADA to their advantage. They sued.

Their lawsuits came in many forms. In 1996, prisoners with IDD sued officials in California, alleging they had been denied access to medication and to work and educational programming, and subjected to excessive discipline not imposed on prisoners without disabilities. After prevailing on the issue of whether the ADA may be constitutionally applied against the State, the case, Clark v. California, settled. California agreed to create a Developmental Disability Program to accommodate inmates/parolees with IDD and to monitor provision of their services.

Similar challenges to how public entities provide services to people with IDD sprung up during the ADA’s first decade. While Clark was being litigated in California, Lois Curtis and Elaine Wilson, two women living in a State psychiatric hospital in Georgia, were suing State officials for the right to receive services in the “most integrated setting” possible, consistent with their needs. Their challenge, Olmstead v. L.C., drastically changed the ADA landscape for persons with IDD and other disabilities.

Olmstead and its Aftermath

The U.S. Supreme Court’s 1999 decision in Olmstead v. L.C. (1999) is now so widely known it has become shorthand for the requirement that services, programs, and activities be provided in the most integrated setting appropriate to the needs of qualified individuals with disabilities. In their effort to obtain community services, Ms. Curtis and Ms. Wilson persevered and won at each level of the case, with the Supreme Court definitively holding that the unjustified isolation of individuals in institutional settings is a form of actionable discrimination under the ADA.

Many States responded to Olmstead by developing “Olmstead plans” (or creating workgroups to develop such plans) intended to conform their service systems to the ADA’s integration mandate. The U.S. Department of Health and Human Services issued a series of five letters to state Medicaid directors providing guidance on the requirements of Olmstead. Notwithstanding this flurry of administrative activity immediately following Olmstead, the need to litigate failures to provide services in “the most integrated setting” persisted. Those lawsuits have been relatively successful.

In 2010, Georgia settled a class action lawsuit, U.S. v. Georgia, brought by legal aid offices and the U.S. Department of Justice (DOJ) on behalf of persons with IDD and mental illness who were institutionalized in psychiatric hospitals and other facilities. The comprehensive settlement was the first to cover all of a state’s public psychiatric hospitals. It ensured that more than 2,500 persons would be offered appropriate community supports tailored to meet their needs.

After the Georgia litigation settled, the Obama administration redoubled its efforts to enforce Olmstead, with the DOJ aggressively starting and joining Olmstead lawsuits. One such case was a class action in Illinois, Ligas v. Maram. The Ligas plaintiffs alleged that Illinois violated the ADA by failing to provide services for them to live in the community, relying instead on large, privately-run institutions called Intermediate Care Facilities for People with Developmental Disabilities (ICFs/DD). After prolonged litigation, the DOJ filed a “statement of interest” in the case in 2010. One year later, the case settled. Illinois agreed to expand its community

Overview
services both for individuals living in ICFs/DD and those living in the community but on a “waiting list” for community services.

**Beyond Public Services**

While *Olmstead* addressed how public services are to be provided, there has also been significant ADA litigation in the area of employment. In one particularly poignant case, *EEOC v. CEC Entertainment*, Donald Perkyl, an employee with IDD, sued the pizza restaurant chain, Chuck E. Cheese’s, with help from the Equal Employment Opportunity Commission (EEOC). Hired as a janitor, Mr. Perkyl was summarily fired—against the express wishes of his own supervisor—by a district manager who allegedly did not want “those kind of people” working in the restaurant. In November 1999, a Wisconsin jury found that the company had violated the ADA, awarding Mr. Perkyl over $13 million in punitive and other damages. Although the court later reduced the award to $300,000, the maximum amount recoverable for such violations, it affirmed the verdict, noting that “the breathtaking magnitude of an eight-figure punitive damages award demonstrates that the jury wanted to send Chuck E. Cheese’s a loud, clear message.”

The EEOC obtained its biggest jury verdict ever in an ADA employment case, *EEOC v. Hill Country Farms*, brought by 32 workers with IDD against an Iowa turkey processing plant. Over their 20 years of employment, the plaintiffs claimed that they suffered wage discrimination and were subjected to multiple and repeated forms of verbal and physical harassment and mistreatment. Litigated in two parts, the plaintiffs first won a court judgment of over $1.3 million on their wage claims. In the subsequent 2013 jury trial on their a hostile work environment claims, the plaintiffs provided evidence that they were frequently called pejorative and offensive terms, denied bathroom breaks, and given discriminatory job assignments. Concluding that the company violated the ADA, the jury awarded each plaintiff $2 million in punitive damages and $5.5 million in compensatory damages, for a total award of $240 million.

Although such enormous awards are rare, they illustrate the power of the ADA. Fundamentally, these verdicts reflect society’s developing appreciation for how people with IDD deserve to be treated.

**Current Cases and Where We’re Heading**

Traditional, deinstitutionalization litigation under *Olmstead* continues to the present day. However, persons with IDD also continue to push the edge of the *Olmstead* envelope.

In Oregon, eight individuals with IDD who received services in sheltered workshops sued various state agencies in early January 2012, alleging that the failure to provide services in “the most integrated setting” violates the ADA. In a landmark, interim decision, the federal district court determined that the ADA and *Olmstead* apply not just to residential services but to employment supports as well. The court’s decision in *Lane v. Kitzhaber* effectively allows the plaintiffs’ employment-based claims to continue; currently the case is ongoing.

Similar litigation in Rhode Island recently reached a quick, comprehensive and precedent-setting settlement. In a case echoing *Lane*, the DOJ sued Rhode Island officials on behalf of individuals with IDD who have been unnecessarily segregated in sheltered workshops and facility-based day programs. The case, *U.S. v. State of Rhode Island*, settled in 2014. The settlement and consent decree address the State’s over-reliance on segregated settings in its day services programs and aim to help approximately 3,250 individuals with IDD over the next 10 years. With detailed, numerical goals regarding the people to be served and the employment outcomes to achieve, the State will provide community supports and placements to people currently in sheltered workshops and in facility-based non-work programs, as well as to students leaving high school.

Recognizing that Medicaid Home and Community-based (HCBS) waiver programs are primary tools that States can use to comply with *Olmstead*, the Centers for Medicare and Medicaid Services recently released a new rule describing the types and characteristics of permissible, “community based” settings (CMS, 2014). Many states have funded HCBS services in congregate settings that are not truly integrated and do not afford people independence and access to their communities. This new HCBS settings rule and related regulations requires States to develop detailed transition plans for how they will comply with the rule within the next five years.

The HCBS settings rule explicitly merges Medicaid’s service expectations with the ADA’s integration mandate. In so doing, the federal government has opened up new opportunities for people with IDD (and other disabilities). Although the failure to comply with the new rule could eventually lead to future litigation, for now, the changes represent one more step toward fulfilling the ADA’s promise of integration and inclusion.

**References**


**Notes**

1. *Olmstead* was not the first integration mandate case. Started in 1992, Helen L v. DiDorio challenged Pennsylvania’s refusal to provide in-home attendant care services rather than nursing home care. After losing at the district court level, the Helen L plaintiffs appealed, with the support of the DOJ. In early 1995, the Third Circuit Court of Appeals reversed the lower court’s decision, holding for the first time that the unnecessary institutionalization of individuals with disabilities violates the integration mandate of the ADA.

2. The Statement of Interest is a procedural option that the DOJ can take to make its position known in a case without affirmatively joining the litigation as a party. The DOJ has filed such statements with increasing frequency over the past few years.

3. The ADOS actual impact on employment opportunities for people with disabilities has been mixed. In 2010, The Arc conducted a national, online Family and Individual Needs for Disability Supports (FINDS) survey regarding a range of IEP issues. Of the over 5,000 people who participated, only 15% of survey respondents reported that their family member with an IDD was employed. Regular jobs in the community with competitive wages were rare. Most individuals who received services worked in sheltered workshops and enlaced settings. For more see http://www.thearc.org/FINDS.

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The Olmstead Decision and Its Aftermath

by Sue Jamieson

Sue Jamieson was the lead attorney in the Olmstead v. L.C. Supreme Court case. In January 2014, she gave the following presentation reflecting on the case as part of a colloquium hosted by The Institute on Human Development and Disability, University of Georgia, and held at the David A. Clarke School of Law at the University of the District of Columbia (UDC). A video of this presentation can be found at https://www.youtube.com/watch?v=Xz5-n-4na_E.

It is really great to be at UDC tonight. This law school has been so welcoming since the day in August last year when I walked in off the street on a visit from Atlanta. I mentioned the Olmstead project to Karen Foreman and the next thing I knew she and Professor Joe Tulman had helped me conceptualize this panel.

