

Carroll L. Lucht
Yale University

Stephen Wizner
Yale University

Of Scarce Resources and Gilded Cages: A case study

Abstract

This paper examines the debate over whether persons with developmental disabilities can or should be served in the community or within larger facilities/institutions. The cases of two institutionalized persons are discussed, along with vivid descriptions of their institutional surroundings. This part of the paper is followed by the outcome of a court case brought by their advocates with regard to patient rights. Key legal cases involving the constitutional rights of institutionalized mentally retarded persons are also discussed.

Résumé

Le présent document traite de la question controversée des personnes souffrant de troubles du développement sous l'angle de la possibilité ou du devoir de desservir cette population au sein même de la collectivité ou dans de vastes établissements. On y présente le cas de deux personnes internées et on y donne des descriptions frappantes de ce milieu. Cette section du document est suivie de l'issue d'une affaire portée dans les tribunaux par des avocats, relativement aux droits des patients. On y traite également d'autres causes importantes touchant les droits constitutionnels des personnes souffrant d'arriération mentale et qui sont internées.

The debate among professionals and advocates over whether persons with developmental disabilities can or should be served in the community instead of large congregate facilities is largely over. Experience over the last two decades has demonstrated that people with disabilities can lead meaningful and productive lives in integrated settings if provided with the opportunity to do so. The question now is not whether the community is appropriate but whether special programs and facilities can be successfully replaced with supports and generic services so that true integration can successfully occur.

Recent data demonstrate that both Canada and the United States have made progress in the last decade in depopulating institutions and increasing available residential placements in the community (Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D. 1990).¹ That progress notwithstanding, the United States remains a country where in most states the primary treatment model for persons with mental retardation remains institutionalization. A recently published study [by the Institute for the Study of Developmental Disabilities at the University of Illinois at Chicago] reveals that in the fiscal year 1988, 51.9% of the total national mental retardation/developmental disability expenditures in the United States went for congregate residential services. Further, of that money spent for congregate residential services, 84.6% was spent for care in state institutions. In thirty states, more money is being spent to maintain persons with developmental disabilities in congregate facilities than in community settings. As of 1988, there were still some 91,400 people in state-operated institutions in the United States (Braddock *et al.*, 1991).

The continued institutionalization of persons with developmental disabilities remains inexcusable. Advocates argue that community placement is right; it is impossible for people to develop meaningful and full lives isolated from that part of the community where normal life activities take place. But advocates are increasingly being faced with the harsh reality that the political, legal, and social climate dictates that institutions will not soon vanish. They must choose between holding out for unavailable remedies and settling for available improvements. The dilemma for advocates then becomes whether they can morally and ethically accept, at least for the time being, a solution which falls short of complete community integration.

The Cases of A.B. and L.M.²

In 1971, A.B., a 28-year-old woman was transferred from a state training school for the retarded, where she had been confined since the age of seven, to a state psychiatric hospital, reportedly because of "unmanageable" behaviour. As a child she had been diagnosed as having infantile autism.

During her two decades of psychiatric hospitalization A.B. was never diagnosed as having a mental illness. Her only diagnoses were autism and mental retardation. She was "treated" with psychotropic medication, physical restraints, and seclusion. Hospital staff repeatedly stated that, in their clinical judgment, A.B. did not belong in a psychiatric hospital; was receiving only custodial care; was deteriorating as a result of her inappropriate confinement and treatment, and lack of behavioural programming; and should be discharged from the hospital to a small, specialized group home in the community.

The 1971 admission note in the hospital chart of A.B. read: "Therapeutic plans: Essentially this patient is going to be custodial." Twenty years later a belated evaluation by a speech and language pathologist from the department

of mental retardation confirmed that A.B. had received only custodial care, and concluded:

Placement for [A.B.] should be sought in an habilitative residential program in which the possible development of communication, social and daily living skills can be initiated. Her current placement in [name withheld] Hospital precludes the development of such an habilitative plan at present.

