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Civil Rights and Individuals with Developmental Disabilities

January 12, 2022

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2023 Disability Law Series:

Civil Rights and Individuals with Developmental Disabilities

Presented by the Government Law Center at Albany Law School

Overview of Civil Rights of People with Developmental Disabilities

January 12, 2023

Moderated by Tara Pleat, Esq.

Introduction (1:00 p.m.)

Honorable Leslie E. Stein (ret.), Director, Government Law Center at Albany Law School

Importance of Olmstead v. LC to New York (1:10 p.m.)

Roger Bearden, Executive Deputy Commissioner, NYS Office for People with Developmental Disabilities

Principle of Capacity and its Role in Decision-making (1:30 p.m.)

Prianka Nair, Brooklyn Law School Assistant Professor of Clinical Law, Co-Director of the Disability and Civil Rights Clinic

Standards of Capacity in New York Laws (1:50 p.m.)

Mira Weiss, Esq.

Article 12, Convention on the Rights of People with Disabilities & Supported Decision-making (2:10 p.m.)

Honorable Kristin Booth Glen (ret.)

Q&A (2:30 p.m.)

Closing Remarks (2:50 p.m.)

The Government Law Center at Albany Law School Presents:
2023 Disability Law Series: Civil Rights and Individuals with Developmental Disabilities

Overview of Civil Rights of People with Developmental Disabilities

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Speaker Biographies

ROGER BEARDEN recently announced his decision to leave New York state government after 12 years of service to two governors. Mr. Bearden served in a variety of leadership roles during his time in government, as Commissioner of the Commission on Quality of Care and Advocacy for People with Disabilities, Special Counsel to the Governor for Olmstead, Assistant Counsel to the Governor for Mental Hygiene and Human Services, General Counsel of the Office for People with Developmental Disabilities, and, most recently, as Executive Deputy Commissioner of the Office for People with Developmental Disabilities, where he led the agency's response to the COVID-19 pandemic. Mr. Bearden was previously the Director of the Disability Law Center at New York Lawyers for the Public Interest, Chief Health Counsel to the New York State Senate, a staff attorney at Disability Advocates, Inc., and an attorney for a boutique litigation firm in New York City. Mr. Bearden is a graduate of Brown University and Harvard Law School, and a former clerk to Walter J. Cummings of the Seventh Circuit United States Court of Appeals.

HON. KRISTIN BOOTH GLEN (RET.) is Director of Supported Decision Making New York and Dean Emerita at CUNY School of Law. After earning her J.D. from Columbia University Law School, Judge Glen clerked for the U.S. Court of Appeals for the Second Circuit and spent 12 years in private practice and 15 years as a member of the judiciary, serving on the New York City Civil Court and the New York State Supreme Court. Judge Glen served as Dean of the CUNY School of Law from 1995 to 2005. She then served as a judge for the New York County Surrogate's Court from 2006 to 2012.

PRIANKA NAIR is Assistant Professor of Clinical Law and Co-Director of the Disability and Civil Rights Clinic at Brooklyn Law School. Prior to joining the faculty at Brooklyn Law School, Professor Nair worked as a public interest attorney at Disability Rights New York. She conducted abuse and neglect investigations, focusing on access to services in correctional facilities across New York State. She has also litigated cases and led policy changes to achieve equal rights for persons with disabilities. Her litigation included cases involving violations of the Americans

with Disabilities Act, the Individuals with Disabilities Education Act and the Fourteenth Amendment. She has also represented clients in all aspects of guardianship and related proceedings in state and federal court.

TARA ANNE PLEAT, ESQ., CLEA '02 practices law in upstate New York in the Saratoga/Adirondack region. She practices in the areas of special needs estate planning and administration, traditional estate planning and administration, long-term care planning, and elder law. Ms. Pleat is a past Chair of the Elder Law and Special Needs Section of the New York State Bar Association. She is also an active member of the Trusts and Estates Law Section. She is a member of the Special Needs Alliance, where she serves as Vice-President of the Board of Directors. She is also a Member of the Academy of Special Needs Planners and the National Academy of Elder Law Attorneys. She currently serves on the Board of Directors of New York NAELA. She is a Past President of the Board of Directors of the Estate Planning Council of Eastern New York. She is an advisory board member of Supported Decision Making New York as we all as a Member of the Arc of New York's Statewide Guardianship committee. In March of 2016, Ms. Pleat was elected as a Fellow of the American College of Trust and Estate Counsel (ACTEC) where she now serves as the Upstate New York Chair and the Chair of the Mid-Atlantic Region. Ms. Pleat has been an adjunct professor of law at Albany Law School for the last ten years, where she teaches a course in the spring semester on estate and financial planning for the elderly and individuals with special needs and a course on estate planning in the fall. She is a co-author of the Lexis-Nexis Publication, New York Elder Law.

MIRA WEISS, ESQ., is the founder and managing attorney of Weiss Law Group, PLLC. She brings to her practice a unique set of skills and experience in public health, health law, and insurance. Before launching the Weiss Law Group, Ms. Weiss served as Deputy Director of Operations of the world-famous Bellevue Hospital Center ("Bellevue") and as counsel to Columbia-Presbyterian Medical Center, Bellevue, and private medical practices. She also worked in the health insurance industry as counsel and senior executive for insurers such as Horizon New Jersey and Horizon Pennsylvania (Blue Cross Blue Shield-affiliated companies) and as General Counsel and Vice President at Touchstone Health (a Medicare company). Ms. Weiss is a graduate of George Washington University School of Law, winner of the Court Practice award, and a *cum laude* graduate of the Honors Program of Temple University, where she studied Theater and Communications. She is admitted to practice in New York, the District of Columbia, and the U.S. Court of Appeals.

Syllabus

OLMSTEAD, COMMISSIONER, GEORGIA DEPARTMENT OF HUMAN RESOURCES, ET AL. *v.* L. C., BY ZIMRING, GUARDIAN AD LITEM AND NEXT FRIEND, ET AL.

CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE ELEVENTH CIRCUIT

No. 98–536. Argued April 21, 1999—Decided June 22, 1999

In the Americans with Disabilities Act of 1990 (ADA), Congress described the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination. 42 U. S. C. §§ 12101(a)(2), (5). Title II of the ADA, which proscribes discrimination in the provision of public services, specifies, *inter alia*, that no qualified individual with a disability shall, "by reason of such disability," be excluded from participation in, or be denied the benefits of, a public entity's services, programs, or activities. § 12132. Congress instructed the Attorney General to issue regulations implementing Title II's discrimination proscription. See § 12134(a). One such regulation, known as the "integration regulation," requires a "public entity [to] administer . . . programs . . . in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR § 35.130(d). A further prescription, here called the "reasonable-modifications regulation," requires public entities to "make reasonable modifications" to avoid "discrimination on the basis of disability," but does not require measures that would "fundamentally alter" the nature of the entity's programs. § 35.130(b)(7).

Respondents L. C. and E. W. are mentally retarded women; L. C. has also been diagnosed with schizophrenia, and E. W., with a personality disorder. Both women were voluntarily admitted to Georgia Regional Hospital at Atlanta (GRH), where they were confined for treatment in a psychiatric unit. Although their treatment professionals eventually concluded that each of the women could be cared for appropriately in a community-based program, the women remained institutionalized at GRH. Seeking placement in community care, L. C. filed this suit against petitioner state officials (collectively, the State) under 42 U. S. C. § 1983 and Title II. She alleged that the State violated Title II in failing to place her in a community-based program once her treating professionals determined that such placement was appropriate. E. W. intervened, stating an identical claim. The District Court granted partial summary judgment for the women, ordering their

placement in an appropriate community-based treatment program. The court rejected the State's argument that inadequate funding, not discrimination against L. C. and E. W. "by reason of [their] disabilit[ies]," accounted for their retention at GRH. Under Title II, the court concluded, unnecessary institutional segregation constitutes discrimination *per se*, which cannot be justified by a lack of funding. The court also rejected the State's defense that requiring immediate transfers in such cases would "fundamentally alter" the State's programs. The Eleventh Circuit affirmed the District Court's judgment, but remanded for reassessment of the State's cost-based defense. The District Court had left virtually no room for such a defense. The appeals court read the statute and regulations to allow the defense, but only in tightly limited circumstances. Accordingly, the Eleventh Circuit instructed the District Court to consider, as a key factor, whether the additional cost for treatment of L. C. and E. W. in community-based care would be unreasonable given the demands of the State's mental health budget.

Held: The judgment is affirmed in part and vacated in part, and the case is remanded.

138 F. 3d 893, affirmed in part, vacated in part, and remanded.

JUSTICE GINSBURG delivered the opinion of the Court with respect to Parts I, II, and III–A, concluding that, under Title II of the ADA, States are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. Pp. 596–603.

(a) The integration and reasonable-modifications regulations issued by the Attorney General rest on two key determinations: (1) Unjustified placement or retention of persons in institutions severely limits their exposure to the outside community, and therefore constitutes a form of discrimination based on disability prohibited by Title II, and (2) qualifying their obligation to avoid unjustified isolation of individuals with disabilities, States can resist modifications that would fundamentally alter the nature of their services and programs. The Eleventh Circuit essentially upheld the Attorney General's construction of the ADA. This Court affirms the Court of Appeals decision in substantial part. Pp. 596–597.

