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Litigating the Right of People with Disabilities to Live in the Community

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Integrating People with Disabilities in the Community Through Innovative Collaboration

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Over the past two years, federal courts have given final approval to consent decrees in three class actions brought to deal with the long-standing segregation of people with disabilities in Illinois. Once implemented, the consent decrees will give thousands of people with disabilities the opportunity to live in the community—a civil right denied to them for far too long. Here I discuss how a model of collaboration among several public interest organizations and law firms working on a pro bono basis achieved these landmark agreements.

Institutionalization of People with Disabilities in Illinois

Since the 1960s, experts, and the disability community itself, have recognized the benefits of community living for people with disabilities. The benefits can be more participation in community activities, greater self-direction, higher employment rates, and an overall improved sense of well-being. Over the past fifty years, most states have reduced their institutional census and increased opportunities for community living for people with disabilities.

Illinois, however, lags behind almost every other state in its efforts to increase community integration and instead relies on large, congregate care settings to house people with disabilities. For example, Illinois ranks fiftieth out of the fifty states and the District of Columbia in the percentage of adults who have developmental disabilities and are living outside the family home and being served in settings of one-to-six persons.[1] Mississippi is the only state that serves a smaller percentage of people in small community settings. In Illinois only 38 percent of people with developmental disabilities are served in settings of one-to-six persons. By contrast, neighboring Great Lakes states serve a higher percentage of people in small community settings: Minnesota, 93 percent; Michigan, 89 percent; and Wisconsin, 77 percent.[2]

[1] David L. Braddock et al., The State of the States in Developmental Disabilities (2011).

[2] *Id.* at 16, tbl.5.

Opponents of downsizing and closing institutions in Illinois have largely succeeded in maintaining the status quo, and new resources for community services have been woefully inadequate. These opponents are, among others, state employee unions, nursing home owners, and some family members of people with disabilities. As a result, many people with disabilities in Illinois have not had the option of living in the most integrated settings, and advocates have been stymied in their efforts to change this reality on a widespread scale.

Americans with Disabilities Act. In 1990, when Congress passed the Americans with Disabilities Act (ADA), it found a serious and pervasive social problem: the isolation and segregation of people with disabilities.[3] Following the passage of the ADA, the U.S. Department of Justice issued regulations requiring that state and local governments administer their programs in the "most integrated setting appropriate to the needs of" people with disabilities.[4] The attorney general's Title II regulations define "the most integrated setting" to mean "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible."[5] The regulations also require public entities to make "reasonable modifications in policies, practices, or procedures … to avoid discrimination on the basis of disability."[6] Despite the new federal law and regulations, Illinois made no meaningful changes and continued its reliance on large institutions.

Olmstead v. L.C. In 1999 two women who had intellectual disabilities and mental illness and were residents of a state-operated hospital in Georgia filed suit alleging that the state violated the ADA's integration mandate by denying them community placements, notwithstanding that they had been deemed appropriate for the community. Their case ultimately ended up before the U.S. Supreme Court. In *Olmstead v. L.C.* the Court's holding that the unjustified institutionalization of people with disabilities is discrimination under the ADA is a historic decision.[7] Segregation perpetuates unjustified assumptions that institutionalized persons are incapable or unworthy of participating in community life, the Court explained. Institutional confinement severely diminishes individuals' everyday activities, such as family relations, social contacts, work, educational advancement, and cultural enrichment, the Court also found.[8]

The ADA requires states to serve people with disabilities in community settings, rather than in segregated institutions, when, the Supreme Court ruled, three factors are present: (1) treatment professionals determine that community placement is appropriate; (2) the person with a disability does not oppose community placement; and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported services.[9] The Court also held that a state could demonstrate compliance with the ADA if it had a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."[10]

Illinois After Olmstead. When the Supreme Court ruled in *Olmstead*, Illinois did not have a "comprehensive effective-

[3]Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213.

[4]28 C.F.R. § 35.130(d) (2011).