For two decades A.B. resided on a locked ward with thirty other female patients. Although the ward had a common sleeping area, A.B. had her own room because of her problematic behaviour, which involved self-mutilation behaviour that was manifested by striking herself, pulling her hair, vigorous rocking, agitation and restlessness, crying, rubbing and poking her eyes, running up and down the halls, spitting, vomiting, incontinence, assaulting others, taking off her clothes, repetitive changing of clothing, and stuffing clothing in the toilet.

The response of hospital staff to the behaviour of A.B. consisted of psychotropic medications administered on an "as needed" (*prn*) basis and the application of mechanical restraints. During a three-month period in 1990, A.B. received 298 *prn*'s (in addition to her regular dosage of medications) and was placed in four-point restraints on 72 occasions.

A visitor to A.B.'s ward described it in the following grim terms:

Upon entering the ward I saw a long hallway with a few single rooms each containing only a metal-framed bed without blankets. [A.B.] lives in just such a stark room. There was also the large, crowded room of small, partitioned sleeping areas. One woman was just getting up. . . from a bed next to the window - and was finishing dressing in full view of everyone standing in the hallway. The walls of the hallway have one or two small, plastic-framed pictures poorly replicating a real painting. The large room on the women's ward contained a few chairs and two-seated couches. . . made of black vinyl. . . . The television room had chairs lined up against the walls facing each other, but not facing the television, which makes it very uncomfortable to watch television and difficult to carry on a conversation with fellow patients. One small couch towards the back of the room faced the television, but a patient was sleeping on it. Several other women on the ward were sprawled out on the seats sleeping as well. Empty bookshelves lined one wall and the paint throughout the ward, which is pink, was also dingy and peeling. Heavy, dirty screens obscured the view of the women's ward and there were

no rugs or carpeting on the hard, industrial-grey floors. . . . [T]he women's ward is barren, containing nothing other than a television to occupy patients' time. . . . [T]here were smells of urine and body-odor which followed us as we left the building.

A.B. spent most of her day "twirling a sock" while sitting on a sofa in the day room on her ward. On a typical day, in the early summer of 1990, A.B. was observed "sitting with her legs apart and rocking on a plastic couch wearing only a hospital gown and no underwear." A.B. rarely left the ward, taking her meals there, and leaving only for occasional medical appointments.

Repeated instances of self-injurious behaviour appear throughout A.B.'s hospital record. The most dramatic evidence of the unsafe conditions on A.B.'s ward and of the deterioration of her basic self-care skills is the fact that she lost her sight while in the hospital. Hospital staff did not notice or, if they did, did not act to correct A.B.'s declining eyesight until her blindness was irreversible. However, even before staff acknowledged that A.B. had lost her sight, they noted in her record that she would move "up and down the hall and bump against every other door and pat her hands against the back of the door."

In 1978, seven years after A.B.'s arrival at the hospital, L.M., a 29-year-old man with "moderate mental retardation", was admitted to the hospital from the same training school from which A.B. had come. Unlike A.B., L.M. had only been at the training school for a few months before his transfer. L.M.'s family learned of his hospitalization when they went to the training school to visit him. As in A.B.'s case, the only reason given for L.M.'s hospitalization was his "unmanageable" behaviour.

More than a decade later L.M. remains confined at the hospital, notwithstanding the fact that he has never been diagnosed as mentally ill. His only "treatment" (until very recently) has consisted of confinement on a locked ward, psychotropic medication, mechanical restraints, and seclusion. The question of whether the care and treatment available at the hospital was appropriate for L.M. was raised at the time of his admission. A staff psychiatrist wrote the following in L.M.'s admission note:

Admission of [L.M.] is appropriate only as an emergency action. Continued hospitalization . . . is inappropriate because there is no peer group, educational or recreational program available to maintain the very good adjustment [L.M.] has been able to make with his deficiencies.

Similar concerns were raised in a psychological evaluation five years later in 1983:

Mr. M. is moderately mentally retarded and does not possess the cognitive resources necessary to allow him to cope with the environmental demands he encounters in a living placement which is tailored for normal intelligence psychiatric patients.