(b) Undue institutionalization qualifies as discrimination "by reason of . . . disability." The Department of Justice has consistently advocated that it does. Because the Department is the agency directed

by Congress to issue Title II regulations, its views warrant respect. This Court need not inquire whether the degree of deference described in *Chevron U. S. A. Inc.* v. *Natural Resources Defense Council, Inc.*, 467 U. S. 837, 844, is in order; the well-reasoned views of the agencies implementing a statute constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance. *E. g., Bragdon* v. *Abbott*, 524 U. S. 624, 642. According to the State, L. C. and E. W. encountered no discrimination "by reason of" their disabilities because they were not denied community placement on account of those disabilities, nor were they subjected to "discrimination," for they identified no comparison class of similarly situated individuals given preferential treatment. In rejecting these positions, the Court recognizes that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA. The ADA stepped up earlier efforts in the Developmentally Disabled Assistance and Bill of Rights Act and the Rehabilitation Act of 1973 to secure opportunities for people with developmental disabilities to enjoy the benefits of community living. The ADA both requires all public entities to refrain from discrimination, see § 12132, and specifically identifies unjustified "segregation" of persons with disabilities as a "for[m] of discrimination," see §§ 12101(a)(2), 12101(a)(5). The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, cf., *e. g., Allen* v. *Wright*, 468 U. S. 737, 755; and institutional confinement severely diminishes individuals' everyday life activities. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice. The State correctly uses the past tense to frame its argument that, despite Congress' ADA findings, the Medicaid statute "reflected" a congressional policy preference for institutional treatment over treatment in the community. Since 1981, Medicaid has in fact provided funding for state-run home and community-based care through a waiver program. This Court emphasizes that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. In this case, however, it is not genuinely disputed that L. C. and E. W. are individuals "quali-

fied" for noninstitutional care: The State's own professionals determined that community-based treatment would be appropriate for L. C. and E. W., and neither woman opposed such treatment. Pp. 597–603.

JUSTICE GINSBURG, joined by JUSTICE O'CONNOR, JUSTICE SOUTER, and JUSTICE BREYER, concluded in Part III–B that the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless. The reasonable-modifications regulation speaks of "reasonable modifications" to avoid discrimination, and allows States to resist modifications that entail a "fundamenta[l] alter[ation]" of the States' services and programs. If, as the Eleventh Circuit indicated, the expense entailed in placing one or two people in a community-based treatment program is properly measured for reasonableness against the State's entire mental health budget, it is unlikely that a State, relying on the fundamental-alteration defense, could ever prevail. Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities. The ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. Nor is it the ADA's mission to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter, a placement the State proposed, then retracted, for E. W. Some individuals, like L. C. and E. W. in prior years, may need institutional care from time to time to stabilize acute psychiatric symptoms. For others, no placement outside the institution may ever be appropriate. To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate that 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, the reasonable-modifications standard would be met. In such circumstances, a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions. The case is remanded for further consideration of the appropriate relief, given the range of the State's facilities for the care of persons with diverse mental disabilities, and its obligation to administer services with an even hand. Pp. 603–606.

Syllabus

JUSTICE STEVENS would affirm the judgment of the Court of Appeals, but because there are not five votes for that disposition, joined the Court's judgment and Parts I, II, and III–A of its opinion. Pp. 607–608.

JUSTICE KENNEDY concluded that the case must be remanded for a determination of the questions the Court poses and for a determination whether respondents can show a violation of 42 U. S. C. § 12132's ban on discrimination based on the summary judgment materials on file or any further pleadings and materials properly allowed. On the ordinary interpretation and meaning of the term, one who alleges discrimination must show that she received differential treatment vis-à-vis members of a different group on the basis of a statutorily described characteristic. Thus, respondents could demonstrate discrimination by showing that Georgia (i) provides treatment to individuals suffering from medical problems of comparable seriousness, (ii) as a general matter, does so in the most integrated setting appropriate for the treatment of those problems (taking medical and other practical considerations into account), but (iii) without adequate justification, fails to do so for a group of mentally disabled persons (treating them instead in separate, locked institutional facilities). This inquiry would not be simple. Comparisons of different medical conditions and the corresponding treatment regimens might be difficult, as would be assessments of the degree of integration of various settings in which medical treatment is offered. Thus far, respondents have identified no class of similarly situated individuals, let alone shown them to have been given preferential treatment. Without additional information, the Court cannot address the issue in the way the statute demands. As a consequence, the partial summary judgment granted respondents ought not to be sustained. In addition, it was error in the earlier proceedings to restrict the relevance and force of the State's evidence regarding the comparative costs of treatment. The State is entitled to wide discretion in adopting its own systems of cost analysis, and, if it chooses, to allocate health care resources based on fixed and overhead costs for whole institutions and programs. The lower courts should determine in the first instance whether a statutory violation is sufficiently alleged and supported in respondents' summary judgment materials and, if not, whether they should be given leave to replead and to introduce evidence and argument along the lines suggested. Pp. 611–615.

GINSBURG, J., announced the judgment of the Court and delivered the opinion of the Court with respect to Parts I, II, and III–A, in which STEVENS, O'CONNOR, SOUTER, and BREYER, JJ., joined, and an opin-

ion with respect to Part III–B, in which O'CONNOR, SOUTER, and BREYER, JJ., joined. STEVENS, J., filed an opinion concurring in part and concurring in the judgment, *post*, p. 607. KENNEDY, J., filed an opinion concurring in the judgment, in which BREYER, J., joined as to Part I, *post*, p. 608. THOMAS, J., filed a dissenting opinion, in which REHNQUIST, C. J., and SCALIA, J., joined, *post*, p. 615.

Beverly Patricia Downing, Senior Assistant Attorney General of Georgia, argued the cause for petitioners. With her on the briefs were *Thurbert E. Baker*, Attorney General, *Kathleen M. Pacious*, Deputy Attorney General, *Jefferson James Davis*, Special Assistant Attorney General, and *Jeffrey S. Sutton*.

Michael H. Gottesman argued the cause for respondents. With him on the brief were *Steven D. Caley*, *Susan C. Jamieson*, and *David A. Webster*.

Irving L. Gornstein argued the cause for the United States as *amicus curiae* urging affirmance. With him on the brief were *Solicitor General Waxman*, *Acting Assistant Attorney General Lee*, *Deputy Solicitor General Underwood*, *Jessica Dunsay Silver*, and *Gregory B. Friel*.*

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*Briefs of *amici curiae* urging reversal were filed for the State of Nevada et al. by *Frankie Sue Del Papa*, Attorney General of Nevada, and *Anne B. Cathcart*, Special Assistant Attorney General, *Mike Moore*, Attorney General of Mississippi, and *Robert E. Sanders*, Assistant Attorney General, *John Cornyn*, Attorney General of Texas, *Andy Taylor*, First Assistant Attorney General, *Linda S. Eads*, Deputy Attorney General, and *Gregory S. Coleman*, Solicitor General, and by the Attorneys General for their respective States as follows: *Ken L. Salazar* of Colorado, *Jeffrey A. Modisett* of Indiana, *Margery S. Bronster* of Hawaii, *Richard P. Ieyoub* of Louisiana, *Thomas F. Reilly* of Massachusetts, *Joseph P. Mazurek* of Montana, *Charles M. Condon* of South Carolina, *Paul G. Summers* of Tennessee, *Christine O. Gregoire* of Washington, and *Gay Woodhouse* of Wyoming; and for the National Conference of State Legislatures et al. by *Richard Ruda* and *James I. Crowley*.

Briefs of *amici curiae* urging affirmance were filed for the American Association on Mental Retardation et al. by *Alan M. Wiseman*, *Timothy K. Armstrong*, and *Ira A. Burnim*; for the American Civil Liberties Union et al. by *Laurie Webb Daniel* and *Steven R. Shapiro*; for the American

JUSTICE GINSBURG announced the judgment of the Court and delivered the opinion of the Court with respect to Parts I, II, and III–A, and an opinion with respect to Part III–B, in which JUSTICE O'CONNOR, JUSTICE SOUTER, and JUSTICE BREYER join.

This case concerns the proper construction of the anti-discrimination provision contained in the public services portion (Title II) of the Americans with Disabilities Act of 1990 (ADA), 104 Stat. 337, 42 U. S. C. § 12132. Specifically, we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. In so ruling, we affirm the decision of the Eleventh Circuit in substantial part. We remand the case, however, for further consideration of the appropriate relief, given the range of facilities the State maintains for the care and treatment of persons with diverse mental disabilities, and its obligation to administer services with an even hand.

Psychiatric Association et al. by *Richard G. Taranto;* for 58 Former State Commissioners and Directors of Mental Health and Developmental Disabilities et al. by *Neil V. McKittrick;* for the National Council on Disability by *Robert L. Burgdorf, Jr.;* for the National Mental Health Consumers' Self-Help Clearinghouse et al. by *Loralyn McKinley;* for Dick Thornburgh et al. by *Mr. Thornburgh, pro se, James E. Day,* and *David R. Fine;* for People First of Georgia et al. by *Thomas K. Gilhool;* and for the Voice of the Retarded et al. by *William J. Burke* and *Tamie Hopp.*

Stephen F. Gold filed a brief for ADAPT et al. as *amici curiae.*

I

This case, as it comes to us, presents no constitutional question. The complaints filed by plaintiffs-respondents L. C. and E. W. did include such an issue; L. C. and E. W. alleged that defendants-petitioners, Georgia health care officials, failed to afford them minimally adequate care and freedom from undue restraint, in violation of their rights under the Due Process Clause of the Fourteenth Amendment. See Complaint ¶¶ 87–91; Intervenor's Complaint ¶¶ 30–34. But neither the District Court nor the Court of Appeals reached those Fourteenth Amendment claims. See Civ. No. 1:95–cv–1210–MHS (ND Ga., Mar. 26, 1997), pp. 5–6, 11–13, App. to Pet. for Cert. 34a–35a, 40a–41a; 138 F. 3d 893, 895, and n. 3 (CA11 1998). Instead, the courts below resolved the case solely on statutory grounds. Our review is similarly confined. Cf. *Cleburne* v. *Cleburne Living Center, Inc.*, 473 U. S. 432, 450 (1985) (Texas city's requirement of special use permit for operation of group home for mentally retarded, when other care and multiple-dwelling facilities were freely permitted, lacked rational basis and therefore violated Equal Protection Clause of Fourteenth Amendment). Mindful that it is a statute we are construing, we set out first the legislative and regulatory prescriptions on which the case turns.

In the opening provisions of the ADA, Congress stated findings applicable to the statute in all its parts. Most relevant to this case, Congress determined that

> "(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 . . . institutionalization . . . ;
>
> . . . . .