[5]28 C.F.R. pt. 35 app. A (2011).

[6]28 C.F.R. § 35.130(b)(7) (2011).

[7]*Olmstead v. L.C.*, 527 U.S. 581, 600 (1999).

[8]*Id.* at 600–601.

[9]*Id.* at 607.

[10]*Id.* at 605–6.

ly working plan" for evaluating and placing people with disabilities in the community; nor did it have a waiting list for community services. The disability community was hopeful that *Olmstead* would be a catalyst for Illinois to transform from a primarily institution-based model into a more community-based system. Equip for Equality, along with other advocacy groups, attempted to cooperate with the state to move Illinois toward compliance with the principles of the *Olmstead* case. For example, the advocacy groups participated in committees that initially looked promising but yielded no results.

In June 2004, on the fifth anniversary of the Supreme Court's decision in *Olmstead,* disability advocacy groups issued, at a press conference, two community integration reports: *"… shunted aside, hidden and ignored …": A Blueprint to Implement* Olmstead v. L.C. *and End the Unnecessary Institutionalization of People with Disabilities in Illinois*, prepared by Access Living of Metropolitan Chicago, and *A Nationwide Study of Deinstitutionalization and Community Integration*, prepared by Equip for Equality.[11] At the press conference and in a letter to Gov. Rod Blagojevich, the groups requested a meeting with the governor and called upon him to lead the implementation of *Olmstead* consistent with the two reports. Tellingly, Governor Blagojevich did not even respond to this request.

Developing a Model of Collaboration for Systemic Change in Illinois

After more than five years of attempting to work collaboratively with the state, we realized that litigation would be the only way to achieve meaningful change in Illinois. Accordingly, Equip for Equality began meeting with Access Living and the American Civil Liberties Union (ACLU) of Illinois, two Illinois public interest advocacy groups that also were very concerned about the state's failure to comply with the ADA and *Olmstead*. All three groups committed to participating in a coordinated litigation strategy against the state.

Even though the *Olmstead* decision was brought on behalf of people with disabilities in state-operated facilities, most institutionalized people in Illinois reside in privately owned state-funded facilities. Our team of advocacy groups therefore decided that the litigation would focus on people who had disabilities and were living in private institutions funded by the state. Because Illinois's disability-service system is quite fractured and administered by a variety of state agencies, we quickly realized that we could not challenge the unjustified institutionalization of people with disabilities through one lawsuit.

After significant discussions, Access Living, ACLU of Illinois, and Equip for Equality agreed to file three community-integration class actions against Illinois officials for failing to serve people with disabilities in the most integrated setting. One case, *Ligas v. Maram*, would be on behalf of people who had developmental disabilities and were living in large, privately owned, state-funded facilities known as "intermediate care facilities for the developmentally disabled." A second case, *Williams v. Blagojevich*, would be on behalf of people who had mental illness and were residing in large, privately owned, state-funded facilities known as "institutions for mental disease." *Colbert v. Blagojevich* was the third case, and it would be on behalf of people who had physical disabilities or mental illness or both and were residing in traditional nursing homes. The institutions in the three cases, though falling under different categories, have much in common. Generally at these institutions residents have little contact with nondisabled people, few opportunities to participate in community life, limited privacy, infrequent choice in roommates, and little or no choice in daily decisions such as when to wake up, what and when to eat, and when to go to bed.

We also agreed that each organization would serve as lead counsel in one of the three class actions, with the other organizations serving as cocounsel. Lead

[11]See Access Living, "… shunted aside, hidden and ignored": A Blueprint to Implement *Olmstead v. L.C.* and End the Unnecessary Institutionalization of People with Disabilities in Illinois (n.d.), http://bit.ly/HlXs2a; E.G. Enbar et al., Equip for Equality, A Nationwide Study of Deinstitutionalization and Community Integration (June 2004), http://bit.ly/FPRUT6.

counsel was responsible for recruiting a pro bono law firm, a crucial component to our litigation strategy. These cases would be extremely complex and involve thousands of documents. We could not litigate these cases without the resources, support, and expertise that a large law firm could contribute. Once recruited, each law firm agreed to donate any attorney fees it received to lead counsel in the case. Lead counsel for each case was also responsible for shepherding the team through all aspects of preparing the case and litigating the case, scheduling and chairing team strategy sessions, taking the lead in any settlement negotiations, coordinating public relations efforts, and overseeing all costs and expenses, including expert witness costs, a significant component of these cases.