The case is part of a complex, heroic fabric woven by the efforts of those who went before and those who continue to struggle now.

Our idea is to focus on how the Supreme Court finally articulated, in the Olmstead decision, the civil right under the Americans with Disabilities Act (ADA) of a person with a disability to freedom from segregation. And beyond that, to emphasize the need for ongoing enforcement of this right. The Olmstead case is now 15 years old. What matters to people who are still institutionalized, still segregated, is its enforcement. We hope tonight you will get a feel for the long struggle for disability rights that preceded Olmstead and, more importantly, a feel for the ongoing struggle represented by a case here in the District of Columbia, Thorpe v. D.C. The plaintiffs in Olmstead were confined in a State psychiatric hospital. Thorpe takes the disability integration struggle to another important frontier, one of the most important disability integration frontiers today – nursing homes.

My role tonight is to tell you how the Olmstead case got started, which will include a little about my own journey and that of the two plaintiffs. Then, I will cover the very basic outline of the decision itself.

How the Case Got Started

By way of background, I worked for 10 years as a legal services attorney for legal services programs before I became interested in representing people in institutions. I had no particular background in disability rights. I had never even been inside a State institution until I had occasion to visit one in north Florida. I was so shocked at the inhumanity of the place that I had one of those light bulb moments. I decided that this is a place where the most fundamental rights of individuals are obviously at risk. I thought to myself it is unlikely that the people locked up in here have any idea what rights they have and it is a huge understatement to say that they could definitely use some legal assistance.

When I say fundamental rights at risk, I mean rights related to basic freedom and autonomy. The individuals I saw, and later came to know over the years, were locked up against their will in crowded spaces, sometimes for years, placed in restraints that tied their arms and legs to a bed for hours, left for days in seclusion rooms, medicated with powerful drugs without consent, cut off from family and friends. Most shocking was the utter disregard of human dignity, lack of privacy, and danger. Of course, there were well-meaning staff, but there was also cruelty and indifference.

When I moved to Georgia, I wanted Atlanta Legal Aid to serve people in State hospitals. I decided to go into the hospitals, pass out my cards and look for sympathetic social workers. Before long, we were able to start a little outreach project to the hospitals.

By the time Lois Curtis and Elaine Wilson, the plaintiffs in the Olmstead case, were Atlanta Legal Aid clients, the project had been operating for about 15 years. We did not typically file federal court cases. In fact, we would often just write letters, make phone calls, and, if that didn’t work, file a case in state court or probate court or try administrative advocacy with state officials. Mostly, we were challenging practices that violated the rights of people who were confined in the hospitals – rights related to commitment hearings, forced medication, restraints, seclusion, and due process rights related to denials of various disability community services.

By 1995, however, when we filed the Olmstead case, two factors led us to federal court. First, although both plaintiffs had experienced abuse in the hospital, the legal problem they presented to me was not a violation of a right to appropriate treatment in the institution. The major problem for Lois and Elaine, and for many of our clients, had become the need for a decent, safe community alternative. “Community alternative” means not only a place to live, but support staff, if needed, counseling, supported employment, peer supporters, and help managing daily life. In other words, more than a brief moment of freedom... more than a few months in a personal care home before returning to a State hospital through the revolving door.

And second, state law remedies were inadequate. Most state laws required a showing that involuntary commitment was “the least restrictive alternative,” but did not impose any affirmative obligation to fund community programs. We hoped that a federal law, the ADA, would offer the solution we needed.

Just a few words about Lois and Elaine. Lois and Elaine both had diagnoses of...
schizophrenia, developmental disabili-
ties, and “behavior problems.” It was
clear that the “behavior problems” re-
sulted from the many years both women
were confined in institutions.

Lois was in her early 30s when we
filed. She had been institutionalized for
most of her life since she was 14. She
was raised by a single mom in a public
housing project. Her mom lived in con-
stant fear that Lois would get herself
in trouble, especially when she became
a teenager. When Lois, who was intel-
lectually limited and vulnerable, would
wander the neighborhood, her mom
would call the police and have her com-
titted to a State hospital.

Shortly after the case was filed, Lois
was finally released to a group home with
a detailed community-based service plan
developed through the litigation. She
now lives on her own with personal sup-
ports. She never went back to a hospital.

Although the Olmstead plaintiffs
were segregated in a State psychiatric
institutions, the case applies also to
people in nursing homes because private
nursing homes provide services through
public programs. The most prevalent of
these is Medicaid, but there are other
publicly-funded programs that serve
people in nursing homes.

The Supreme Court, in an opinion
by Justice Ginsberg, summarized in two
sentences the claim that Lois and Elaine
presented:

This case concerns the proper con-
struction of the anti-discrimination
provision contained in the public
services portion (Title II) of the
Americans with Disabilities Act
of 1990...Specifically, we confront
the question whether the proscrip-
tion of discrimination may require
placement of persons with mental
disabilities in community settings
rather than in institutions. [Olmstead
v. L.C., 1999, p. 587]

Justice Ginsberg answered her own
question with a “qualified yes.” The “yes”
was qualified by three “conditions.”
These are sometimes referred to as the
three prongs of Olmstead: (1) The per-
son’s treatment professionals need to
agree that community placement is ap-
propriate; (2) the person is not opposed
to community placement; and (3) place-
ment can be “reasonably accommodated”
given the needs of others in the State’s
disability service system [Olmstead v.
L.C., 1999, p. 587]. Another way to put
this third prong is that the State is not re-
quired to fundamentally alter its system
if it has a plan of action to move people
into the community and a waiting list
that moves at a reasonable pace.

There are problems with this lan-
guage, but as the cases emerge over time
the basic integration principle is carry-
ing the day. The big step forward is that
the State cannot justify segregation by
showing that it provides treatment or
habilitation in the State facility. If the
person could receive that support in the
community, then segregation in an insti-
tution is discriminatory. The State has

[Sue Jamieson (left) with Elaine Wilson (center) and Lois Curtis. Photo courtesy of The Institute on Human Development and Disability/UCEDD at the University of Georgia.]

Basics of the Olmstead Decision

It is Title II of the ADA that prohibits
discrimination by public entities and in
public programs. A regulation promul-
gated under the ADA, called the integra-
tion regulation, obligates public entities
to provide services in the most integrated
setting. This is the section of the ADA
and the particular regulation that formed
the basis of the plaintiffs’ argument.

[Jamieson, continued on page 35]
Lois Curtis on Life After Olmstead

by Lois Curtis with Lee Sanders

On June 22, 1999, the U.S. Supreme Court held in Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act (ADA). Following is a compilation of three conversations with Lois Curtis, the surviving plaintiff in the Olmstead case. In these conversations from Fall 2014, Lois draws pictures throughout while answering questions. She doesn’t address the ADA directly – that’s not her way. Instead, she shares her memories and thoughts, infused with her characteristic innocence, generosity, and liberating spirit.

Lee: How did what became the Olmstead Decision begin? How did you get out of the institution?

Lois: Well, I prayed to God. I cried at night so I prayed to God every night in my bed. Elaine [Elaine Wilson, co-plaintiff], asked me to pray for her to get out too, so I did. We sued and they closed our case [won our case]. Elaine and me was the first ones to get out. Elaine died. She in heaven now. I miss her sometimes. Why I have to go away? I’m sorry what I did.

Lee: Lois, it was a mistake. You did nothing wrong. You’re a good friend to many people. Tell me, what do you wish for all the people you’ve helped move out of the institution to live in their communities?

Lois: I hope they live long lives and have their own place. I hope they make money. I hope they learn every day. I hope they meet new people, celebrate their birthdays, write letters, clean up, go to friends’ houses and drink coffee. I hope they have a good breakfast every day, call people on the phone, feel safe.

Lee: Could someone have the possibility of all these wonderful things in their life if they lived in an institution?

Lois: Nah.

Lee: And President Obama invited you to the Oval Office because of your part in the Olmstead Decision. He said that he wanted to help others live in their communities, “just like Lois.” What was it like to meet the President?

Lois: It was real nice. He a good person to me. They took our picture and he smile real big. He wrote me a letter.

Lee: And you gave him a piece of your artwork, too.

Lois: Yeah!! He like my picture. He said I am a real good artist.

Lee: What is your life like today? Tell me some of the things you do.