"(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . failure to make modifications to existing facilities and practices, . . . [and] segregation . . . ." 42 U. S. C. §§ 12101(a)(2), (3), (5).[1]

Congress then set forth prohibitions against discrimination in employment (Title I, §§ 12111–12117), public services furnished by governmental entities (Title II, §§ 12131–12165), and public accommodations provided by private entities (Title III, §§ 12181–12189). The statute as a whole is intended "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." § 12101(b)(1).[2]

This case concerns Title II, the public services portion of the ADA.[3] The provision of Title II centrally at issue reads:

"Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such

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[1] The ADA, enacted in 1990, is the Federal Government's most recent and extensive endeavor to address discrimination against persons with disabilities. Earlier legislative efforts included the Rehabilitation Act of 1973, 87 Stat. 355, 29 U. S. C. § 701 *et seq.* (1976 ed.), and the Developmentally Disabled Assistance and Bill of Rights Act, 89 Stat. 486, 42 U. S. C. § 6001 *et seq.* (1976 ed.), enacted in 1975. In the ADA, Congress for the first time referred expressly to "segregation" of persons with disabilities as a "for[m] of discrimination," and to discrimination that persists in the area of "institutionalization." §§ 12101(a)(2), (3), (5).

[2] The ADA defines "disability," "with respect to an individual," as

"(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

"(B) a record of such an impairment; or

"(C) being regarded as having such an impairment." § 12102(2).

There is no dispute that L. C. and E. W. are disabled within the meaning of the ADA.

[3] In addition to the provisions set out in Part A governing public services generally, see §§ 12131–12134, Title II contains in Part B a host of provisions governing public transportation services, see §§ 12141–12165.

> disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." § 201, as set forth in 42 U. S. C. § 12132.

Title II's definition section states that "public entity" includes "any State or local government," and "any department, agency, [or] special purpose district." §§ 12131(1)(A), (B). The same section defines "qualified individual with a disability" as

> "an individual with a disability who, with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity." § 12131(2).

On redress for violations of § 12132's discrimination prohibition, Congress referred to remedies available under § 505 of the Rehabilitation Act of 1973, 92 Stat. 2982, 29 U. S. C. § 794a. See § 203, as set forth in 42 U. S. C. § 12133 ("The remedies, procedures, and rights set forth in [§ 505 of the Rehabilitation Act] shall be the remedies, procedures, and rights this subchapter provides to any person alleging discrimination on the basis of disability in violation of section 12132 of this title.").[4]

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[4] Section 505 of the Rehabilitation Act incorporates the remedies, rights, and procedures set forth in Title VI of the Civil Rights Act of 1964 for violations of § 504 of the Rehabilitation Act. See 29 U. S. C. § 794a(a)(2). Title VI, in turn, directs each federal department authorized to extend financial assistance to any department or agency of a State to issue rules and regulations consistent with achievement of the objectives of the statute authorizing financial assistance. See 78 Stat. 252, 42 U. S. C. § 2000d–1. Compliance with such requirements may be effected by the termination or denial of federal funds, or "by any other means authorized by law." *Ibid.* Remedies both at law and in equity are available for violations of the statute. See § 2000d–7(a)(2).

Congress instructed the Attorney General to issue regulations implementing provisions of Title II, including § 12132's discrimination proscription. See § 204, as set forth in § 12134(a) ("[T]he Attorney General shall promulgate regulations in an accessible format that implement this part.").[5] The Attorney General's regulations, Congress further directed, "shall be consistent with this chapter and with the coordination regulations . . . applicable to recipients of Federal financial assistance under [§ 504 of the Rehabilitation Act]." § 204, as set forth in 42 U. S. C. § 12134(b). One of the § 504 regulations requires recipients of federal funds to "administer programs and activities in the most integrated

[5] Congress directed the Secretary of Transportation to issue regulations implementing the portion of Title II concerning public transportation. See 42 U. S. C. §§ 12143(b), 12149, 12164. As stated in the regulations, a person alleging discrimination on the basis of disability in violation of Title II may seek to enforce its provisions by commencing a private lawsuit, or by filing a complaint with (a) a federal agency that provides funding to the public entity that is the subject of the complaint, (b) the Department of Justice for referral to an appropriate agency, or (c) one of eight federal agencies responsible for investigating complaints arising under Title II: the Department of Agriculture, the Department of Education, the Department of Health and Human Services, the Department of Housing and Urban Development, the Department of the Interior, the Department of Justice, the Department of Labor, and the Department of Transportation. See 28 CFR §§ 35.170(c), 35.172(b), 35.190(b) (1998).

The ADA contains several other provisions allocating regulatory and enforcement responsibility. Congress instructed the Equal Employment Opportunity Commission (EEOC) to issue regulations implementing Title I, see 42 U. S. C. § 12116; the EEOC, the Attorney General, and persons alleging discrimination on the basis of disability in violation of Title I may enforce its provisions, see § 12117(a). Congress similarly instructed the Secretary of Transportation and the Attorney General to issue regulations implementing provisions of Title III, see §§ 12186(a)(1), (b); the Attorney General and persons alleging discrimination on the basis of disability in violation of Title III may enforce its provisions, see §§ 12188(a)(1), (b). Each federal agency responsible for ADA implementation may render technical assistance to affected individuals and institutions with respect to provisions of the ADA for which the agency has responsibility. See § 12206(c)(1).

setting appropriate to the needs of qualified handicapped persons." 28 CFR § 41.51(d) (1998).

As Congress instructed, the Attorney General issued Title II regulations, see 28 CFR pt. 35 (1998), including one modeled on the § 504 regulation just quoted; called the "integration regulation," it reads:

> "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR § 35.130(d) (1998).

The preamble to the Attorney General's Title II regulations defines "the most integrated setting appropriate to the needs of qualified individuals with disabilities" to mean "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 CFR pt. 35, App. A, p. 450 (1998). Another regulation requires public entities to "make reasonable modifications" to avoid "discrimination on the basis of disability," unless those modifications would entail a "fundamenta[l] alter[ation]"; called here the "reasonable-modifications regulation," it provides:

> "A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 CFR § 35.130(b)(7) (1998).

We recite these regulations with the caveat that we do not here determine their validity. While the parties differ on the proper construction and enforcement of the regulations, we do not understand petitioners to challenge the regulatory formulations themselves as outside the congressional authorization. See Brief for Petitioners 16–17, 36, 40–41;

Reply Brief 15–16 (challenging the Attorney General's interpretation of the integration regulation).

II

With the key legislative provisions in full view, we summarize the facts underlying this dispute. Respondents L. C. and E. W. are mentally retarded women; L. C. has also been diagnosed with schizophrenia, and E. W. with a personality disorder. Both women have a history of treatment in institutional settings. In May 1992, L. C. was voluntarily admitted to Georgia Regional Hospital at Atlanta (GRH), where she was confined for treatment in a psychiatric unit. By May 1993, her psychiatric condition had stabilized, and L. C.'s treatment team at GRH agreed that her needs could be met appropriately in one of the community-based programs the State supported. Despite this evaluation, L. C. remained institutionalized until February 1996, when the State placed her in a community-based treatment program.

E. W. was voluntarily admitted to GRH in February 1995; like L. C., E. W. was confined for treatment in a psychiatric unit. In March 1995, GRH sought to discharge E. W. to a homeless shelter, but abandoned that plan after her attorney filed an administrative complaint. By 1996, E. W.'s treating psychiatrist concluded that she could be treated appropriately in a community-based setting. She nonetheless remained institutionalized until a few months after the District Court issued its judgment in this case in 1997.

In May 1995, when she was still institutionalized at GRH, L. C. filed suit in the United States District Court for the Northern District of Georgia, challenging her continued confinement in a segregated environment. Her complaint invoked 42 U. S. C. § 1983 and provisions of the ADA, §§ 12131–12134, and named as defendants, now petitioners, the Commissioner of the Georgia Department of Human Resources, the Superintendent of GRH, and the Executive Director of the Fulton County Regional Board (collectively,

the State). L. C. alleged that the State's failure to place her in a community-based program, once her treating professionals determined that such placement was appropriate, violated, *inter alia,* Title II of the ADA. L. C.'s pleading requested, among other things, that the State place her in a community care residential program, and that she receive treatment with the ultimate goal of integrating her into the mainstream of society. E. W. intervened in the action, stating an identical claim.[6]

The District Court granted partial summary judgment in favor of L. C. and E. W. See App. to Pet. for Cert. 31a–42a. The court held that the State's failure to place L. C. and E. W. in an appropriate community-based treatment program violated Title II of the ADA. See *id.,* at 39a, 41a. In so ruling, the court rejected the State's argument that inadequate funding, not discrimination against L. C. and E. W. "by reason of" their disabilities, accounted for their retention at GRH. Under Title II, the court concluded, "unnecessary institutional segregation of the disabled constitutes discrimination *per se,* which cannot be justified by a lack of funding." *Id.,* at 37a.

In addition to contending that L. C. and E. W. had not shown discrimination "by reason of [their] disabilit[ies]," the State resisted court intervention on the ground that requiring immediate transfers in cases of this order would "fundamentally alter" the State's activity. The State reasserted that it was already using all available funds to provide services to other persons with disabilities. See *id.,* at 38a. Re-

[6] L. C. and E. W. are currently receiving treatment in community-based programs. Nevertheless, the case is not moot. As the District Court and Court of Appeals explained, in view of the multiple institutional placements L. C. and E. W. have experienced, the controversy they brought to court is "capable of repetition, yet evading review." No. 1:95–cv–1210–MHS (ND Ga., Mar. 26, 1997), p. 6, App. to Pet. for Cert. 35a (internal quotation marks omitted); see 138 F. 3d 893, 895, n. 2 (CA11 1998) (citing *Honig* v. *Doe,* 484 U. S. 305, 318–323 (1988), and *Vitek* v. *Jones,* 445 U. S. 480, 486–487 (1980)).

jecting the State's "fundamental alteration" defense, the court observed that existing state programs provided community-based treatment of the kind for which L. C. and E. W. qualified, and that the State could "provide services to plaintiffs in the community at considerably *less* cost than is required to maintain them in an institution." *Id.*, at 39a.