Virtually from the moment of his arrival at the hospital, staff members maintained that L.M. had received "maximum benefit" from his hospitalization, was experiencing deterioration in his condition and abilities because of his inappropriate hospitalization, and required a group home and day program in the community. Until very recently—and only then in response to a lawsuit brought on behalf of A.B., L.M., and more than forty others like them at the hospital—L.M. received no educational or behavioural programming appropriate to his needs.

When L.M. was first admitted to the hospital he was described as being clean, continent, and able to communicate his needs and follow instructions. He could feed, dress, and bathe himself, and care for his other needs, independently. On home visits L.M. rode a mini-bike, played basketball, made his own bed, and took out the garbage. Four years later, in 1982, L.M. was still able to feed, dress, and bathe himself, and to brush his teeth. However, the ensuing years witnessed a dramatic deterioration in L.M.'s basic self-care skills. A psychological evaluation in 1988 observed that L.M. "needed to take five or six showers a day and changes of clothes because of incontinence, behaving as though... not toilet-trained at all." By 1990 L.M. was no longer feeding himself on a regular basis. His case manager reported that "he wears a large sheet to cover his body because he spills things on himself." In early 1991, L.M. had regressed to such primitive behaviour as smearing his feces.

For more than ten years L.M. resided on a ward with some thirty other patients, half of whom, like L.M., were diagnosed as mentally retarded, the others suffering from chronic severe mental illness. The ward door was locked at all times and visitors could enter the ward only after a staff member unlocked it. The ward had a common sleeping area with each bed separated from the others by movable dividers. Areas within the ward that were accessible to patients, consisted of a long hallway leading from the door to the open nursing station, a large day room, and two large rooms off the day room, one of which served as a telephone room and the other as a television and smoking room.

A visitor to L.M.'s ward described it in the following manner:

After the door leading to Ward [name deleted], where [L.M.] resides was unlocked for us, we walked down a short hallway to the nurses' desk. The walls of the entire ward are painted blue. There are several rooms on each side of the hall, each containing

one metal-framed bed without blankets, and surrounded by bare walls. Directly across from the nurses' station was a large room, which we could view through a long window. The room was crowded with roughly six-and-a-half-foot-high partitions separating the patients' beds. One bed lay next to the window and a patient was still sleeping there, at approximately 9:15 a.m., in full view of everyone in the hall.

Ahead lay a large room, called the day room, empty but for three or four hard, orange, plastic seats, each situated across the room from each other. The floor is hard and cold without carpeting or floor rugs. Some of the male patients walked about the room bare-footed. The adjoining room, called the television room, also had several hard, plastic, orange seats situated across from each other on either side of the room, with a longer seat in the middle of the room facing the television. The seats are placed at such a distance from each other that it does not allow for casual conversation among the patients. Built-in bookshelves covered half of one wall of the television room, but they stood completely empty, adding to the austerity of the room. The view outside the windows is pleasant, however, heavy, dirty and aging screens obscure the view significantly. The dull, blue paint that covers the walls of the men's ward was dirty and the paint was peeling in many places. One of the patients kept pointing out to me the places where the paint was chipped and small chunks of the wall were actually missing.

There were no pictures or paintings on the walls. Only a few Valentine decorations, photos of some of the patients at a Halloween party and some cartoon figures with sayings that began with "Bullwinkle says. . . ." These decorations seemed a little too young for the patients.

[L.M.'s] ward was barren—there are no plants or flowers of any kind and there are no books or magazines to occupy oneself with. In fact, with the exception of the television, there is absolutely nothing available in the day room or television room which the patients can use to constructively pass the time each day. Harsh, fluorescent track-lighting covers the ceiling. Also, the smell of the air of the men's ward was stale with strong hints of urine and body-odor, which clung to our clothes even after we left.