Lois: Well, I make grits, eggs, and sausage in the morning and sweep the floor. I go out to eat sometimes. I take art classes. I draw pretty pictures and make money. I go out of town and sell me artwork. I go to church and pray to the Lord. I raise my voice high! In the summer I go to the pool and put my feet in the water. Maybe I’ll learn to swim someday. I been fishing. I seen a pig and a horse on a farm. I buy clothes and shoes. I have birthday parties. They a lot of fun. I’m not afraid of big dogs no more. I feel good about myself. My life a better life.

Lee: You know that there are still people living in institutions that would like to have a better life, like you. What would you like to say to give them hope?

(Lois is uncertain) Shall I read you the letter you wrote a couple of years ago? (Lois stops drawing and nods. She then tilts and bows her head slightly and closes her eyes):

Hello to all the people living in institutions, I remember you. Give me a prayer. Sometimes I feel good about my life. When I feel bad about my life I name my country, sing the gospel, and bring my mind back home. I will sing with you again. Have a beautiful day.

Love, Lois

Lois: (Huge smile and deep laugh) Yeah! I think some day it always gonna be a beautiful day!

Lois Curtis is an artist living in Stone Mountain, Georgia. Lee Sanders is a Career Specialist with Briggs & Associates, Roswell, Georgia.
Why We Still Need the ADA

by Nathan Perry

For Nathan Perry, an Information Technology Specialist at the Institute on Community Integration, the Americans with Disabilities Act (ADA) has been an important advocate. In this February 2015 interview he talks about that advocacy. Video clips of Nathan discussing the ADA are at http://www.selfadvocacyonline.org/stories.

Q: What difference has the ADA made in your life?
A: I have had some experience with the ADA and employment, with it helping me have a job. Since the ADA was enacted, it now makes it discriminatory to not hire somebody who has a disability if they’re otherwise qualified. I’ve had places where I’ve worked where they were much more open to working with somebody who has a disability because of the ADA. I haven’t run into anybody that blatantly refused to hire me because of my disability, but because the ADA is there they’re much more open to trying to work with people with disabilities.

Q: Do you think it opened up some job opportunities for you that might not have been open before?
A: Yes. One of the things that I’ve used is a job coach. I still use a job coach to this day. If it wasn’t for the ADA it would’ve been much harder to use a job coach in a work setting. So I’m really grateful for the ADA and that aspect of it. I’m also glad that I have rights so that if I do run into any kind of issues or discrimination there are steps I can follow to remedy it.

Also another thing that’s happened with the ADA is that we have Disability Services here on campus and I know people – staff and students – who use Disability Services. If we hadn’t had the ADA in place I’m not sure we’d have the kind of services we have here today to provide supports if they need supports in the classroom and in the workforce area. For instance, they provide for a friend of mine who works here a headset so she can talk on the phone without holding the receiver. That wouldn’t have been provided if the ADA hadn’t been there.

One thing that I’m thrilled about is that this is the ADA’s 25th anniversary and it’s still going strong and hasn’t fizzled out, and there hasn’t been anything that’s dismantled it. It’s survived and continued to be a really strong advocate for people with disabilities. A lot of people wouldn’t be in the positions they’re in now if it hadn’t been for the ADA. People with disabilities working in professional jobs, actually getting out in the community and not staying home all the time, being able to get funding for providers to train their staff to provide supports to people who need supports such as PCAs.

Q: Do you think the ADA is an important safety net for people?
A: It is a nice safety net. I will always try to do stuff on my own, and a lot of other people will, too. But it’s nice to know it’s there in case you need help, in case you run into some sort of roadblock, so you can get something done. It’s nice to have something that’s a law so if there is some discriminatory action going on or something’s not in compliance with ADA regulations, there’s something that people can actually go to and use to right the situation.

Q: It is 25 years since it passed. Do you think it’s still important?
A: I think it gets more important as time goes on. We have a lot of people who are aging in the community who need supports who have never needed them before. Without the ADA, back in the day when people got older and needed supports, the only supports they had were nursing homes, and now they have assisted living communities, or they can have people modify their houses so they can live independently in their houses. People that are getting older are going to need to move into ADA-compliant homes, ADA-compliant assisted living and nursing homes, and the ADA will be there to make sure they have the stuff that they need to live in that environment. So as far as I see, with each year that goes by it gets more important, and it gets broader as far as the supports that are provided. Everybody recognizes the ADA now and that it’s a good thing. They know that it’s not just going to be temporary, but is here for the long haul.

Q: What’s your experience with how familiar people are with the ADA?
A: Most people that I interact with who have disabilities pretty much know what the ADA is because they have disabilities and they’ve lived it, and they have people in their lives who know how the ADA works. The more interesting question would be whether people without disabilities know what the ADA is. That would be where people would not necessarily know enough. They’ve heard about the ADA, but don’t necessarily know what it is. In my experience when you mention ADA, they’re really curious about what it is, and they want to know about it and how they can better provide supports.

Q: Is there anything else you want to say about the ADA and its importance?
A: I think the ADA is a critical infrastructure for people with disabilities and I think it’ll be here for the long haul, and will continue to grow, and will continue to advocate for people with disabilities.

Nathan Perry may be reached at perry211@umn.edu or 612/624-2008.
Any article marking the 25th anniversary of the Americans with Disabilities Act (ADA) would be incomplete without a contribution from the ADA’s chief architect, Iowa Senator Tom Harkin. In the opinion piece below, Senator Harkin commemorates the ADA as an “Emancipation Proclamation” for people with disabilities, while highlighting additional steps that need to be taken to realize its promise. Those additional steps involve commitment and action at the state and local levels to bring Congressional intent to the street level. Therefore, this article also includes opinion pieces by an Iowa state legislator, Representative Dave Heaton, and a member of the Regional Advisory Committee for Mental Health and Disability Services of East Central Iowa, Terry Cunningham. These three pieces together underscore how implementation of the ADA requires a partnership at the federal, state, and local levels.

Equally important, it is clear that implementation requires increased expectations on the part of all Americans that individuals with disabilities are fully included. (Bob Bacon)

The Honorable Tom Harkin, United States Senator, Iowa

Our nation will soon mark the 25th anniversary of the signing of the Americans with Disabilities Act, one of the landmark civil rights laws of the 20th century. In addition to being an Emancipation Proclamation for people with disabilities, the ADA has the very down-to-earth purpose of ensuring that people with disabilities can go places and do things that other Americans take for granted.

Over the past quarter-century, the ADA has provided opportunity and access for more than 56 million Americans with disabilities. Prior to passage of this landmark civil rights legislation, these Americans routinely faced prejudice, exclusion, and insurmountable physical barriers in their everyday lives. And while there is still more work to do, we can now say that across the country, Americans with disabilities have an opportunity to participate more fully in our national life through the removal of barriers in employment, transportation, public services, telecommunications, and public accommodations.

As we look forward, we must build on the progress we have made to make all of American life accessible for all our citizens. To accomplish that goal, this past July, America took another big step forward when the President signed into law the Workforce Innovation and Opportunity Act, which ensures that all workers – including those with disabilities – have access to 21st-century job training and employment opportunities. This is a big step in the push to strengthen employment opportunities for people with disabilities and will make a tremendous difference in the lives of people around the country.

As the world leader in disability rights, we also have a responsibility to ensure all of the world’s one billion people with disabilities have the right to access all aspects of their communities. That’s why, in 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD), modeled on our own ADA. The Convention was negotiated by President George W. Bush and signed by President Obama, and it now needs to be ratified by the Senate so the United States can continue to be the world leader in disability policy and practices. The passage of the CRPD is a central component of the work still ahead to expand disability rights and I will continue to raise awareness until it is approved by the full Senate. It’s an uphill fight, but I am optimistic. For the U.S. to be a shining city on a hill, an example to the world, the Senate needs to ratify this treaty and reassert American leadership on disability rights.

Senator Harkin was one of the authors of the ADA, and upon its passage delivered the first-ever speech on the Senate floor in American Sign Language; view the video at https://www.youtube.com/watch?v=BomPot6POOo. He may be reached at harkininstitute@drake.edu.

State Representative Dave Heaton, Iowa House District 84

I have served in the Iowa House of Representatives for 20 years. After winning the November 2014 election I will proudly serve the citizens of southern Iowa, House District 84, for two more years. I am happy to provide my reflections of the impact of the ADA both on my legislative career as well as my constituents of my District.

As the Chair of the Health and Human Services Budget Committee, I am acutely aware of the impact the ADA is having on the direction of services provided by our
state to its citizens with disabilities. I am happy to say that our state continues to make meaningful changes in the service delivery system to better ensure that all Iowans with disabilities have opportunities to live, work, and fully participate in their community. The recent redesign efforts of our Mental Health and Disability Services System draw heavily on the Olmstead decision. The Olmstead decision would not have been reached if not for the ADA.