The Court of Appeals for the Eleventh Circuit affirmed the judgment of the District Court, but remanded for reassessment of the State's cost-based defense. See 138 F. 3d, at 905. As the appeals court read the statute and regulations: When "a disabled individual's treating professionals find that a community-based placement is appropriate for that individual, the ADA imposes a duty to provide treatment in a community setting—the most integrated setting appropriate to that patient's needs"; "[w]here there is no such finding [by the treating professionals], nothing in the ADA requires the deinstitutionalization of th[e] patient." *Id.*, at 902.

The Court of Appeals recognized that the State's duty to provide integrated services "is not absolute"; under the Attorney General's Title II regulation, "reasonable modifications" were required of the State, but fundamental alterations were not demanded. *Id.*, at 904. The appeals court thought it clear, however, that "Congress wanted to permit a cost defense only in the most limited of circumstances." *Id.*, at 902. In conclusion, the court stated that a cost justification would fail "[u]nless the State can prove that requiring it to [expend additional funds in order to provide L. C. and E. W. with integrated services] would be so unreasonable given the demands of the State's mental health budget that it would fundamentally alter the service [the State] provides." *Id.*, at 905. Because it appeared that the District Court had entirely ruled out a "lack of funding" justification, see App. to Pet. for Cert. 37a, the appeals court remanded, repeating that the District Court should consider, among other things, "whether the additional expenditures necessary to treat L. C. and E. W. in community-based care would be unreason-

able given the demands of the State's mental health budget." 138 F. 3d, at 905.[7]

We granted certiorari in view of the importance of the question presented to the States and affected individuals. See 525 U. S. 1054 (1998).[8]

III

Endeavoring to carry out Congress' instruction to issue regulations implementing Title II, the Attorney General, in the integration and reasonable-modifications regulations, see *supra*, at 591–592, made two key determinations. The first concerned the scope of the ADA's discrimination proscription, 42 U. S. C. § 12132; the second concerned the obligation of the States to counter discrimination. As to the first, the Attorney General concluded that unjustified placement or retention of persons in institutions, severely limiting their exposure to the outside community, constitutes a form of discrimination based on disability prohibited by Title II. See 28 CFR § 35.130(d) (1998) ("A public entity shall administer services . . . in the most integrated setting appropriate to the needs of qualified individuals with disabilities."); Brief for United States as *Amicus Curiae* in *Helen L.* v. *DiDario*, No. 94–1243 (CA3 1994), pp. 8, 15–16 (unnecessary segregation of persons with disabilities constitutes a form of discrimination prohibited by the ADA and the integration

[7] After this Court granted certiorari, the District Court issued a decision on remand rejecting the State's fundamental-alteration defense. See 1:95–cv–1210–MHS (ND Ga., Jan. 29, 1999), p. 1. The court concluded that the annual cost to the State of providing community-based treatment to L. C. and E. W. was not unreasonable in relation to the State's overall mental health budget. See *id.*, at 5. In reaching that judgment, the District Court first declared "irrelevant" the potential impact of its decision beyond L. C. and E. W. 1:95–cv–1210-MHS (ND Ga., Oct. 20, 1998), p. 3, App. 177. The District Court's decision on remand is now pending appeal before the Eleventh Circuit.

[8] Twenty-two States and the Territory of Guam joined a brief urging that certiorari be granted. Ten of those States joined a brief in support of petitioners on the merits.

regulation). Regarding the States' obligation to avoid unjustified isolation of individuals with disabilities, the Attorney General provided that States could resist modifications that "would fundamentally alter the nature of the service, program, or activity." 28 CFR § 35.130(b)(7) (1998).

The Court of Appeals essentially upheld the Attorney General's construction of the ADA. As just recounted, see *supra,* at 595–596, the appeals court ruled that the unjustified institutionalization of persons with mental disabilities violated Title II; the court then remanded with instructions to measure the cost of caring for L. C. and E. W. in a community-based facility against the State's mental health budget.

We affirm the Court of Appeals' decision in substantial part. Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand. Accordingly, we further hold that the Court of Appeals' remand instruction was unduly restrictive. In evaluating a State's fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably.

A

We examine first whether, as the Eleventh Circuit held, undue institutionalization qualifies as discrimination "by reason of . . . disability." The Department of Justice has consistently advocated that it does.[9] Because the Department

[9] See Brief for United States in *Halderman* v. *Pennhurst State School and Hospital,* Nos. 78–1490, 78–1564, 78–1602 (CA3 1978), p. 45 ("[I]nstitutionalization result[ing] in separation of mentally retarded persons for no

is the agency directed by Congress to issue regulations implementing Title II, see *supra*, at 591–592, its views warrant respect. We need not inquire whether the degree of deference described in *Chevron U. S. A. Inc.* v. *Natural Resources Defense Council, Inc.*, 467 U. S. 837, 844 (1984), is in order; "[i]t is enough to observe that the well-reasoned views of the agencies implementing a statute 'constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance.'" *Bragdon* v. *Abbott*, 524 U. S. 624, 642 (1998) (quoting *Skidmore* v. *Swift & Co.*, 323 U. S. 134, 139–140 (1944)).

The State argues that L. C. and E. W. encountered no discrimination "by reason of" their disabilities because they were not denied community placement on account of those disabilities. See Brief for Petitioners 20. Nor were they subjected to "discrimination," the State contends, because "'discrimination' necessarily requires uneven treatment of similarly situated individuals," and L. C. and E. W. had identified no comparison class, *i. e.*, no similarly situated individuals given preferential treatment. *Id.*, at 21. We are satisfied that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA.[10]

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permissible reason . . . is 'discrimination,' and a violation of Section 504 [of the Rehabilitation Act] if it is supported by federal funds."); Brief for United States in *Halderman* v. *Pennhurst State School and Hospital*, Nos. 78–1490, 78–1564, 78–1602 (CA3 1981), p. 27 ("Pennsylvania violates Section 504 by indiscriminately subjecting handicapped persons to [an institution] without first making an individual reasoned professional judgment as to the appropriate placement for each such person among all available alternatives."); Brief for United States as *Amicus Curiae* in *Helen L.* v. *DiDario*, No. 94–1243 (CA3 1994), p. 7 ("Both the Section 504 coordination regulations and the rest of the ADA make clear that the unnecessary segregation of individuals with disabilities in the provision of public services is itself a form of discrimination within the meaning of those statutes."); *id.*, at 8–16.

[10] The dissent is driven by the notion that "this Court has never endorsed an interpretation of the term 'discrimination' that encompassed disparate treatment among members of the *same* protected class," *post*, at 616 (opinion of THOMAS, J.), that "[o]ur decisions construing various

The ADA stepped up earlier measures to secure opportunities for people with developmental disabilities to enjoy the benefits of community living. The Developmentally Disabled Assistance and Bill of Rights Act, a 1975 measure, stated in aspirational terms that "[t]he treatment, services, and habilitation for a person with developmental disabilities . . . *should be* provided in the setting that is least restrictive of the person's personal liberty." 89 Stat. 502, 42 U. S. C. § 6010(2) (1976 ed.) (emphasis added); see also *Pennhurst State School and Hospital* v. *Halderman*, 451 U. S. 1, 24 (1981) (concluding that the § 6010 provisions "were intended to be hortatory, not mandatory"). In a related legislative endeavor, the Rehabilitation Act of 1973, Congress used mandatory language to proscribe discrimination against persons with disabilities. See 87 Stat. 394, as amended, 29 U. S. C. § 794 (1976 ed.) ("No otherwise qualified individual with a disability in the United States . . . *shall*, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal fi-

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statutory prohibitions against 'discrimination' have not wavered from this path," *post*, at 616, and that "a plaintiff cannot prove 'discrimination' by demonstrating that one member of a particular protected group has been favored over another member of that same group," *post*, at 618. The dissent is incorrect as a matter of precedent and logic. See *O'Connor* v. *Consolidated Coin Caterers Corp.*, 517 U. S. 308, 312 (1996) (The Age Discrimination in Employment Act of 1967 "does not ban discrimination against employees because they are aged 40 or older; it bans discrimination against employees because of their age, but limits the protected class to those who are 40 or older. The fact that one person in the protected class has lost out to another person in the protected class is thus irrelevant, so long as he has lost out *because of his age.*"); cf. *Oncale* v. *Sundowner Offshore Services, Inc.*, 523 U. S. 75, 76 (1998) ("[W]orkplace harassment can violate Title VII's prohibition against 'discriminat[ion] . . . because of . . . sex,' 42 U. S. C. § 2000e–2(a)(1), when the harasser and the harassed employee are of the same sex."); *Jefferies* v. *Harris County Community Action Assn.*, 615 F. 2d 1025, 1032 (CA5 1980) ("[D]iscrimination against black females can exist even in the absence of discrimination against black men or white women.").

nancial assistance." (Emphasis added.)) Ultimately, in the ADA, enacted in 1990, Congress not only required all public entities to refrain from discrimination, see 42 U. S. C. § 12132; additionally, in findings applicable to the entire statute, Congress explicitly identified unjustified "segregation" of persons with disabilities as a "for[m] of discrimination." See § 12101(a)(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"); § 12101(a)(5) ("individuals with disabilities continually encounter various forms of discrimination, including . . . segregation").[11]

Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Cf. *Allen* v. *Wright*, 468 U. S. 737, 755 (1984) ("There can be no doubt that [stigmatizing injury often caused by racial discrimination] is one of the most serious consequences of discriminatory government action."); *Los Angeles Dept. of Water and Power* v. *Manhart*, 435 U. S. 702, 707, n. 13 (1978) ("'In forbidding employers to discriminate against individuals because of their sex, Congress intended to strike at the entire spectrum of disparate treatment of men and women resulting from sex stereotypes.'" (quoting *Sprogis* v. *United Air Lines, Inc.*, 444 F. 2d 1194, 1198 (CA7

[11] Unlike the ADA, § 504 of the Rehabilitation Act contains no express recognition that isolation or segregation of persons with disabilities is a form of discrimination. Section 504's discrimination proscription, a single sentence attached to vocational rehabilitation legislation, has yielded divergent court interpretations. See Brief for United States as *Amicus Curiae* 23–25.