L.M. existed in this grim setting for more than a decade. His life on the ward was one of frequent conflict with other patients involving repeated incidents of hitting, kicking, and biting. As L.M.'s condition deteriorated he

engaged in increasingly disruptive behaviour such as screaming, crying, removing his clothes, and stuffing toilets. His case manager attributed this behaviour to the fact that L.M. "is auditorially very sensitive and, when the noise level on the ward increases, [L.M.] becomes anxious and sometimes will lash out and hit someone or he will start to yell and scream." Trained observers concluded that L.M.'s conflicts and behaviours "appear to be his way of coping with the impoverished environment of the ward." Hospital staff have responded to L.M.'s "challenging behaviours" with the administration of psychotropic medications and the application of restraints. During a three-month period, in 1990, L.M. received 86 *prn*'s (in addition to his regular dosage of medication), and was placed in four-point restraints ten times.

The only service provided to L.M. by the department of mental retardation during a decade of hospitalization was "case management," which consisted of irregular visits by a case manager and periodic interdisciplinary team meetings at which an overall plan of services was developed and reviewed. At these meetings the team invariably concluded that L.M. was inappropriately placed and was deteriorating at the hospital, and that he required community-based group home placement and a day program, both designed to meet his special needs as a person with mental retardation and related behavioural symptoms. L.M.'s case manager from the department of mental retardation stated that when she visited L.M. at the hospital she would observe him walking around in circles or "just sitting, occasionally pacing, or in restraints." On the ward L.M. received weekly "music therapy" on Friday nights in which the male patients "just dance to the music or they sit and listen to the music. . . . It's meant to be like a party and it's just kind of a party sort of thing."

Mental Retardation and the Law

During the summer of 1990 a team of psychologists with extensive experience in the field of mental retardation visited the state hospital wards where A.B. and L.M. were confined. They observed the activities on the ward, spoke with patients and staff, and reviewed patient records. They reported that "what [A.B. and L.M.] experience is an anachronism—a service approach for people with mental retardation that existed almost a quarter of a century ago and has long since been abandoned."

What these observers saw were individuals with mental retardation confined on locked wards in a state mental hospital, together with patients suffering from chronic mental illness, being "managed" with psychotropic medication and mechanical restraints. There was no training to help these individuals develop or improve self-care skills, or to prevent the deterioration or loss of the skills they had; there was no training of patients and few other measures taken to ensure the protection of patients with retardation from their own self-injurious behaviour or from assaults by other patients; there was no

systematic process for assessing patients' needs, planning for addressing those needs, and providing appropriate services to meet those needs.

In its landmark decision on the rights of persons with mental retardation, *Youngberg v. Romeo* (1982), the United States Supreme Court held that persons with mental retardation in state-operated institutions have constitutional rights to safe conditions of confinement, freedom from unreasonable physical restraint, and training that is reasonably required to ensure their safety and to facilitate their ability to function free from bodily restraints. These basic constitutional rights have been held to include a right to training sufficient to prevent basic self-care skills from deteriorating (*Society for Good Will to Retarded Children v. Cuomo*, 1984); and, for those institutionalized at too young an age to have learned basic self-care skills, the right to such training as would match the improvement that they would have experienced if they had not been so confined (*Clark v. Cohen*, 1986).

Although the Supreme Court in *Youngberg v. Romeo* recognized these constitutional rights, it declined to articulate substantive criteria for assessing whether the rights have been violated. Rather, the Court deferred to the judgment of professionals, holding that state authorities must ensure that "professional judgment has been exercised" regarding treatment and conditions of confinement. In the Court's words,

[L]iability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such judgment.

Thus, the constitutional rights of institutionalized persons with mental retardation are violated either when treatment plans and the care provided fail to conform to accepted professional standards, or when treatment recommendations by qualified professionals that do meet accepted professional standards are not implemented.

While courts have held that institutionalized persons with mental retardation do not have a constitutional right to placement in the least restrictive environment appropriate to their needs, such as community-based group homes (*S.H. v. Edwards*, 1989; *Thomas S. by Brooks v. Flaherty*, 1990; *Society for Good Will to Retarded Children v. Cuomo*, 1990), individuals might be entitled to community placement if professional evaluators determine that habilitation in a community setting is necessary to provide adequate care in accordance with professional standards (*S.H. v. Edwards*; *Thomas S. by Brooks v. Flaherty*).