Several years ago I had the opportunity to visit with a young man in Midland, Michigan, who had significant disabilities, but yet was self-directing his services. The visit showed me that when barriers to inclusion are removed and appropriate services and supports are provided, individuals who once were thought of as unable to live in the community could successfully do so.

Challenges remain in fulfilling the intent of the ADA. One problem for policymakers and politicians is that we can’t have an open checkbook to meet all the needs of all individuals. There is simply not enough money to go around. Sometimes we have to make tough decisions. Federal fiscal participation to encourage, provide direction, and assist us to move forward is critical.

My chief concern is that we must have the infrastructure, services, and providers to serve our citizens with disabilities in the most inclusive environment. We have issues with affordable housing, securing meaningful integrated employment, and accessible transportation. My goal is that all Iowans with disabilities live a meaningful and fully participatory life. The ADA has influenced that.

It is also interesting to note how the ADA is affecting every citizen, even those without disabilities. For example, a house built on one level will often be more marketable than one with stairs. Curb cuts help a lot of individuals to have easier access to community settings or events. Here in my hometown of Mount Pleasant, mothers with children in strollers and older citizens who might use walkers all enjoy the new curb cuts for easier access to our central park. Oftentimes people use the elevator in our courthouse for convenience rather than take the stairs. These latter two improvements were the direct result of the ADA.

Rep. Heaton may be reached at dave.heaton@legis.iowa.gov.

Terry Cunningham, Member, Regional Advisory Committee for Mental Health and Disability Services of East Central Iowa

Since the Americans with Disabilities Act was signed into law on July 26, 1990, many significant strides have been made to enable individuals with disabilities to fully participate on an equal basis in everyday life:

- Accessibility at the local level has included, but not been limited to, expanded use of curb cuts that allow individuals with mobility issues to enjoy not only their neighborhoods, but their entire community. Accessibility at the local level also improves access to schools, entertainment venues, retail stores, restaurants, and public buildings. These features also make life easier for persons with children, persons with aging issues, postal personnel, and many others.

- Transportation systems, while still not what they should be, have made improvements which were mere dreams when the ADA came into effect. Now school systems, public transit systems, trains, cross-country buses, and airplanes offer individuals with disabilities accessible options to travel around not only home communities, but around the world.

- Housing that is affordable, accessible, and safe has become more common, although units are not growing nearly as fast as the demand for them. Individuals with disabilities have the opportunity to live in a setting designed for their own needs while being a truly integrated member of society as they enjoy the American Dream of home ownership.

The last major portion of the ADA left unfilled is related to employment. This could be the most difficult accomplishment yet because it requires an entire attitude adjustment by employers of all types regarding just what persons with disabilities are able to accomplish in the workforce. This will also require an attitude adjustment by future co-workers. Instead of looking at persons with disabilities as individuals who need to be pitied or cared for, now they must be viewed as equals and capable of performing the same jobs as their coworkers without disabilities.

This is going to require a change of expectations from everyone involved: parents, educators, individuals with disabilities themselves, and employers. No longer will qualifying for Supplemental Security Income (SSI) become a career accomplishment; individuals with disabilities must be expected, and given the opportunity, to support themselves to the fullest extent possible. These changes in societal expectations from the earliest possible time will change individual expectations and result in persons with disabilities having the same expectations placed on them as individuals without disabilities. This will also give individuals with disabilities opportunities to set and achieve goals of their own and benefit from the rewards of their successes.

Sadly, as this article went to press, Mr. Cunningham passed away on March 19, 2015, in Iowa City. He will be remembered as a powerful disability advocate.

Bob Bacon is Director of the Iowa University Center for Excellence on Disabilities, University of Iowa, Iowa City. He may be reached at robert-bacon@uiowa.edu or 319/356-1335.
Hunter Sargent, a community leader and self-advocate living in the Twin Cities, was interviewed in February 2015 about what the Americans with Disabilities Act (ADA) has meant in his life. Below are the thoughts he shared during that interview at the Institute on Community Integration. Video clips of the interview can be found at http://www.selfadvocacyonline.org/stories.

The Americans with Disabilities Act means that I get to participate politically as well as community-wise in discussions regarding things involving people like myself with intellectual and developmental disabilities, like our right to live in the community, be removed from the institutions, and be part of the decisions that are made with regard to us. It has helped me learn how to advocate for myself and not be afraid, and to know that when it comes to advocating for your rights you’ve got to be patient, and follow-up and stay in touch with your legislators and lawmakers. The ADA has helped me live successfully in the community. It has helped me to gain access to programs like the First Time Homebuyers program, and just basically finally live independently in the community without any discrimination or unnecessary challenges.

I think self-advocates should care about the ADA because of the long, hard road we had to go down to reach this point in history in our country. It’s this that has helped us stay more politically active and more involved in our communities. And it has helped us and strengthened us to overcome our own fears about whether or not we fit in. We’ve become stronger by trying really hard not to worry about what people think of us. We realize that we just have to teach people about how to diversify our adaptations, being people with disabilities, and people of different ethnic backgrounds, and how all those challenges are pretty much the same and we’re really not much different. We just have an adaptive lifestyle. The adaptation I have is that I have staff that work with me and I stay involved with self-advocacy.

I’ve worked on so many different ways to communicate respect for people with intellectual and developmental disabilities, like getting rid of the “R” word. I have a family member who’s said, “Well I’m sorry but I can’t change my vocabulary.” You can change your vocabulary, it is possible. You need to be mindful of that with me having a disability as well as my auntie. My auntie’s not verbal when it comes to saying how she feels; I’m kind of giving a voice to the voiceless and giving a voice to those who feel they’re not heard.

I see the ADA as a civil rights act because we literally have to fight to maintain our rights as people with intellectual and developmental disabilities just like everyone else does. I shouldn’t say fight, I should say continually educate our politicians because if I say fight it’s like saying we don’t get what we want, and we do get what we want because we learn how to express our emotions, with respect, but in political language. This is the other thing the ADA has taught me, how to talk multiple different languages – to still be me but to talk in different environments. Like when I talk with my representatives I’ve got to talk politics for them to understand me, but do so in a way that I understand, too. The same is true when I talk with the State and County.

Without the ADA I don’t think I’d be where I am today. It is so cool to see the changes. Sixty or seventy years ago people were institutionalized, not heard, left in a corner and forgotten about, and look at us now. We’re happily married, we’re playing regular sports, we’re doing our life like everybody else does. Adaptations make us stronger, not weaker. There are some days when I love speaking up for my rights as a person with an intellectual disability, and other days when I wish I could just sit back and watch and see that my voice is strong enough that I don’t need to keep repeating myself. You find yourself being a good strong self-advocate, and then you find yourself asking why don’t they just get it. It doesn’t change, it’s grown, but it hasn’t changed.

What I’ve Learned From the ADA

by Hunter Sargent

Hunter Sargent testifying at a Minnesota legislative hearing about the harm that bullying can cause. This hearing was on the Safe and Supportive Minnesota Schools Act, a bill being considered to address school bullying.
On the flip side of that, I’ve learned with politics and being involved that things are forever changing. You get new leaders, new people who have no idea what this is all about, or about the struggles we’ve been through in the past 60 years. For me it’s painful to even have to go down that road to get my point across, but at the same time I’m stronger. I can have all the political lingo you want, but if you don’t have some form of spirituality or some form of your culture in you, you tend to lose your way.

Over the next 25 years of the ADA I want to see us grow stronger, and continue to be louder and more present, and be very persistent in making sure that our rights are protected. I want us to stay involved in our communities and continue the importance of inclusion, not exclusion, because that’s what keeps us strong.

Hunter Sargent can be reached by e-mail at nativewarrior94@hotmail.com.

The ADA Has Given Me Access

by Cliff Poetz

In this February 2015 interview, Cliff Poetz, Community Liaison at the Institute on Community Integration, talked about what the ADA means in his life. Cliff is a long-time self-advocate who is frequently at the State capitol meeting with legislators, and is also an avid football fan. Video clips of the interview can be viewed at http://www.selfadvocacyonline.org/stories.

Q: What difference has the ADA made for you?
A: The ADA has made my life more accessible than it was before. For example, my apartment has an automatic door opener on my door. That means I don’t have to use a key anymore – I press a button to get into my apartment. It also has made it easier for people to go to the state Capitol and get around in the buildings. Accessibility in transportation. Metro Mobility [a local paratransit provider] has lifts so it can take wheelchairs – a couple of their buses have ramps that come up that you can wheel off. And there are regular buses that have lifts. Before you had to walk up steps. That was not good.