1971)). Second, 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. See Brief for American Psychiatric Association et al. as *Amici Curiae* 20–22. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice. See Brief for United States as *Amicus Curiae* 6–7, 17.

The State urges that, whatever Congress may have stated as its findings in the ADA, the Medicaid statute "reflected a congressional policy preference for treatment in the institution over treatment in the community." Brief for Petitioners 31. The State correctly used the past tense. Since 1981, Medicaid has provided funding for state-run home and community-based care through a waiver program. See 95 Stat. 812–813, as amended, 42 U. S. C. § 1396n(c); Brief for United States as *Amicus Curiae* 20–21.[12] Indeed, the United States points out that the Department of Health and Human Services (HHS) "has a policy of encouraging States to take advantage of the waiver program, and often approves more waiver slots than a State ultimately uses." *Id.*, at 25–26 (further observing that, by 1996, "HHS approved up to 2109 waiver slots for Georgia, but Georgia used only 700").

We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community

[12] The waiver program provides Medicaid reimbursement to States for the provision of community-based services to individuals who would otherwise require institutional care, upon a showing that the average annual cost of such services is not more than the annual cost of institutional services. See § 1396n(c).

settings. Title II provides only that "qualified individual[s] with a disability" may not "be subjected to discrimination." 42 U. S. C. § 12132. "Qualified individuals," the ADA further explains, are persons with disabilities who, "with or without reasonable modifications to rules, policies, or practices, . . . mee[t] the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity." § 12131(2).

Consistent with these provisions, the State generally may rely on the reasonable assessments of its own professionals in determining whether an individual "meets the essential eligibility requirements" for habilitation in a community-based program. Absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting. See 28 CFR § 35.130(d) (1998) (public entity shall administer services and programs in "the most integrated setting *appropriate* to the needs of qualified individuals with disabilities" (emphasis added)); cf. *School Bd. of Nassau Cty.* v. *Arline*, 480 U. S. 273, 288 (1987) ("[C]ourts normally should defer to the reasonable medical judgments of public health officials.").[13] Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. See 28 CFR § 35.130(e)(1) (1998) ("Nothing in this part shall be construed to require an individual with a disability to accept an accommodation . . . which such individual chooses not to accept."); 28 CFR pt. 35, App. A, p. 450 (1998) ("[P]ersons with disabilities must be provided the option of declining to accept a particular accommodation."). In this case, however, there is no genuine dispute concerning the status of L. C. and E. W. as individuals "quali-

[13] Georgia law also expresses a preference for treatment in the most integrated setting appropriate. See Ga. Code Ann. § 37–4–121 (1995) ("It is the policy of the state that the least restrictive alternative placement be secured for every client at every stage of his habilitation. It shall be the duty of the facility to assist the client in securing placement in noninstitutional community facilities and programs.").

fied" for noninstitutional care: The State's own professionals determined that community-based treatment would be appropriate for L. C. and E. W., and neither woman opposed such treatment. See *supra*, at 593.[14]

B

The State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless. The reasonable-modifications regulation speaks of "reasonable modifications" to avoid discrimination, and allows States to resist modifications that entail a "fundamenta[l] alter[ation]" of the States' services and programs. 28 CFR § 35.130(b)(7) (1998). The Court of Appeals construed this regulation to permit a cost-based defense "only in the most limited of circumstances," 138 F. 3d, at 902, and remanded to the District Court to consider, among other things, "whether the additional expenditures necessary to treat L. C. and E. W. in community-based care would be unreasonable given the demands of the State's mental health budget," *id.*, at 905.

The Court of Appeals' construction of the reasonable-modifications regulation is unacceptable for it would leave the State virtually defenseless once it is shown that the plaintiff is qualified for the service or program she seeks. If the expense entailed in placing one or two people in a community-based treatment program is properly measured for reasonableness against the State's entire mental health budget, it is unlikely that a State, relying on the fundamental-alteration defense, could ever prevail. See Tr. of Oral Arg. 27 (State's attorney argues that Court of Appeals' understanding of the

[14] We do not in this opinion hold that the ADA imposes on the States a "standard of care" for whatever medical services they render, or that the ADA requires States to "provide a certain level of benefits to individuals with disabilities." Cf. *post*, at 623, 624 (THOMAS, J., dissenting). We do hold, however, that States must adhere to the ADA's nondiscrimination requirement with regard to the services they in fact provide.

fundamental-alteration defense, as expressed in its order to the District Court, "will always preclude the State from a meaningful defense"); cf. Brief for Petitioners 37–38 (Court of Appeals' remand order "mistakenly asks the district court to examine [the fundamental-alteration] defense based on the cost of providing community care to just two individuals, not all Georgia citizens who desire community care"); 1:95–cv–1210–MHS (ND Ga., Oct. 20, 1998), p. 3, App. 177 (District Court, on remand, declares the impact of its decision beyond L. C. and E. W. "irrelevant"). Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.

When it granted summary judgment for plaintiffs in this case, the District Court compared the cost of caring for the plaintiffs in a community-based setting with the cost of caring for them in an institution. That simple comparison showed that community placements cost less than institutional confinements. See App. to Pet. for Cert. 39a. As the United States recognizes, however, a comparison so simple overlooks costs the State cannot avoid; most notably, a "State . . . may experience increased overall expenses by funding community placements without being able to take advantage of the savings associated with the closure of institutions." Brief for United States as *Amicus Curiae* 21.[15]

As already observed, see *supra*, at 601–602, the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. Cf. *post*, at

[15] Even if States eventually were able to close some institutions in response to an increase in the number of community placements, the States would still incur the cost of running partially full institutions in the interim. See Brief for United States as *Amicus Curiae* 21.

610 (KENNEDY, J., concurring in judgment). Nor is it the ADA's mission to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter, a placement the State proposed, then retracted, for E. W. See *supra*, at 593. Some individuals, like L. C. and E. W. in prior years, may need institutional care from time to time "to stabilize acute psychiatric symptoms." App. 98 (affidavit of Dr. Richard L. Elliott); see 138 F. 3d, at 903 ("[T]here may be times [when] a patient can be treated in the community, and others whe[n] an institutional placement is necessary."); Reply Brief 19 (placement in a community-based treatment program does not mean the State will no longer need to retain hospital accommodations for the person so placed). For other individuals, no placement outside the institution may ever be appropriate. See Brief for American Psychiatric Association et al. as *Amici Curiae* 22–23 ("Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times—perhaps in the short run, perhaps in the long run—for the risks and exposure of the less protective environment of community settings"; for these persons, "institutional settings are needed and must remain available."); Brief for Voice of the Retarded et al. as *Amici Curiae* 11 ("Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution."); *Youngberg* v. *Romeo*, 457 U. S. 307, 327 (1982) (Blackmun, J., concurring) ("For many mentally retarded people, the difference between the capacity to do things for themselves within an institution and total dependence on the institution for all of their needs is as much liberty as they ever will know.").

To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate that 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, the reasonable-modifications standard would be met. See Tr. of Oral Arg. 5 (State's attorney urges that, "by asking [a] person to wait a short time until a community bed is available, Georgia does not exclude [that] person by reason of disability, neither does Georgia discriminate against her by reason of disability"); see also *id.*, at 25 ("[I]t is reasonable for the State to ask someone to wait until a community placement is available."). In such circumstances, a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions.[16]

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[16] We reject the Court of Appeals' construction of the reasonable-modifications regulation for another reason. The Attorney General's Title II regulations, Congress ordered, "shall be consistent with" the regulations in part 41 of Title 28 of the Code of Federal Regulations implementing § 504 of the Rehabilitation Act. 42 U. S. C. § 12134(b). The § 504 regulation upon which the reasonable-modifications regulation is based provides now, as it did at the time the ADA was enacted:

"A recipient shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program." 28 CFR § 41.53 (1990 and 1998 eds.).

While the part 41 regulations do not define "undue hardship," other § 504 regulations make clear that the "undue hardship" inquiry requires not simply an assessment of the cost of the accommodation in relation to the recipient's overall budget, but a "case-by-case analysis weighing factors that include: (1) [t]he overall size of the recipient's program with respect to number of employees, number and type of facilities, and size of budget; (2) [t]he type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) [t]he nature and cost of the accommodation needed." 28 CFR § 42.511(c) (1998); see 45 CFR § 84.12(c) (1998) (same).

Under the Court of Appeals' restrictive reading, the reasonable-modifications regulation would impose a standard substantially more

* * *

For the reasons stated, we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. The judgment of the Eleventh Circuit is therefore affirmed in part and vacated in part, and the case is remanded for further proceedings.

It is so ordered.

JUSTICE STEVENS, concurring in part and concurring in the judgment.

Unjustified disparate treatment, in this case, "unjustified institutional isolation," constitutes discrimination under the Americans with Disabilities Act of 1990. See *ante*, at 600. If a plaintiff requests relief that requires modification of a State's services or programs, the State may assert, as an affirmative defense, that the requested modification would cause a fundamental alteration of a State's services and programs. In this case, the Court of Appeals appropriately remanded for consideration of the State's affirmative defense. On remand, the District Court rejected the State's "fundamental-alteration defense." See *ante*, at 596, n. 7. If the District Court was wrong in concluding that costs unrelated to the treatment of L. C. and E. W. do not support such a defense in this case, that arguable error should be corrected either by the Court of Appeals or by this Court in review of that decision. In my opinion, therefore, we should simply affirm the judgment of the Court of Appeals.

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difficult for the State to meet than the "undue burden" standard imposed by the corresponding § 504 regulation.