Each member organization of our legal team logically fit as lead counsel in a particular case. Because Equip for Equality had experience in assisting people with developmental disabilities—especially in advocating to move them into more integrated settings—Equip for Equality assumed the role of lead counsel in *Ligas.* ACLU of Illinois had filed another class action on behalf of people who had mental illness and were residing in state-operated facilities, so it served as lead counsel in *Williams.* And because Access Living, the Center for Independent Living in Chicago, had historically focused on the advocacy needs of people with physical disabilities and had assisted in reintegrating into the community many people living in nursing homes, it was the natural choice for lead counsel in *Colbert*.

We also determined that we would benefit from having a national perspective as part of our legal team. The Public Interest Law Center of Philadelphia, which had extensively worked on systemic community-integration litigation for people with developmental disabilities, agreed to join us as cocounsel in *Ligas*.[12] The Bazelon Center for Mental Health Law had recently filed a class action in New York on behalf of people with mental illness in facilities similar to the institutions for mental disease in Illinois and was very interested in bringing similar litigation in Illinois.[13] Having Bazelon as part of the litigation team in *Williams* would turn out to be a tremendous asset. And, Steven Gold, one of the country's leading lawyers focusing on the community-integration rights of people with disabilities in nursing homes, was an ideal addition to our litigation team in *Colbert.*

Although our collaboration worked out extremely well, several public interest organizations collaborating on multiple class actions is highly unusual. In many instances, public interest organizations are so focused on their own specific issues that efforts to collaborate are not explored. In some cases, collaboration is inhibited because of "turf wars" among the organizations. Some public interest groups fear collaboration because of the inherently complex decision making when several different organizations serve as class counsel.

Despite these potential barriers, our experience should encourage other public interest organizations to explore similar systemic litigation collaboration opportunities. In the wake of the recent economic downturn, funding for public interest legal organizations has declined, and thus bringing systemic litigation on one's own has become more challenging for an organization. By collaborating, public interest organizations can pool limited resources to achieve common goals. Moreover, collaboration expands the expertise of the legal team by capturing the varied substantive and litigation experience of the attorneys within each organization.

Each public interest organization has, along with substantive and legal expertise, its own relationships with the private bar. For each of our cases, such relationships facilitated the successful recruitment of a pro bono law firm. Collaboration can also result in economies

[12]Following a change in staffing in 2009, the Public Interest Law Center of Philadelphia withdrew as cocounsel in *Ligas.*

[13]See Complaint, *Disability Advocates Incorporated v. Paterson*, 653 F. Supp. 2d 184 (E.D.N.Y. 2009) (No. 03-CV-3209), http://bit.ly/xgcqwQ.

of scale and consistency. Although the three consent decrees in our cases have some differences, the first consent decree served as a model for the other two. The lessons learned from one class action may inform another litigation. This frequently occurred in our three cases. After a contentious fairness hearing resulted in the decertification of the class in *Ligas*, we learned from that experience and worked to avoid a similar result in the subsequent fairness hearings in *Williams* and *Colbert*.

Ligas v. Hamos: Advocacy for People with Developmental Disabilities. With Equip for Equality serving as lead counsel, *Ligas v. Maram* (later *Ligas v. Hamos*) was filed in 2005 on behalf of nine people who had developmental disabilities and resided in large private state-funded facilities ("intermediate care facilities for the developmentally disabled") or who were likely to be placed in such facilities. Because so many people with developmental disabilities live at home awaiting services, the proposed class had to include not only people residing in these facilities but also those who were at risk of moving into an institution if they were not given community services.[14] Both types of plaintiffs had requested community services, but their requests had been denied by the state.