Most of the places I go are accessible. The University is doing bidding on some new facilities for the football field and a new education center for the athletes. They’ll have to be ADA-compliant because they’re new buildings, which is a good thing because people with disabilities will be able to go anywhere in them. And the new Vikings stadium has to be ADA-accessible. Then there’s the hospital – I remember in the early 1950s they didn’t have a ramp or anything, and where their clinic was had an incline and it was hard to get up and down that to get in and out. Now it’s accessible.

Also, the ADA allows people with disabilities to vote more easily. There are voting machines that, after you make your choices, automatically read out your choices. People at the polls show you how to use the machine and all that. There are some parts of the state where it’s not accessible for people to vote in the polls. The state needs to spend money on making them accessible. You don’t want anyone making their choices sitting in a van and not being able to go into a voting place. But that’s getting better.

Most of the makers of cell phones and computers are now looking at the market of people with disabilities. A lot of people with disabilities are going to college now, and even in high school and grade school all students are using computers and iPads, like for assignments, so they have to be accessible. Students in elementary and high schools are using the technology and will go on to use it as adults. This includes students with disabilities. Things will be made accessible because more people with disabilities need to and will use them.

Q: Do you remember when the ADA passed what your reaction was?
A: Well, it was a good thing because for so long there were no standards that people could work with. But once it passed and President Bush signed it, that was a good thing. Now the Convention on the Rights of People with Disabilities has been passed by the Senate Foreign Relations Committee, but it hasn’t come to the floor yet. President Obama has said he’d sign it. This will shine a light on the rights of people with disabilities around the world and this would be a good thing. It would help a lot of people.

Q: Anything else you want to say?
A: I think the ADA has done what it was intended to do.

Cliff Poetz can be reached at 612/625-0171.
As a father of six beautiful children—all of which need some level of support, some more than others—I know that getting involved in their lives and empowering them to be independent-thinking individuals is the best thing I can do for them. Ensuring that there are laws and systems in place to support and empower them, and everyone else’s children with disabilities, throughout their lives is a shared responsibility of us all.

Throughout history, it is people who have changed the world, for better or worse. It has never been enough to get a law created and passed; we must then ensure that it is enforced effectively, as enforcement take place. Otherwise, the law and the efforts expended to get the law in place are meaningless.

The important of advocacy can be summed up with two quotes that we have used for many years. The first is “Injustice anywhere, is a threat to justice everywhere” (Dr. Martin Luther King Jr.). And one we use most often now, the assertion of self-advocates and their families that there should be “Nothing About Us Without Us.” The meaning of the latter is clear—do not make plans and do not create policies and programs without our input. No one knows our needs and desires better than we ourselves.

Advocacy efforts to ensure enforcement of the ADA have led to the inclusion of people with disabilities in all aspects of implementing and enforcing the law from the federal to the local levels. When the state and national offices of The Arc, national and local Independent Living programs, and others successfully advocate with federal programs—such as the Centers for Medicare and Medicaid Services or the U.S. Department of Health and Human Services—for inclusion of people with disabilities in development of policy and procedure, there is a trickle-down effect to the local level. A good example from Mississippi is the involvement of individuals with various disabilities in development of the Money Follows the Person plan, which became known as the Bridge to Independence demonstration project. This project is designed to ensure that individuals with disabilities have an option to live in the most integrated setting. This requirement, that states provide services in the most integrated setting, is mandated in the Americans with Disabilities Act and the subsequent Olmstead decision. Individuals with intellectual and other related developmental disabilities have benefitted tremendously from this requirement.

While there is not an exhaustive list of services, it certainly includes housing, employment, personal care assistance, transportation, and more. Without the advocacy efforts of The Arc of Mississippi, Living Independence for Everyone (LIFE) of Mississippi, the state’s non-profit Center for Independent Living, Disability Rights of Mississippi, the Parent Training and Information Center and others, the disability community would not have been represented in the Money Follows the Person project. Not only would the program have not successfully served individuals well, people with intellectual and developmental disabilities would have been, at a minimum, disenfranchised and, at a maximum, discriminated against and left in institutional settings without other choices for services had advocacy not occurred.

Another example of the importance of advocacy is the enforcement of ADA comes from the experience of Mississippi with Hurricane Katrina. In the days following the hurricane, as advocacy agencies searched for people with disabilities to determine their safety and well-being, we saw “accessible” FEMA trailers being delivered by the hundreds. The trouble was, the only accessible thing about the trailers was the ramps that were set up at the front doors. Wheelchair users were able to roll up the ramp, but the doorways themselves were not accessible. Many wheelchair users had to camp in tents next to their FEMA trailers. As a result of the advocacy efforts of the disability community in response to this appalling situation, FEMA trailers of the future are promised to be based upon universal design, benefiting all.

Equal access, as required under the Americans with Disabilities Act, has benefitted every person with a disability of any age and any type of disability. There is a freedom of movement in the community that people with disabilities had not previously enjoyed, and it encourages involvement of individuals...
with disabilities in all aspects of society – work, church, volunteerism, neighborhood development, and much more. Everyone benefits from that!

As advocates, we encourage all people with disabilities and their families to get involved in their futures and to represent themselves at the “seats of power” in our country. Some of the ways that advocacy organizations can do this is to encourage individuals with disabilities and their families to do the following five things:

- Get to know your rights and the systems designed to support you.
- Develop a personal relationship with your state legislators, who can be your voice in the law-making process.
- Develop relationships with state officials who are responsible for implementing the services designed to support those in need of services.
- Volunteer to sit on boards and councils to better effect the changes needed and to get a disability point of view.
- Remember YOU are a “disability ambassador” and what you say really does matter. Organize your thoughts, and speak from the heart. And know a positive interaction will resonate and create better access for others coming behind you!!

We all had to start somewhere. Most of us started advocating for ourselves and our children or other family members. Please know that another responsibility lies far beyond our own immediate circle, and that true empowerment and support are about helping those in need – whether they share our genes or not.

Matt Nalker is Executive Director of the Arc of Mississippi, Jackson. He may be reached at matt@arcms.org.

More Resources Related to the Americans with Disabilities Act and to the Olmstead Decision

The following resources from around the U.S. address a range of ADA and Olmstead topics:

- **ADA.gov** (http://www.ada.gov). This Web site operated by the U.S. Department of Justice, Civil Rights Division, provides extensive information on laws/regulations, design standards, enforcement, rights, court cases, and other topics related to the ADA. It also includes directions and forms for filing discrimination complaints under the ADA with the Justice Department.

- **Job Accommodation Network** (http://askjan.org). JAN offers online resources, as well as confidential technical assistance, for individuals with disabilities, employers, unions, rehabilitation professionals, and others on topics including rights and responsibilities under the ADA, job accommodations, and accessibility. Resources include the Employees’ Practical Guide to Negotiating and Requesting Reasonable Accommodations Under the Americans with Disabilities Act (https://askjan.org/EeGuide/), Employers’ Practical Guide to Reasonable Accommodation Under the Americans with Disabilities Act (https://askjan.org/ErGuide/Two.htm), and the guide for employers, Accommodation and Compliance Series: Employees with Intellectual or Cognitive Disabilities (http://askjan.org/media/ntcog.html).

- **Recorded Interview with Olmstead Plaintiffs Elaine Wilson and Lois Curtis** (https://www.youtube.com/watch?v=P4KC3GHGjXA). In this audio recording with photos, Elaine and Lois talk about their lives in the community after Olmstead, and about the experience of going to court. Created and curated by the Center for Persons with Disabilities, Utah State University, as part of its Olmstead Modules series.

- **Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community** (http://www.ncd.gov/publications/2015/02242015). This new report from the National Council on Disability reviews the research on outcomes for people with disabilities since the Supreme Court’s integration mandate in the Olmstead court case. The report can help guide State policymakers, service providers, people with disabilities, and their advocates in a collaborative effort to align support systems with Olmstead and with the requirements of Home and Community Based Services regulations.

- **Olmstead Rights** (http://www.olmsteadrights.org). This Web site, created by the Atlanta Legal Aid Society, Inc. in partnership with the National Disability Rights Network, is a place for everyone to learn about the Olmstead decision. It shares how the Olmstead decision has positively impacted people’s lives in their own words through stories, photos, and videos, and uses its “I am Olmstead!” campaign to spread the word about the greater opportunities for building lives of choice, meaning, and independence in the community. It also provides resources and information for self-advocates, family and friends of people with disabilities, and legal advocates.