But because there are not five votes for that disposition, I join the Court's judgment and Parts I, II, and III–A of its opinion. Cf. *Bragdon* v. *Abbott*, 524 U. S. 624, 655–656 (1998) (STEVENS, J., concurring); *Screws* v. *United States*, 325 U. S. 91, 134 (1945) (Rutledge, J., concurring in result).

JUSTICE KENNEDY, with whom JUSTICE BREYER joins as to Part I, concurring in the judgment.

I

Despite remarkable advances and achievements by medical science, and agreement among many professionals that even severe mental illness is often treatable, the extent of public resources to devote to this cause remains controversial. Knowledgeable professionals tell us that our society, and the governments which reflect its attitudes and preferences, have yet to grasp the potential for treating mental disorders, especially severe mental illness. As a result, necessary resources for the endeavor often are not forthcoming. During the course of a year, about 5.6 million Americans will suffer from severe mental illness. E. Torrey, Out of the Shadows 4 (1997). Some 2.2 million of these persons receive no treatment. *Id.*, at 6. Millions of other Americans suffer from mental disabilities of less serious degree, such as mild depression. These facts are part of the background against which this case arises. In addition, of course, persons with mental disabilities have been subject to historic mistreatment, indifference, and hostility. See, *e. g.*, *Cleburne* v. *Cleburne Living Center, Inc.*, 473 U. S. 432, 461–464 (1985) (Marshall, J., concurring in judgment in part and dissenting in part) (discussing treatment of the mentally retarded).

Despite these obstacles, the States have acknowledged that the care of the mentally disabled is their special obligation. They operate and support facilities and programs, sometimes elaborate ones, to provide care. It is a continu-

ing challenge, though, to provide the care in an effective and humane way, particularly because societal attitudes and the responses of public authorities have changed from time to time.

Beginning in the 1950's, many victims of severe mental illness were moved out of state-run hospitals, often with benign objectives. According to one estimate, when adjusted for population growth, "the actual decrease in the numbers of people with severe mental illnesses in public psychiatric hospitals between 1955 and 1994 was 92 percent." Brief for American Psychiatric Association et al. as *Amici Curiae* 21, n. 5 (citing Torrey, *supra,* at 8–9). This was not without benefit or justification. The so-called "deinstitutionalization" has permitted a substantial number of mentally disabled persons to receive needed treatment with greater freedom and dignity. It may be, moreover, that those who remain institutionalized are indeed the most severe cases. With reference to this case, as the Court points out, *ante,* at 593, 603, it is undisputed that the State's own treating professionals determined that community-based care was medically appropriate for respondents. Nevertheless, the depopulation of state mental hospitals has its dark side. According to one expert:

> "For a substantial minority . . . deinstitutionalization has been a psychiatric *Titanic.* Their lives are virtually devoid of 'dignity' or 'integrity of body, mind, and spirit.' 'Self-determination' often means merely that the person has a choice of soup kitchens. The 'least restrictive setting' frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies." Torrey, *supra,* at 11.

It must be remembered that for the person with severe mental illness who has no treatment the most dreaded of confinements can be the imprisonment inflicted by his own mind,

which shuts reality out and subjects him to the torment of voices and images beyond our own powers to describe.

It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision. The opinion of a responsible treating physician in determining the appropriate conditions for treatment ought to be given the greatest of deference. It is a common phenomenon that a patient functions well with medication, yet, because of the mental illness itself, lacks the discipline or capacity to follow the regime the medication requires. This is illustrative of the factors a responsible physician will consider in recommending the appropriate setting or facility for treatment. JUSTICE GINSBURG's opinion takes account of this background. It is careful, and quite correct, to say that it is not "the ADA's mission to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter . . . ." *Ante*, at 605.

In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition. This danger is in addition to the federalism costs inherent in referring state decisions regarding the administration of treatment programs and the allocation of resources to the reviewing authority of the federal courts. It is of central importance, then, that courts apply today's decision with great deference to the medical decisions of the responsible, treating physicians and, as the Court makes clear, with appropriate deference to the program funding decisions of state policymakers.

II

With these reservations made explicit, in my view we must remand the case for a determination of the questions the Court poses and for a determination whether respondents can show a violation of 42 U. S. C. § 12132's ban on discrimination based on the summary judgment materials on file or any further pleadings and materials properly allowed.

At the outset it should be noted there is no allegation that Georgia officials acted on the basis of animus or unfair stereotypes regarding the disabled. Underlying much discrimination law is the notion that animus can lead to false and unjustified stereotypes, and vice versa. Of course, the line between animus and stereotype is often indistinct, and it is not always necessary to distinguish between them. Section 12132 can be understood to deem as irrational, and so to prohibit, distinctions by which a class of disabled persons, or some within that class, are, by reason of their disability and without adequate justification, exposed by a state entity to more onerous treatment than a comparison group in the provision of services or the administration of existing programs, or indeed entirely excluded from state programs or facilities. Discrimination under this statute might in principle be shown in the case before us, though further proceedings should be required.

Putting aside issues of animus or unfair stereotype, I agree with JUSTICE THOMAS that on the ordinary interpretation and meaning of the term, one who alleges discrimination must show that she "received differential treatment vis-à-vis members of a different group on the basis of a statutorily described characteristic." *Post*, at 616 (dissenting opinion). In my view, however, discrimination so defined might be shown here. Although the Court seems to reject JUSTICE THOMAS' definition of discrimination, *ante*, at 598, it asserts that unnecessary institutional care does lead to "[d]issimilar treatment," *ante*, at 601. According to the Court, "[i]n order to receive needed medical services, persons with mental dis-

abilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice." *Ibid.*

Although this point is not discussed at length by the Court, it does serve to suggest the theory under which respondents might be subject to discrimination in violation of § 12132. If they could show that persons needing psychiatric or other medical services to treat a mental disability are subject to a more onerous condition than are persons eligible for other existing state medical services, and if removal of the condition would not be a fundamental alteration of a program or require the creation of a new one, then the beginnings of a discrimination case would be established. In terms more specific to this case, if respondents could show that Georgia (i) provides treatment to individuals suffering from medical problems of comparable seriousness, (ii) as a general matter, does so in the most integrated setting appropriate for the treatment of those problems (taking medical and other practical considerations into account), but (iii) without adequate justification, fails to do so for a group of mentally disabled persons (treating them instead in separate, locked institutional facilities), I believe it would demonstrate discrimination on the basis of mental disability.

Of course, it is a quite different matter to say that a State without a program in place is required to create one. No State has unlimited resources, and each must make hard decisions on how much to allocate to treatment of diseases and disabilities. If, for example, funds for care and treatment of the mentally ill, including the severely mentally ill, are reduced in order to support programs directed to the treatment and care of other disabilities, the decision may be unfortunate. The judgment, however, is a political one and not within the reach of the statute. Grave constitutional concerns are raised when a federal court is given the author-

ity to review the State's choices in basic matters such as establishing or declining to establish new programs. It is not reasonable to read the ADA to permit court intervention in these decisions. In addition, as the Court notes, *ante*, at 592, by regulation a public entity is required only to make "reasonable modifications in policies, practices, or procedures" when necessary to avoid discrimination and is not even required to make those if "the modifications would fundamentally alter the nature of the service, program, or activity." 28 CFR § 35.130(b)(7) (1998). It follows that a State may not be forced to create a community-treatment program where none exists. See Brief for United States as *Amicus Curiae* 19–20, and n. 3. Whether a different statutory scheme would exceed constitutional limits need not be addressed.

Discrimination, of course, tends to be an expansive concept and, as legal category, it must be applied with care and prudence. On any reasonable reading of the statute, § 12132 cannot cover all types of differential treatment of disabled and nondisabled persons, no matter how minimal or innocuous. To establish discrimination in the context of this case, and absent a showing of policies motivated by improper animus or stereotypes, it would be necessary to show that a comparable or similarly situated group received differential treatment. Regulations are an important tool in identifying the kinds of contexts, policies, and practices that raise concerns under the ADA. The congressional findings in 42 U. S. C. § 12101 also serve as a useful aid for courts to discern the sorts of discrimination with which Congress was concerned. Indeed, those findings have clear bearing on the issues raised in this case, and support the conclusion that unnecessary institutionalization may be the evidence or the result of the discrimination the ADA prohibits.

Unlike JUSTICE THOMAS, I deem it relevant and instructive that Congress in express terms identified the "isolat[ion] and segregat[ion]" of disabled persons by society as a "for[m]

of discrimination," §§ 12101(a)(2), (5), and noted that discrimination against the disabled "persists in such critical areas as . . . institutionalization," § 12101(a)(3). These findings do not show that segregation and institutionalization are always discriminatory or that segregation or institutionalization are, by their nature, forms of prohibited discrimination. Nor do they necessitate a regime in which individual treatment plans are required, as distinguished from broad and reasonable classifications for the provision of health care services. Instead, they underscore Congress' concern that discrimination has been a frequent and pervasive problem in institutional settings and policies and its concern that segregating disabled persons from others can be discriminatory. Both of those concerns are consistent with the normal definition of discrimination—differential treatment of similarly situated groups. The findings inform application of that definition in specific cases, but absent guidance to the contrary, there is no reason to think they displace it. The issue whether respondents have been discriminated against under § 12132 by institutionalized treatment cannot be decided in the abstract, divorced from the facts surrounding treatment programs in their State.