The Lawsuit and the Settlement

It was these rights that advocates for A.B. and L.M. sought to vindicate when, in the summer of 1989, they commenced a legal action against the departments of mental retardation and mental health on their behalf and on behalf of the others with mental retardation confined with them at the state hospital—the right to live in a safe environment, the right to be free from undue restraint, and the right to receive training to prevent the deterioration of basic self-care skills. The class consisted of thirty-nine other persons who shared the wards where A.B. and L.M. lived. Although all had "treatment plans," they consisted of little more than a recitation of major medical and behavioural problems with global statements regarding the ultimate amelioration of those problems. There were no assessments or behavioural management plans beyond tranquilizing medications and restraints. A few of the class members had day programs but most, like A.B. and L.M., spent their days wandering aimlessly around the wards.

It was clear to the attorneys that the conditions on the wards and the care and treatment of the class members fell woefully short of even the minimum required by professional judgement. The case on the merits seemed clear; what was unclear to the class attorneys was the question of remedies.

What the advocates really wanted for their clients was that they be discharged from the state hospital to small, supervised group homes and to appropriate day programs, where they might live more normal, satisfying lives and receive habilitation and training that would enable them to realize their potential for productive activity and the enjoyment of life. The advocates were committed to the ideal of normalization, an ideal that could not be achieved so long as their clients remained institutionalized. The hard reality, however, was that the state of Connecticut was in a serious economic recession and faced a multi-million dollar deficit. Short of a federal court order requiring the state to levy additional taxes—a prospect which was highly unlikely – it was clear that funds were not available to create residential placements in the community for all class members. On the other hand, the possibility of the court ordering the state to make improvements in the institution and to develop minimally adequate programs was real, but wholly unacceptable, to the advocates.

Despite the uncertainties, in May of 1991, the plaintiffs' attorneys filed a motion for summary judgment contending that they were entitled to a judgment as a matter of law without trial or further factual development. In the papers submitted, the plaintiffs requested that the court appoint a special master to oversee the treatment of the class. Concerned about the possibility of the appointment of a special master, the defendants immediately called for settlement negotiations. An interesting and creative proposal was presented. The commissioners proposed a series of individually-oriented, interdepartmental

case conferences for the class members, to be chaired by the commissioners of both agencies. The purposes of the conferences would be to provide: (1) the commissioners with information regarding the care and treatment of each class member and the interrelationship of the two departments relative to that care and treatment; (2) a means by which the service needs of each class member could be reviewed and strategies developed to meet those needs with the resources currently available; and (3) a forum in which a candid interchange of ideas and perspectives could take place among the professional staff of the departments in order to assure that the class members would receive appropriate care, treatment programs, and services. The information and strategies generated at the case conferences would serve as the basis for a consolidated treatment and service plan for each class member. Additionally, and of paramount importance, the commissioners reaffirmed an earlier commitment that the department of mental retardation would be responsible for placement in the community of all hospitalized individuals with mental retardation and that future admissions of persons with mental retardation to the mental health facility would be limited to those justified as a result of a psychiatric emergency. Finally, the commissioners agreed to place one-third of the class members in community residences within the current fiscal year, and the remainder within a "reasonable" period thereafter.

The Gilded Cage, and Beyond

By the end of the first six months of the settlement, every member of the plaintiff class was participating in a day program. The majority were leaving the hospital grounds to participate in sheltered workshops, supported employment, or social and recreational programs. L.M. is one of them. A small number are being served in an on-grounds program at the hospital where they are learning daily living and self-help skills, and engaging in recreational activities in the community.

During that same six-month period fourteen class members had either moved or been accepted into community residences. A.B. had moved into an interim placement at a department of mental retardation regional centre pending development of an appropriate community residence. L.M. has been placed in a group home near the home of his mother.