Finding that the class included people who had developmental disabilities and were currently institutionalized, as well as those who were at risk of being institutionalized, the judge granted our class certification motion.[15] The judge also denied several motions to intervene; those motions were filed by groups opposed to the lawsuit. One group of potential intervenors appealed to the Seventh Circuit, which upheld the denial of intervention.[16] The parties engaged in extensive discovery, and we hired five expert witnesses who together made an extremely compelling case that Illinois was violating the ADA.

Prior to trial, the parties entered into settlement negotiations and reached a proposed consent decree that would have resulted in more than five thousand people in institutions being given the choice of moving into the community and several thousand others who were at risk of institutionalization being given community services. However, after a fairness hearing in which more than two thousand family members raised objections to the proposed agreement, the judge found that the class definition was too broad because it included people who did not desire to live in the community. The judge was unpersuaded that no class member would be forced to move into the community under the proposed agreement. Accordingly the judge decertified the class on the grounds of lack of typicality and commonality, and the agreement was not approved.

To meet the judge's concerns but still seek systemic relief, we filed an amended complaint seeking relief only for people who had developmental disabilities and who affirmatively requested community services. Thereafter the parties reached a new proposed consent decree, but the former objectors still felt that the agreement would harm their clients and sought to intervene in the case. The judge granted their motion for limited intervention and strongly encouraged the parties to meet with the intervenors to negotiate a comprehensive solution.[17] After extensive negotiations, in January 2011, the plaintiffs, the state, and the intervenors reached a new agreement. Thereafter, on June 15, 2011, the judge held a second fairness hearing. Due to the agreement reached with the intervenors, those who objected at the first fairness hearing did not object to the new consent decree, and the judge granted final approval.[18] The parties agreed to the following terms:

[14]The *Olmstead* case involved plaintiffs in institutions, but *Olmstead* also includes people who are at risk of institutionalization, courts have held (see, e.g., *Bruggeman v. Blagojevich*, 324 F.3d 906 (7th Cir. 2003) (*Olmstead* covers adults who have developmental disabilities and live with their parents but await community services)).

[15]*Ligas v. Maram*, 2006 WL 644474 (N.D. Ill. March 7, 2006).

[16]*Ligas v. Maram*, 478 F.3d 771 (7th Cir. 2007).

[17]*Ligas v. Maram*, 2010 WL 1418583 (N.D. Ill. April 7, 2010).

[18]Consent Decree, *Ligas v. Hamos*, No. 05 C 4331 (N.D. Ill. June 15, 2011), http://bit.ly/zLKcXn.

- Those who reside in intermediate care facilities for the developmentally disabled and who desire community placement will receive an individualized, independent evaluation and the opportunity to live in the community with appropriate services.
- Over a six-year period, any of the approximately 5,400 who reside in intermediate care facilities for the developmentally disabled and who desire placement in the community will transition to the most integrated, appropriate community-based setting.
- All who reside in intermediate care facilities for the developmentally disabled and are happy with their current placement are not part of the class and will not be required to move. The consent decree ensures that resources necessary to meet the needs of those who choose to continue to reside in these facilities will be made available.
- Over a six-year period, 3,000 people who have developmental disabilities and are living at home without services will be given community services.[19]
- The judge will appoint an independent monitor with expertise in developmental disabilities to oversee implementation and compliance with the consent decree; the monitor will serve for a minimum of nine years.
- People who have developmental disabilities and want to join the class may make with the state a record confirming their desire for community services during the pendency of the consent decree.
- After six years, the state will establish a waiting list that moves at a reasonable pace.[20]

SNR Denton (formerly Sonnenschein Nath & Rosenthal), together with Equip for Equality, ACLU of Illinois, and Access Living, represented the class pro bono. SNR Denton served as lead litigation counsel and spent enormous resources to achieve this systemic change for people with developmental disabilities in Illinois. Over the course of the litigation, the firm contributed approximately 9,000 hours of attorney time. SNR Denton not only was extremely generous in donating its attorneys' time and expertise but also donated to Equip for Equality all of the attorney fees awarded to the firm under the consent decree.