- **ADA National Network** (https://adata.org). Through its 10 regional centers, the ADA National Network provides information, guidance, and training on the Americans with Disabilities Act (ADA). Its services are tailored to meet the needs of business, government, and individuals at local, regional, and national levels.
The ADA, Section 504 and Postsecondary Education:
Information for Students and Their Families

by Deborah Leuchovius

Many parents of students with disabilities have learned the basics of the Individuals with Disabilities Education Act (IDEA). However, as students and their families prepare for the transition from secondary school to postsecondary options they often find they are less familiar with the protections provided by the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.

It is crucial that students and their advocates become knowledgeable about their rights and responsibilities in postsecondary education because, although protections exist, the student has considerably more responsibility to request and design their own accommodations.

It is crucial that students and their advocates become knowledgeable about their rights and responsibilities in postsecondary education.

And this responsibility is ongoing. For many students with disabilities, good self-advocacy skills will be key to success, and knowing your rights is one essential element of effective self-advocacy.

The following questions reflect those most commonly asked of PACER staff regarding the ADA and postsecondary institutions.

Q. How does the ADA affect postsecondary schools?
A. Title II of the ADA covers state-funded schools such as universities, community colleges, and vocational schools. Title III of the ADA covers private colleges and vocational schools. If a school receives federal dollars—regardless of whether it is private or public—it is also covered by the regulations of Section 504 of the Rehabilitation Act requiring schools to make their programs accessible to qualified students with disabilities.

Q. What are the differences between the ADA and Section 504?
A. For most postsecondary schools, there are not many practical differences. Although Section 504 only applies to schools that receive federal financial assistance, the reality is that most postsecondary schools do receive federal dollars. In addition, the ADA Title II requirements affecting state-funded schools were modeled on Section 504. Only private postsecondary institutions that do not receive government funds are not covered by the broader 504 or ADA Title II requirements. Under Title III of the ADA these schools have a lower standard of burden—in other words, assuming their resources are less, they wouldn’t have to do as much as government-funded schools. But they are still required to accommodate students with disabilities in similar ways.

Q. How does the ADA and Section 504 affect admissions requirements?
A. The postsecondary program cannot have eligibility requirements that screen out people with physical or mental disabilities. Application forms cannot ask applicants if they have a history of mental illness or any other disability. Institutions may impose criteria that relate to safety risks, but these criteria must be based on actual risk and not on stereotypes or assumptions. It is also illegal for an institution to serve students with disabilities differently because it believes its insurance costs will be increased. (It is illegal for insurance companies to refuse to insure, continue to insure, or limit the amount of insurance solely because individuals with disabilities are to be included in a program—unless the practice is based on sound actuarial principles or actual experience.)

Q. What do postsecondary programs generally have to do for students with disabilities?
A. A school may not discriminate on the basis of disability. It must insure that the programs it offers, including extracurricular activities, are accessible to students with disabilities. Postsecondary schools can do this in a number of ways: by providing architectural access, providing aids and services necessary for effective communication, and by modifying policies, practices, and procedures.

Q. What are the architectural accessibility requirements that affect postsecondary educational programs?
A. Buildings constructed or altered after June 3, 1977, must comply with the relevant accessibility code required by Section 504 and, after Jan. 26, 1992, the ADA. Buildings constructed before the 1977 date need not be made accessible if the college or school can ensure that its students with disabilities enjoy the full range of its programs through other means—such as relocating classes to an accessible building. All programs and services, however, must be provided in an integrated setting. In some instances, architectural access may be the only way to make a program accessible.

Q. Does the college that accepted me into its program have to provide me with an accessible dorm room?
A. Yes, if that is what they provide to students without disabilities. A school that provides housing to its students must provide comparable accessible housing to students with disabilities at the same cost as to others. This housing should be available in sufficient quantity and variety so that the housing options available to students with disabilities are equivalent to those without disabilities.

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Q. What kinds of aids and services must postsecondary institutions provide to insure effective communication?
A. Qualified interpreters, assistive listening systems, captioning, TTYs, qualified readers, audio recordings, taped texts, Braille materials, large-print materials, materials on computer disk, and adapted computer terminals are examples of auxiliary aids and services that provide effective communication. Such services must be provided unless doing so would result in a fundamental alteration of the program or would result in undue financial or administrative burdens. Public entities must give primary consideration to the individual with a disability’s preferred form of communication unless it can be demonstrated that another equally effective means of communication exists.

Q. How would postsecondary programs modify their policies, practices or procedures to make programs accessible?
A. The most challenging aspect of modifying classroom policies or practices for students with disabilities is that it requires thought and some prior preparation. The difficulty lies in the need to anticipate needs and be prepared in advance. The actual modifications themselves are rarely substantive or expensive. Some examples are rescheduling classes to an accessible location; early enrollment options for students with disabilities to allow time to arrange accommodations; substitution of specific courses required for completion of degree requirements; allowing service animals in the classroom; providing students with disabilities with a syllabus prior to the beginning of class; clearly communicating course requirements, assignments, due dates, grading criteria both orally and in written form; providing written outlines or summaries of class lectures, or integrating this information into comments at the beginning and end of class; and allowing students to use notetakers or tape record lectures. Modifications will always vary based on the individual student’s needs. Modifications of policies and practices are not required when it would fundamentally alter the nature of the service, program, or activity.

Q. I am planning to attend a college that provides transportation to classes on the campuses of other colleges in a local consortium. Do they have to provide me with wheelchair accessible transportation?
A. Yes. Under the ADA, the college is obligated to provide equivalent transportation for its students with disabilities.

Q. Can a school charge me for the cost of providing an accommodation?
A. No.

Q. Do I have to provide documentation of my disability to request accommodations?
A. Schools may request current documentation of a disability. If a person obviously uses a wheelchair or is Deaf, no further documentation may be necessary. For those with hidden disabilities, however, such as learning disabilities, psychiatric disabilities or a chronic health impairment, it is reasonable and appropriate for a school to request documentation to establish the validity of the request for accommodations, and to help identify what accommodations are required.

Q. What kind of documentation might be necessary?
A. Documentation should be completed and signed by a professional familiar with the applicant and the applicant’s disability – such as a physician, psychologist or rehabilitation counselor. It should verify the disability and suggest appropriate accommodations. If previous documentation exists, it will likely be sufficient unless it is not current (usually no more than three years old). If no current documentation is available, it is the responsibility of the student to have new documentation prepared. This can mean paying to have an appropriate professional conduct a new evaluation. It would be prudent to get an evaluation the year before you leave high school. This information is confidential and not a part of the student’s permanent record.

Q. Are students with disabilities required to disclose their disability?
A. If you do not require any accommodations, you can choose to keep this information private. If you do need accommodations because of your disability, however, you must disclose in order to receive them. A school cannot provide any service, modification or accommodation when it does not know one is required. It is a student’s responsibility to make their needs known in advance. This process is often facilitated by an Office for Students with Disabilities. It is then the school’s responsibility to work with the student to make reasonable modifications or provide appropriate services in a timely way.

Q. Are schools required to make testing accommodations for students with disabilities?
A. Yes. Schools must establish a process for making their tests accessible to people with disabilities. Schools can do this by providing appropriate accommodations to students with disabilities. Remember, each student’s needs are individual, but examples of accommodations include allowing a student extended time to complete a test or providing a distraction-free space, sign language interpreters, readers or alternative test formats. [Note: Testing accommodations are also required of agencies which administer college entrance exams, and agencies or businesses that administer licensure and certification.]

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Passed 25 years ago, the Americans with Disabilities Act (ADA) of 1990, a civil rights law, has provided guidelines for municipalities to pass codes that prohibit places of public accommodation to discriminate on the basis of disability. Consequently, the ADA has been instrumental in promoting barrier-free access for people with physical disabilities and, to a certain extent, people with vision and hearing loss, in private and public sectors in the United States. For example, it is not uncommon to see buildings with ramps, enlarged restroom stalls, and lowered switches and buttons that operate doors and lights, all with the intended purpose of accommodating someone with a physical disability.

While the ADA has provided greater assurance that people with physical disabilities have better access to and within buildings, this law has not as fully addressed many of the barriers that affect accessibility for people with intellectual and developmental disabilities (IDD). Upon closer examination, it becomes apparent that the ADA falls short in supporting people with IDD in a number of ways. This article identifies some of those remaining barriers to inclusion for people with IDD, and offers some ideas on how to address them today in ways consistent with the vision of the ADA.