On the hospital wards, where the class members resided, their care and treatment improved significantly. Most had their medications reduced. The incidence of use of mechanical restraints plummeted. The staff became energized and "professionalized" by the attention being paid to their work by the commissioners at the weekly meetings, and by the advocates coming onto the wards to meet with them for the purpose of improving services for the patients.

Notwithstanding these positive developments in conditions and programs resulting from the settlement of the lawsuit, the majority of class members remain confined on locked wards of the state mental hospital. In effect, their advocates have settled for a "gilded cage" rather than holding out for what they knew to be right and in their clients' long-term best interests—the opportunity to lead more enjoyable, productive, "normal" lives in integrated settings in the community.

Conclusion

Fulfilling ethical and humanitarian obligations to institutionalized mentally retarded clients often calls upon the legal advocate to settle for incremental improvements in services and conditions of confinement, rather than holding out for major, costly changes in their programs, such as the development of group homes. In a world of scarce economic resources and political conservatism, large capital and program expenditures for group homes and other community-based services that would "normalize" the lives of institutionalized clients may simply not be economically or politically feasible.

We know that individuals with mental retardation can lead more productive, satisfying, and enjoyable lives in the community than in institutions. Yet, we must also acknowledge the reality that public funds in all likelihood will not be available, now or in the foreseeable future, to permit the movement of all institutionalized mentally retarded people into the community, with adequate supports and services to assure their successful transition from institutionalization to normalization.

People with mental retardation and their legal advocates live in the real world, not in an ideal world imagined by social and legal theorists. It is within the real world that advocates must struggle and make compromises to achieve improvements in the lives of their clients. The settlement in the case of A.B. and L.M. demonstrated the profound tension for advocates between their desire, and duty, to accept immediate measures to alleviate the suffering of clients, and social policy objectives that the advocates believe to be the best way to meet the needs of their clients in the long run, and the legal right of their clients to receive.

In attempting to address the immediate needs of their clients, legal advocates frequently are caught between meeting those needs and achieving long-term solutions to their clients' problems. In the real world advocates may find themselves agreeing to the expenditure of limited public funds to improve conditions and services within institutions, resulting in the expansion of programs, physical improvements, enhanced staff-patient ratios, reductions in the use of medications and mechanical restraints - in effect, the creation of a "gilded cage." At the same time, advocates must continue to push for the

eventual, and inevitable, closing of institutions for persons with retardation, and for their inclusion and integration in society.

NOTES

1. The number of persons with developmental disabilities residing in state-operated institutions across the United States dropped nearly 17% during the 4-year period between 1984 and 1988. Between 1986 and 1988 institutional expenditures increased only 10% while expenditures for community services increased by 38%. Braddock *et al.*, *The state of the States in developmental disabilities*, 1990, p. 13.
2. The case of A.B. and L.M. is an actual case.

REFERENCES

- Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D. (1990). *The state of the states in developmental disabilities*. Baltimore: Brookes.
- Clark v. Cohen, 794 F.2d 79, 96 (3rd Cir. 1986).
- S.H. v. Edwards, *supra* at 292.
- S.H. v. Edwards, 886 F.2d 292 (11th Cir. 1989).
- Society for Good Will to Retarded Children v. Cuomo, 737 F.2d 1239, 1250 (2nd Cir. 1984). ("Good Will I").
- Society for Good Will to Retarded Children v. Cuomo, 902 F.2d 1085 (2nd Cir. 1990). ("Good Will III").
- Thomas S. by Brooks v. Flaherty, *supra* at 254.
- Thomas S. by Brooks v. Flaherty, 902 F.2d 250, 254 (4th Cir. 1990).
- Youngberg v. Romeo, 457 US 307, 324 (1982).
- Youngberg v. Romeo, 457 US 323.

Carroll L. Lucht and Stephen Wizner are clinical professors and supervising attorneys in a Yale Law School legal services program serving individuals with disabilities.

Carroll L. Lucht et Stephen Wizner sont professeurs cliniciens et avocats responsables d'un programme de services juridiques à la faculté de droit de l'Université Yale destiné aux personnes handicapées.