Since final approval of the consent decree, the judge has appointed an independent monitor, the parties have negotiated and filed an implementation plan, and community services and placements have been identified for the named plaintiffs.[21]

Williams v. Quinn: Advocacy for People with Mental Illness. With ACLU of Illinois serving as lead counsel, *Williams v. Blagojevich* (later *Williams v. Quinn*) was filed in 2005 on behalf of two individuals who had mental illness and lived in a large, private, state-funded nursing home for people with mental illness against state officials for their failure to provide sufficient community services. Subsequently we added more named plaintiffs and filed a motion for class certification.[22] Once certified as a class, the case encompassed residents of all Illinois institutions of mental disease, approximately 5,000 people.

The *Williams* case is compelling not only from a civil rights standpoint but also from a fiscal perspective. Under federal regulations, Illinois is not entitled to any federal reimbursement for people residing in institutions of mental disease; if these residents were served in the com-

[19]The State agreed to serve, without any cap, in addition to the 3,000, all people who have developmental disabilities and are deemed to be in "crisis" (e.g., caregiver has become incapacitated).

[20]For documents related to the *Ligas* case, see Equip for Equality, Documents Relevant to *Ligas v. Maram*—Lawsuit Seeking Community Services for People with Developmental Disabilities in Illinois (n.d.), http://bit.ly/x6TrH7.

[21]Equip for Equality, *A Place to Call Home*, Roustabout Media (2011), http://bit.ly/y4j1et (video documenting case and sharing stories of named plaintiffs in *Ligas*).

[22]*Williams v. Blagojevich*, 2006 WL 3332844 (N.D. Ill. Nov. 13, 2006).

munity instead, the state would receive federal reimbursement for a significant portion of the community services. That Illinois maintained this fiscally undesirable model only underscores the political power of the institutional providers. We retained expert witnesses who confirmed both the restrictive nature of the institutions of mental disease and the fiscal advantages of serving people with mental illness in community settings.

After completing discovery, the parties entered into settlement negotiations and reached an agreement in March 2010.[23] The proposed consent decree, though similar to the original consent decree in *Ligas,* did not include the provisions that the *Ligas* objectors and judge found problematic. The original *Ligas* decree required all residents of intermediate care facilities for the developmentally disabled to participate in evaluation for community services. And the original *Ligas* decree had a mandatory "bed closure" provision as people moved out of the facilities. The *Williams* decree did not contain either of these provisions.

Despite the modifications of the *Williams* decree to reduce opposition, more than a thousand objections were filed. However, prior to the fairness hearing, our team learned that a significant source of these objections was inaccurate and misleading information given to residents of institutions for mental disease by the institutions' operators, staff, and legal counsel. Our team brought these improprieties to the attention of the judge, and he ruled that these communications were improper.[24]

To avoid the problems that occurred at the *Ligas* fairness hearing, we presented affirmative testimony at the *Williams* fairness hearing from our expert witnesses, clients, community providers, and other interested parties. This testimony ensured that the judge not only heard from those opposing the proposed consent decree but also heard compelling evidence supporting the community integration of residents of institutions for mental disease. Following the fairness hearing, the judge approved the consent decree on September 29, 2010.[25] The court appointed an independent monitor in October 2010 and approved an implementation plan in July 2011. These are some highlights of the consent decree:

- Interested residents of institutions for mental disease will be informed of community-based options; receive individualized, independent evaluations; and be given the opportunity to live in the community (including in permanent supportive housing) with appropriate services.
- Those who reside in institutions for mental disease and are happy with their current living situations will not be forced to move into the community and will have the right to refuse an evaluation.
- Over a five-year period, all who reside in institutions for mental disease and want placement in the community will transition to the most integrated community-based setting appropriate for their individual needs.