The possibility therefore remains that, on the facts of this case, respondents would be able to support a claim under § 12132 by showing that they have been subject to discrimination by Georgia officials on the basis of their disability. This inquiry would not be simple. Comparisons of different medical conditions and the corresponding treatment regimens might be difficult, as would be assessments of the degree of integration of various settings in which medical treatment is offered. For example, the evidence might show that, apart from services for the mentally disabled, medical treatment is rarely offered in a community setting but also is rarely offered in facilities comparable to state mental hospitals. Determining the relevance of that type of evidence would require considerable judgment and anal-

ysis. However, as petitioners observe, "[i]n this case, no class of similarly situated individuals was even identified, let alone shown to be given preferential treatment." Brief for Petitioners 21. Without additional information regarding the details of state-provided medical services in Georgia, we cannot address the issue in the way the statute demands. As a consequence, the judgment of the courts below, granting partial summary judgment to respondents, ought not to be sustained. In addition, as JUSTICE GINSBURG's opinion is careful to note, *ante,* at 604, it was error in the earlier proceedings to restrict the relevance and force of the State's evidence regarding the comparative costs of treatment. The State is entitled to wide discretion in adopting its own systems of cost analysis, and, if it chooses, to allocate health care resources based on fixed and overhead costs for whole institutions and programs. We must be cautious when we seek to infer specific rules limiting States' choices when Congress has used only general language in the controlling statute.

I would remand the case to the Court of Appeals or the District Court for it to determine in the first instance whether a statutory violation is sufficiently alleged and supported in respondents' summary judgment materials and, if not, whether they should be given leave to replead and to introduce evidence and argument along the lines suggested above.

For these reasons, I concur in the judgment of the Court.

JUSTICE THOMAS, with whom THE CHIEF JUSTICE and JUSTICE SCALIA join, dissenting.

Title II of the Americans with Disabilities Act of 1990 (ADA), 104 Stat. 337, as set forth in 42 U. S. C. § 12132, provides:

> "Subject to the provisions of this subchapter, no qualified individual with a disability shall, *by reason of such disability,* be excluded from participation in or be denied the benefits of the services, programs, or activities

> of a public entity, *or be subjected to discrimination* by any such entity." (Emphasis added.)

The majority concludes that petitioners "discriminated" against respondents—as a matter of law—by continuing to treat them in an institutional setting after they became eligible for community placement. I disagree. Temporary exclusion from community placement does not amount to "discrimination" in the traditional sense of the word, nor have respondents shown that petitioners "discriminated" against them "by reason of" their disabilities.

Until today, this Court has never endorsed an interpretation of the term "discrimination" that encompassed disparate treatment among members of the *same* protected class. Discrimination, as typically understood, requires a showing that a claimant received differential treatment vis-à-vis members of a different group on the basis of a statutorily described characteristic. This interpretation comports with dictionary definitions of the term discrimination, which means to "distinguish," to "differentiate," or to make a "distinction in favor of or against, a person or thing based on the group, class, or category to which that person or thing belongs rather than on individual merit." Random House Dictionary 564 (2d ed. 1987); see also Webster's Third New International Dictionary 648 (1981) (defining "discrimination" as "the making or perceiving of a distinction or difference" or as "the act, practice, or an instance of discriminating categorically rather than individually").

Our decisions construing various statutory prohibitions against "discrimination" have not wavered from this path. The best place to begin is with Title VII of the Civil Rights Act of 1964, 78 Stat. 253, as amended, the paradigmatic antidiscrimination law.[1] Title VII makes it "an unlawful em-

[1] We have incorporated Title VII standards of discrimination when interpreting statutes prohibiting other forms of discrimination. For example, Rev. Stat. § 1977, as amended, 42 U. S. C. § 1981, has been interpreted to forbid all racial discrimination in the making of private and

ployment practice for an employer . . . to *discriminate* against any individual with respect to his compensation, terms, conditions, or privileges of employment, because of such individual's race, color, religion, sex, or national origin." 42 U. S. C. § 2000e–2(a)(1) (emphasis added). We have explained that this language is designed "to achieve equality of employment opportunities and remove barriers that have operated in the past to favor an identifiable group of white employees over other employees." *Griggs* v. *Duke Power Co.*, 401 U. S. 424, 429–430 (1971).[2]

Under Title VII, a finding of discrimination requires a comparison of otherwise similarly situated persons who are in different groups by reason of certain characteristics provided by statute. See, *e. g.*, *Newport News Shipbuilding & Dry Dock Co.* v. *EEOC*, 462 U. S. 669, 683 (1983) (explain-

public contracts. See *Saint Francis College* v. *Al-Khazraji*, 481 U. S. 604, 609 (1987). This Court has applied the "framework" developed in Title VII cases to claims brought under this statute. *Patterson* v. *McLean Credit Union*, 491 U. S. 164, 186 (1989). Also, the Age Discrimination in Employment Act of 1967, 81 Stat. 602, as amended, 29 U. S. C. § 623(a)(1), prohibits discrimination on the basis of an employee's age. This Court has noted that its "interpretation of Title VII . . . applies with equal force in the context of age discrimination, for the substantive provisions of the ADEA 'were derived *in haec verba* from Title VII.'" *Trans World Airlines, Inc.* v. *Thurston*, 469 U. S. 111, 121 (1985) (quoting *Lorillard* v. *Pons*, 434 U. S. 575, 584 (1978)). This Court has also looked to its Title VII interpretations of discrimination in illuminating Title IX of the Education Amendments of 1972, 86 Stat. 373, as amended, 20 U. S. C. § 1681 *et seq.*, which prohibits discrimination under any federally funded education program or activity. See *Franklin* v. *Gwinnett County Public Schools*, 503 U. S. 60, 75 (1992) (relying on *Meritor Savings Bank, FSB* v. *Vinson*, 477 U. S. 57 (1986), a Title VII case, in determining that sexual harassment constitutes discrimination).

[2] This Court has recognized that two forms of discrimination are prohibited under Title VII: disparate treatment and disparate impact. See *Griggs*, 401 U. S., at 431 ("The Act proscribes not only overt discrimination but also practices that are fair in form, but discriminatory in operation"). Both forms of "discrimination" require a comparison among classes of employees.

ing that Title VII discrimination occurs when an employee is treated "'in a manner which but for that person's sex would be different'") (quoting *Los Angeles Dept. of Water and Power* v. *Manhart*, 435 U. S. 702, 711 (1978)). For this reason, we have described as "nonsensical" the comparison of the racial composition of different classes of job categories in determining whether there existed disparate impact discrimination with respect to a particular job category. *Wards Cove Packing Co.* v. *Atonio*, 490 U. S. 642, 651 (1989).[3] Courts interpreting Title VII have held that a plaintiff cannot prove "discrimination" by demonstrating that one member of a particular protected group has been favored over another member of that same group. See, *e. g.*, *Bush* v. *Commonwealth Edison Co.*, 990 F. 2d 928, 931 (CA7 1993), cert. denied, 511 U. S. 1071 (1994) (explaining that under Title VII, a fired black employee "had to show that although he was not a good employee, equally bad employees were treated more leniently by [his employer] if they happened not to be black").

Our cases interpreting § 504 of the Rehabilitation Act of 1973, 87 Stat. 394, as amended, which prohibits "discrimination" against certain individuals with disabilities, have applied this commonly understood meaning of discrimination. Section 504 provides:

> "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be sub-

[3] Following *Wards Cove*, Congress enacted the Civil Rights Act of 1991, Pub. L. 102–166, 105 Stat. 1071, as amended, which, *inter alia*, altered the burden of proof with respect to a disparate impact discrimination claim. See *id.*, § 105 (codified at 42 U. S. C. § 2000e–2(k)). This change highlights the principle that a departure from the traditional understanding of discrimination requires congressional action. Cf. *Field* v. *Mans*, 516 U. S. 59, 69–70 (1995) (Congress legislates against the background rule of the common law and traditional notions of lawful conduct).

jected to discrimination under any program or activity receiving Federal financial assistance."

In keeping with the traditional paradigm, we have always limited the application of the term "discrimination" in the Rehabilitation Act to a person who is a member of a protected group and faces discrimination "by reason of his handicap." Indeed, we previously rejected the argument that § 504 requires the type of "affirmative efforts to overcome the disabilities caused by handicaps," *Southeastern Community College* v. *Davis*, 442 U. S. 397, 410 (1979), that the majority appears to endorse today. Instead, we found that § 504 required merely "the evenhanded treatment of handicapped persons" relative to those persons who do not have disabilities. *Ibid.* Our conclusion was informed by the fact that some provisions of the Rehabilitation Act envision "affirmative action" on behalf of those individuals with disabilities, but § 504 itself "does not refer at all" to such action. *Ibid.* Therefore, "[a] comparison of these provisions demonstrates that Congress understood accommodation of the needs of handicapped individuals may require affirmative action and knew how to provide for it in those instances where it wished to do so." *Id.*, at 411.

Similarly, in *Alexander* v. *Choate*, 469 U. S. 287, 302 (1985), we found no discrimination under § 504 with respect to a limit on inpatient hospital care that was "neutral on its face" and did not "distinguish between those whose coverage will be reduced and those whose coverage will not on the basis of any test, judgment, or trait that the handicapped as a class are less capable of meeting or less likely of having," *id.*, at 302. We said that § 504 does "not . . . guarantee the handicapped equal results from the provision of state Medicaid, even assuming some measure of equality of health could be constructed." *Id.*, at 304.

Likewise, in *Traynor* v. *Turnage*, 485 U. S. 535, 548 (1988), we reiterated that the purpose of § 504 is to guarantee that individuals with disabilities receive "evenhanded treatment"

relative to those persons without disabilities. In *Traynor*, the Court upheld a Veterans' Administration regulation that excluded "primary alcoholics" from a benefit that was extended to persons disabled by alcoholism related to a mental disorder. *Id.*, at 551. In so doing, the Court noted that "[t]his litigation does not involve a program or activity that is alleged to treat handicapped persons less favorably than nonhandicapped persons." *Id.*, at 548. Given the theory of the case, the Court explicitly held: "There is nothing in the Rehabilitation Act that requires that any benefit extended to one category of handicapped persons also be extended to all other categories of handicapped persons." *Id.*, at 549.