Access to Affordable Technology

As society increasingly relies on computing and communication technologies to acquire, utilize, and disseminate knowledge, many people with IDD are being left behind because they do not have the financial means to afford these devices, services, and programs, and because some are not accessible. According to a Pew Research report, 91% of adults in the United States own a cell phone (Pew Research Center, 2013), yet many people with IDD cannot afford to own and pay for the service, especially one that accesses the Internet, due to a poverty rate of over 29% for those 18-64 years compared with 13% of the same age group in the general population (Institute on Disability, 2013). In a world where communication is increasingly done through personal devices such as a cell phone, people with IDD have been left far behind (Pew Research Center, 2012).

An excellent resource on this topic that identifies specific barriers and calls for widespread action to address them (including financial barriers) is, *The Rights of People with Cognitive Disabilities to Technology and Information Access* from the Coleman Institute for Cognitive Disabilities (http://www.colemaninstitute.org/declaration). The Coleman Institute also has an online database of research-based resources on the topic of access to information technology for people with cognitive disabilities; it’s titled the Cognitive Technology Database (http://www.colemaninstitute.org/research-and-development/cognitive-technology-literature-database).

**Wayfinding in the Built Environment**

People with IDD need to access services inside and outside buildings, just like anyone else. However, a substantial barrier often faced by people with IDD is information that helps them locate a specific destination within that setting. This act of getting from one point to another desired location is known as wayfinding. Elements such as signage, directories, landmarks, maps, and human sources of information are just some of the considerations in wayfinding. Too often signage is the only element available. If signage is text-only, this becomes a barrier to navigating within that setting for people who do not read. As an alternative, landmarks can serve as orienting and path-marking devices and are accessible to virtually everyone, including people with IDD (Salmi, 2008). Pairing signage with a landmark can help with recall and direction-giving. For example, a directional sign containing building information paired with a water fountain, clock, or interactive landmark such as an ATM can help in orienting and remembering the building. With careful thought and planning, the wayfinding information in the built environment can be made much more accessible to people with IDD by using a number of strategies. For more information on strategies to improve wayfinding so it works for people with IDD, see *Wayfinding Design: Hidden Barriers to Universal Access* (http://www.informedesign.org/_news/ aug_v05r-p.pdf).

**Access to Transportation**

Many people with IDD do not own or drive a car and must rely on public transit or other funded transportation, if available where they reside. Individuals who do not live near public transit, or have access to other funded transportation services (such as paratransit), must rely on other individuals or personal contacts for transport. This makes it much more complicated to pursue the activities of daily living and quality of life. Transportation (or the lack thereof) can often be an insurmountable barrier to inclusion. It is imperative that states and municipalities ensure that all transportation providers are trained in ADA requirements, and use the technical assistance available to implement the ADA in ways that make all aspects of transportation accessible to people with IDD. One resource that offers training, technical assistance, and publications on the implementation of the ADA in transportation is Easter Seals Project ACTION. Their Web site (http://www.projectaction.org) has extensive resources, including creative solutions to meeting transportation needs.

**Communication**

There are two types of communication that frequently present barriers to inclusion for people with IDD: The systems necessary to aid in communication, and
the act of communication between individuals. As an example of the first, phone systems, such as those typically used by clinics, present a barrier to people with IDD because they often require the listener to select a number on their phone in order to get to the appointment desk, and sometimes it can be multiple numbers. Many people with IDD require assistance with this process, a process that could readily be simplified with thoughtful design such as simplifying the call-in system and not requiring individuals to have to listen closely to which number to push. In “Telecommunications Access for People with Disabilities” the Federal Communications Commission (FCC) provides useful guidance for businesses and people with disabilities regarding ensuring accessible telecommunication systems, including interactive voice response systems that have menus of choices (see http://www.fcc.gov/guides/telecommunications-access-people-disabilities).

Communication between individuals is all too often hindered because individuals don’t have a way to communicate with one another in a straightforward manner. Using the healthcare setting example again, communication between the medical provider and an individual with a disability can be difficult due to the individual’s disability and the complexity of the topic. This barrier can exclude the individual from providing and receiving important medical information. There are tools such as a health advocacy document, sometimes called a health passport, that are designed to support individuals with IDD in sharing critical medical information with health care providers, some of whom might not be familiar with the individual or with IDD. A good example is Passport for Hospital/Clinic Visits from the Florida Center for Inclusive Communities (http://fflic.fmic.fh.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf). In addition, sometimes communication is difficult because the individual without disabilities is unsure of the basic etiquette in communicating with a person with disabilities. A good resource on this is Basic Disability Etiquette Tips from PACER Center (http://www.pacer.org/parent/php/php-c127.pdf).

Conclusion

Expanding thinking about accessibility and its true meaning for all Americans is imperative. The suggestions in this article are provided so that people can act today, but the best solution may be to introduce further amendments to the ADA that address the needs of people with IDD. Understanding the barriers to accessibility and inclusion that are present and recognizing areas for growth in understanding is crucial. Each and every one of us deserves the right to live life to its fullest and to enjoy the benefits of the richness of life. In its current state, ADA provides accessibility rights to a select few. It is time for the ADA to look to the future and be inclusive of all in its mandate.

What Accessibility Means in its Fullness

by Loui Lord Nelson

The ADA helps us look at accessibility in relation to physical structures and systems. But “accessibility” in its fullness goes beyond the physical design of spaces and things to include the richness of interpersonal relationships, the culture of everyday, and personal validation:

• **Interpersonal relationships:** While there are many programs and initiatives in place designed to connect individuals with disabilities to their communities, many fall short of developing interpersonal relationships. For example, participating in volunteer activities is a step toward building relationships, but until the individual’s contributions are recognized and deemed important by both the individual and others in the relationship, then a true interpersonal relationship has not been reached.

• **The culture of everyday:** This refers to those cultures that exist based on our everyday interactions: going to work, going to school, participating in worship, or enjoying leisure activities. Accessible cultures maintain a belief set where individuals accept, support, and rely upon one another in a reciprocal relationship, regardless of disability. For example, the culture of the workplace can provide this kind of accessibility. When a person with a disability is hired, fellow employees make sure there’s acceptance of the person’s individuality and needs, that there are appropriate physical and relationship-building supports, and that employees rely on one another to reach the organization’s goals.

• **Personal validation:** When a culture expects the individual will be a valued and contributing member, then the individual has the opportunity to achieve personal validation. Take, for example, a bird watching club that welcomes a new member who has a disability. All club members, including the individual, are expected to share their logs at the end of each walk and each is congratulated for their sightings. All members achieve personal validation because they are valued and contributing members.

Though beyond the scope of the ADA, these are crucial components of community inclusion and help us push for a broader understanding of accessibility.

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Where Do We Go Next? The ADA Moving Forward

by Amy Hewitt

In the introductory language of the Americans with Disabilities Act (ADA) there is a section titled “Findings and purpose” (Sec 12101). This is what Congress found to be true at the time the ADA was passed, and the conditions that the ADA was intended to address. Thinking about how things are today, we must ask ourselves whether these still ring true:

(a) Findings. The Congress finds that
(1) some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older;
(2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
(3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;
(4) unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;
(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;
(6) census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;
(7) individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society;
(8) the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and
(9) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.

While progress has been made, the intended purposes of the ADA have certainly not been fully realized. People with intellectual and developmental disabilities (IDD) still experience discrimination and stigma, and have limited choices about many important areas of their lives.

There is Much Left to Do

In recent decades, there has been significant progress in people moving out of institutions and into the community. In the mid-1960s, well over 220,000 people with IDD lived in large State-run institutions. In 1990, 84,239 lived in institutions. And in 2012, approximately 27,000 people with IDD still lived in institutions. Since 1962, 220 institutions have closed and State developmental disability agencies report that 14 plan closures in the next few years (Larson et al., 2014). While as a nation we have reduced the numbers of people with IDD who live in large State-run institutions, we have a long way to go at riddling institutional biases and attitudes from residential and community living supports. We need to redefine “institution” as a place where people are controlled, a place where people experience negative attitudes and lack of respect, and a place where people have few, if any, real choices about the most important and the simplest things in their lives. Far too often what we consider community living for people with IDD is not real community living and participation. Small group homes and supported living programs can be institutions if the attitudes of the staff, program rules, and policies and regulations promote institutional behavior, structures, and biases.