As in *Ligas*, pro bono assistance enhanced the *Williams* case. The class was represented pro bono by Kirkland & Ellis, together with ACLU of Illinois, Access Living, the Bazelon Center, and Equip for Equality. Kirkland contributed tremendous litigation support throughout the case and, under the agreement referred to earlier, donated all of the attorney fees awarded to the firm to lead counsel, in this case ACLU of Illinois.

Colbert v. Quinn: Advocacy for People Who Have Disabilities and Are Living in Nursing Homes. With Access Living serving as lead counsel, *Colbert v. Blago-*

[23]For documents related to the *Williams* case, see Equip for Equality, Documents Relevant to *Williams v. Quinn*—Class Action Lawsuit Seeking Community-Living Alternatives for Residents with Mental Illnesses in Illinois (n.d.), http://bit.ly/w6z3ax.

[24]*Williams v. Quinn*, 2010 WL 3021576 (N.D. Ill. July 27, 2010).

[25]*Williams v. Quinn*, 748 F. Supp. 2d 892 (N.D. Ill. 2010).

jevich (later *Colbert v. Quinn*) was filed in 2007 on behalf of five people who had disabilities and were living in private nursing homes against state officials for their failure to provide sufficient community services. Because of the enormous number of people who had disabilities and were living in nursing homes across Illinois, and because we had very compelling eviden http://bit.ly/HlXs2a; E.G. Enbar ce involving Cook County nursing home residents, we decided to limit the *Colbert* class to people who had disabilities and were living in nursing homes in Cook County. In 2008 the judge granted our motion for class certification.[26] Even with the limitation to Cook County, the class is estimated to encompass more than 20,000 people with physical disabilities or mental illness.

After engaging in discovery, the parties entered into settlement negotiations. Thereafter the parties reached an agreement and filed a proposed consent decree in August 2011.[27] In stark contrast to the *Ligas* and *Williams* cases, there were few objections filed in response to the consent decree in *Colbert*, and only two people testified at the fairness hearing. The judge approved the consent decree on December 20, 2011. These are some highlights of the consent decree:

- In the first thirty months the state will assist in housing so that more than a thousand class members living in nursing facilities can move into the community.
- The state will develop community-based services and housing for class members moving out of nursing facilities.
- All people who desire to remain in nursing facilities will not be forced to move.
- After the first thirty months, the state will implement a comprehensive plan to move the remaining class members who desire community placements under a cost-neutral plan based on data collected during the first phase of implementation.
- The court will appoint an independent monitor with expertise in the development and provision of community-based services to persons with mental illness and physical disabilities.

As in *Ligas* and *Williams*, pro bono assistance led to success in the *Colbert* case. In addition to ACLU of Illinois, Access Living, Equip for Equality, and Steven Gold, several pro bono law firms, including the current firm, SNR Denton, represented the class over the course of the litigation. Once again, fees awarded to the pro bono attorneys under the consent decree were donated to lead counsel, which in this case was Access Living.

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The institutionalization of people with disabilities in Illinois has been a long-standing problem. We achieved meaningful change in Illinois only when we developed a systemic litigation collaboration of public interest organizations and pro bono law firms. Other public interest organizations should consider whether a similar model may help in critical systems reform needed in their states.

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I thank my colleagues at Equip for Equality, as well as my cocounsel at Access Living, ACLU of Illinois, the Bazelon Center for Mental Health Law, Kirkland & Ellis, and SNR Denton, for their extraordinary efforts to deal with the systemic segregation of people with disabilities in Illinois.

[26]*Colbert v. Blagojevich*, 2008 WL 4442597 (N.D. Ill. Sept. 29, 2008).

[27]For documents related to the *Colbert* case, see Equip for Equality, Documents Relevant to *Colbert v. Quinn*—Illinois Residents Sue State for Failing to Provide Community Services (n.d.), http://bit.ly/w9fd5X.

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