Though most people with IDD live in the community, they are not necessarily given opportunities to participate in their communities as full citizens. We need to redefine community living so that it is about more than the address...
at which one resides, the size of the place in which one lives or the number of roommates one has. It is also more than a place that provides physical and emotional well-being, and safety. Community living needs to be about the quality of the person’s life and the choices they are able to make about their life. Community living is about being able to live in a community of your choice, with people you want to live with and do not earn livable wages. In 2012, roughly 600,000 people with IDD received day or employment services funded through a State DD agency. However, of these, a little over 100,000 actually had jobs in integrated employment (Butterworth, Smith, Hall, Migliore, Winsor & Domin, 2014). Those that did have jobs made very little money; weekly wages for people with IDD averaged a little over $100 in both competitive and individual supported employment (HSRI, 2014). People with IDD want and need real jobs for which they get paid real wages. Expectations need to be placed on schools to prepare people with IDD for work, and our systems need to support them in preparing for, finding, and keeping jobs, as well as developing careers. Embracing and realizing the promise of Employment First policies is a good place to start. As a nation, we need to expect and support all people with IDD in working.

Access to information is also a significant challenge for people with IDD. While efforts have been made to make the Internet, movies, television, and other forms of media and communication accessible to people with disabilities, little attention has been paid to cognitive accessibility for people with IDD. In today’s society, it is critical to have accessible technology to access, use, and disseminate information. The information gap is significant and the vast majority of people with cognitive disabilities have limited or no access to information they can understand and communication technologies they can use (Coleman Institute, 2014). Information is power. We need to ensure that people with IDD have access to technology devices that use universal design principles and can be used by all citizens irrespective of the nature of their disability. Commercial vendors need to be forced to attend to access issues that make devices and software usable by people with IDD.

Conclusion

While there is much to celebrate in the 25th anniversary year of the ADA, there is still far too much left undone. As a nation, we must move forward with vigilance to fully realize the promise of the ADA for persons with intellectual and developmental disabilities. Ensuring opportunities for true community living, integrated employment, and access to information technology are perhaps the most significant next steps we can take to realize the promise of the ADA in the United States.

While the government has a responsibility to enforce mandates and guidelines, people with IDD, allies, providers, and policymakers have responsibilities, too. Everyone must demand change. The status quo cannot be tolerated. It will take a unified voice to change communities, and the opinions of citizens within our communities.

Ensuring opportunities for true community living, integrated employment, and access to information technology are perhaps the most significant next steps we can take.
with my disability — it may be hard for me, but I can still go from point A to point B. If I want to take an airplane trip I should be able to take my wheelchair with me.

**Q: Do you think the ADA has succeeded in removing some barriers people with disabilities faced in the past?**

**A:** Yes. The Twin Cities has broken some barriers in transportation. Like when the light rail was being built on University Avenue in St. Paul there was a lot of ADA going on. For example, there is a family where both parents have disabilities and they have a child, so we had to think creatively about how this family could take theirPCA with them, and their child, and sit together on the light rail and city buses, and use tie downs for the wheelchairs.

We’ve fought really hard for parks that are in line with the ADA. We’re struggling because we’re running into the ADA not always working because they don’t want to change nature, or they don’t want to change how the building looks or how it works. So we’re being real creative in thinking about how to use the ADA to meet the needs of people with different disabilities so everyone has a chance to be part of the community.

**Q: What kinds of barriers do you still encounter even with the ADA?**

**A:** The way our laws are written and the way human services operates creates barriers, and I know we can go beyond that. Not only funding barriers, but getting the right kind of help to make sure we can get the appropriate equipment and the appropriate people to help people with disabilities. We’re always running into that. Human services sometimes are tied down by what the legislators have done. Or people may be stuck in the old days, meaning they don’t want to grow and move forward. The ADA has helped to open the doors to get appropriate services, but there’s always going to be tweaking of it by the disability community. Like the 5% campaign in Minnesota that we fought for Direct Support Professionals (DSPs) to have better pay, so they can have a raise for the work they do to help us. That was last year at the legislature and we’re now fighting to make it better and stronger. We have to have good DSPs for the ADA to work; there are people who need DSPs to help them get out of bed, and get into their wheelchairs, and get to their jobs. We want to give them good pay because we have DSPs who are passionate about this work, but can’t support themselves or their families on what they’re being paid.

**Q: Do you think the ADA will continue to be important in the future?**

**A:** It’s always going to be important, and we’re always going to be tweaking it. We don’t all need the same things. We have to build it to meet the needs of the people with the lowest end needs — who need the least help — all the way up to those at the highest end with the most needs. For me, I need a good pair of glasses or I couldn’t be here today doing this interview because I wouldn’t have been able to get on the bus. And I need my hearing aids so I can be in my environment and be safe. And I need my brace so I can walk better and get places. But everybody with a disability is slightly different; we don’t all have the same disabilities and needs. Just because you see a person in a wheelchair doesn’t mean all people in wheelchairs have the same disability. It’s a stereotype, and we’re very good at stereotyping. I think the ADA breaks that down and helps us figure out what works and doesn’t work for the person who has very little need to the person with very great needs. And we need people with disabilities out there fighting and making a difference for people in wheelchairs, and people with forearm crutches, and people with hearing impairments, and people who are blind, and people with learning disabilities, and people like me who have multiple disabilities. So the ADA has to be about how does it work for all different kinds of people.

**Q: Is there anything else you’d like to say about the ADA on its anniversary?**

**A:** I’m glad it’s out there because we’re saying you can’t just be left on the street corner. What I mean by that is you don’t really care if we don’t exist. And we do exist. And we’re going to be here. And we’re not a disease, we’re not a defect. The ADA makes it so that I can actually have a life. We aren’t bad people. We don’t need to be shunned away and kept in a house, or a box, or a building. We have a right to be out in the community and be part of the world.

It’s okay once in awhile to bitch and get angry because that’s how the world grows. If we didn’t change we wouldn’t be where we are today. We’d be a dead society. Change is great. I think that’s what makes us human and that’s what makes us grow. The ADA is all about change. History is all about change. It changed when the Civil Rights movement integrated schools, it changed when we integrated students with disabilities in schools, it has changed as people have come here from other countries and
from other cultures, it changed with the current wars. Now we have people who fought to save our country coming back from war with disabilities and we have to think about them. I think in the future we’ll go back to Washington and we are going to re-tweak the ADA to fit what’s going on right now with housing, technology, transportation, health care, science, all the different people from around the world who come to the United States, the veterans from the war, and people who are aging.

So we have to move our ideas, thoughts, and fighting techniques toward making a better community for all. The ADA has to work for all different kinds of people.

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[Dinerstein, continued from page 7]

Conclusion

We would do well to remember that some of the major issues facing people with IDD – such as problems with overuse of guardianships and other forms of intervention that fail to recognize their capacity – may be more a function of state than federal law (though there are some creative arguments for applying the ADA to guardianship, for example) (Salzman, 2010). Even if the ADA were perfectly enforced, people with IDD would still experience stigma and would still face challenges in integrating fully into society. People with IDD are better off because of the passage of the ADA. But it is up to them and their advocates to continue to fight for judicial interpretations and executive action that will give full meaning to the lofty promises that Congress made 25 years ago.

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[Jamieson, continued from page 19]

an affirmative responsibility to provide community alternatives.

My favorite part of the decision is the Court’s powerful analysis of why isolation is discriminatory:

• Unjustified isolation is properly regarded as discrimination based on disability.

• Institutional placement of a person who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.

• Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.


Thus, under Olmstead, unnecessary institutional segregation is discrimination and lack of community supports is no excuse.

Before concluding, I want to remind everyone that things have improved since Olmstead, partly in response to the case, but mostly in response to the determination of advocates in the years since the decision. Now we can look at crumbling massive State institutions and say, what were we thinking? But we can still look around any state in the country and see segregation in community programs, nursing homes, schools, detention centers, and the list goes on. There is, in other words, much work to be done.

Conclusion

In closing, I want to explain that our Supreme Court adventure was never imagined. We were thrilled but also terrified when the Court granted Cert at the State’s request. Happily, that is when the entire national community of civil rights advocates rallied round our legal aid program. This ad hoc coalition of amici and grassroots organizations in every state working together convinced the Supreme Court that Lois and Elaine should not be institutionalized, that they deserved the opportunity to live in neighborhoods and communities like anyone else. If the public system needs improving or expanding then the State needs to get busy because a lack of alternatives does not excuse discrimination.

Ultimately, back at legal aid, we learned that freedom from segregation is not measured by one case. Instead, the case is part of a complex, heroic fabric woven by the efforts of those who went before and those who continue the struggle now.

Reference


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Americans with Disabilities Act of 1990 (ADA), 42 USC §12101 (a)(5).

Americans with Disabilities Act of 1990 (ADA), 42 USC §12101 (b).


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