This same understanding of discrimination also informs this Court's constitutional interpretation of the term. See *General Motors Corp.* v. *Tracy*, 519 U. S. 278, 298 (1997) (noting with respect to interpreting the Commerce Clause, "[c]onceptually, of course, any notion of discrimination assumes a comparison of substantially similar entities"); *Yick Wo* v. *Hopkins*, 118 U. S. 356, 374 (1886) (condemning under the Fourteenth Amendment "illegal discriminations between persons in similar circumstances"); see also *Adarand Constructors, Inc.* v. *Peña*, 515 U. S. 200, 223–224 (1995); *Richmond* v. *J. A. Croson Co.*, 488 U. S. 469, 493–494 (1989) (plurality opinion).

Despite this traditional understanding, the majority derives a more "comprehensive" definition of "discrimination," as that term is used in Title II of the ADA, one that includes "institutional isolation of persons with disabilities." *Ante*, at 600. It chiefly relies on certain congressional findings contained within the ADA. To be sure, those findings appear to equate institutional isolation with segregation, and thereby discrimination. See *ibid.* (quoting §§ 12101(a)(2) and 12101(a)(5), both of which explicitly identify "segregation" of persons with disabilities as a form of "discrimination"); see also *ante*, at 588–589. The congressional findings, however, are written in general, hortatory terms and pro-

vide little guidance to the interpretation of the specific language of § 12132. See *National Organization for Women, Inc.* v. *Scheidler*, 510 U. S. 249, 260 (1994) ("We also think that the quoted statement of congressional findings is a rather thin reed upon which to base a requirement"). In my view, the vague congressional findings upon which the majority relies simply do not suffice to show that Congress sought to overturn a well-established understanding of a statutory term (here, "discrimination").[4] Moreover, the majority fails to explain why terms in the findings should be given a medical content, pertaining to the place where a mentally retarded person is treated. When read in context, the findings instead suggest that terms such as "segregation" were used in a more general sense, pertaining to matters such as access to employment, facilities, and transportation. Absent a clear directive to the contrary, we must read "discrimination" in light of the common understanding of the term. We cannot expand the meaning of the term "discrimination" in order to invalidate policies we may find unfortunate. Cf. *NLRB* v. *Highland Park Mfg. Co.*, 341 U. S. 322, 325 (1951) (explaining that if Congress intended statutory terms "to have other than their ordinarily accepted meaning,

[4] If such general hortatory language is sufficient, it is puzzling that this or any other court did not reach the same conclusion long ago by reference to the general purpose language of the Rehabilitation Act itself. See 29 U. S. C. § 701 (1988 ed.) (describing the statute's purpose as "to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living, for individuals with handicaps *in order to maximize their employability, independence, and integration* into the workplace and the community" (emphasis added)). Further, this section has since been amended to proclaim in even more aspirational terms that the policy under the statute is driven by, *inter alia*, "respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities," "respect for the privacy, rights, and equal access," and "inclusion, integration, and full participation of the individuals." 29 U. S. C. §§ 701(c)(1)–(3).

it would and should have given them a special meaning by definition").[5]

Elsewhere in the ADA, Congress chose to alter the traditional definition of discrimination. Title I of the ADA, § 12112(b)(1), defines discrimination to include "limiting, segregating, or classifying a job applicant or employee in a way that adversely affects the opportunities or status of such applicant or employee." Notably, however, Congress did not provide that this definition of discrimination, unlike other aspects of the ADA, applies to Title II. Ordinary canons of construction require that we respect the limited applicability of this definition of "discrimination" and not import it into other parts of the law where Congress did not see fit. See, *e. g.*, *Bates* v. *United States*, 522 U. S. 23, 29–30 (1997) ("'Where Congress includes particular language in one section of a statute but omits it in another section of the same Act, it is generally presumed that Congress acts intentionally and purposely in the disparate inclusion or exclusion'") (quoting *Russello* v. *United States*, 464 U. S. 16, 23 (1983)). The majority's definition of discrimination—although not specifically delineated—substantially imports the definition of Title I into Title II by necessarily assuming that it is sufficient to focus exclusively on members of one particular

[5] Given my conclusion, the Court need not review the integration regulation promulgated by the Attorney General. See 28 CFR § 35.130(d) (1998). Deference to a regulation is appropriate only "'if Congress has not expressed its intent with respect to the question, and then only if the administrative interpretation is reasonable.'" *Reno* v. *Bossier Parish School Bd.*, 520 U. S. 471, 483 (1997) (quoting *Presley* v. *Etowah County Comm'n*, 502 U. S. 491, 508 (1992)). Here, Congress has expressed its intent in § 12132, and the Attorney General's regulation—insofar as it contradicts the settled meaning of the statutory term—cannot prevail against it. See *NLRB* v. *Town & Country Elec., Inc.*, 516 U. S. 85, 94 (1995) (explaining that courts interpreting a term within a statute "must infer, unless the statute otherwise dictates, that Congress means to incorporate the established meaning of that term" (internal quotation marks omitted)).

group. Under this view, discrimination occurs when some members of a protected group are treated differently from other members of that same group. As the preceding discussion emphasizes, absent a special definition supplied by Congress, this conclusion is a remarkable and novel proposition that finds no support in our decisions in analogous areas. For example, the majority's conclusion that petitioners "discriminated" against respondents is the equivalent to finding discrimination under Title VII where a black employee with deficient management skills is denied in-house training by his employer (allegedly because of lack of funding) because other similarly situated black employees are given the in-house training. Such a claim would fly in the face of our prior case law, which requires more than the assertion that a person belongs to a protected group and did not receive some benefit. See, *e. g., Griggs,* 401 U. S., at 430–431 ("Congress did not intend by Title VII, however, to guarantee a job to every person regardless of qualifications. In short, the Act does not command that any person be hired simply because he was formerly the subject of discrimination, or because he is a member of a minority group").

At bottom, the type of claim approved of by the majority does not concern a prohibition against certain conduct (the traditional understanding of discrimination), but rather concerns imposition of a standard of care.[6] As such, the major-

[6] In mandating that government agencies minimize the institutional isolation of disabled individuals, the majority appears to appropriate the concept of "mainstreaming" from the Individuals with Disabilities Education Act (IDEA), 84 Stat. 175, as amended, 20 U. S. C. § 1400 *et seq.* But IDEA is not an antidiscrimination law. It is a grant program that affirmatively requires States accepting federal funds to provide disabled children with a "free appropriate public education" and to establish "procedures to assure that, to the maximum extent appropriate, children with disabilities . . . are educated with children who are not disabled." §§ 1412(1), (5). Ironically, even under this broad affirmative mandate, we previously rejected a claim that IDEA required the "standard of care"

ity can offer no principle limiting this new species of "discrimination" claim apart from an affirmative defense because it looks merely to an individual in isolation, without comparing him to otherwise similarly situated persons, and determines that discrimination occurs merely because that individual does not receive the treatment he wishes to receive. By adopting such a broad view of discrimination, the majority drains the term of any meaning other than as a proxy for decisions disapproved of by this Court.

Further, I fear that the majority's approach imposes significant federalism costs, directing States how to make decisions about their delivery of public services. We previously have recognized that constitutional principles of federalism erect limits on the Federal Government's ability to direct state officers or to interfere with the functions of state governments. See, *e. g.*, *Printz* v. *United States*, 521 U. S. 898 (1997); *New York* v. *United* States, 505 U. S. 144 (1992). We have suggested that these principles specifically apply to whether States are required to provide a certain level of benefits to individuals with disabilities. As noted in *Alexander*, in rejecting a similar theory under § 504 of the Rehabilitation Act: "[N]othing . . . suggests that Congress desired to make major inroads on the States' longstanding discretion to choose the proper mix of amount, scope, and duration limitations on services . . . ." 469 U. S., at 307. See also *Bowen* v. *American Hospital Assn.*, 476 U. S. 610, 642 (1986) (plurality opinion) ("[N]othing in [§ 504] authorizes [the Secretary of Health and Human Services (HHS)] to commandeer state agencies . . . . [These] agencies are

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analysis adopted by the majority today. See *Board of Ed. of Hendrick Hudson Central School Dist., Westchester Cty.* v. *Rowley*, 458 U. S. 176, 198 (1982) ("We think . . . that the requirement that a State provide specialized educational services to handicapped children generates no additional requirement that the services so provided be sufficient to maximize each child's potential commensurate with the opportunity provided other children" (internal quotation marks omitted)).

not field offices of the HHS bureaucracy, and they may not be conscripted against their will as the foot soldiers in a federal crusade"). The majority's affirmative defense will likely come as cold comfort to the States that will now be forced to defend themselves in federal court every time resources prevent the immediate placement of a qualified individual. In keeping with our traditional deference in this area, see *Alexander, supra,* the appropriate course would be to respect the States' historical role as the dominant authority responsible for providing services to individuals with disabilities.

The majority may remark that it actually does properly compare members of different groups. Indeed, the majority mentions in passing the "[d]issimilar treatment" of persons with and without disabilities. *Ante,* at 601. It does so in the context of supporting its conclusion that institutional isolation is a form of discrimination. It cites two cases as standing for the unremarkable proposition that discrimination leads to deleterious stereotyping, *ante,* at 600 (citing *Allen* v. *Wright,* 468 U. S. 737, 755 (1984); *Manhart,* 435 U. S., at 707, n. 13)), and an *amicus* brief which indicates that confinement diminishes certain everyday life activities, *ante,* at 601 (citing Brief for American Psychiatric Association et al. as *Amici Curiae* 20–22). The majority then observes that persons without disabilities "can receive the services they need without" institutionalization and thereby avoid these twin deleterious effects. *Ante,* at 601. I do not quarrel with the two general propositions, but I fail to see how they assist in resolving the issue before the Court. Further, the majority neither specifies what services persons with disabilities might need nor contends that persons without disabilities need the same services as those with disabilities, leading to the inference that the dissimilar treatment the majority observes results merely from the fact that different classes of persons receive different services—not from "discrimination" as traditionally defined.

Finally, it is also clear petitioners did not "discriminate" against respondents "by reason of [their] disabili[ties]," as § 12132 requires. We have previously interpreted the phrase "by reason of" as requiring proximate causation. See, *e. g.*, *Holmes* v. *Securities Investor Protection Corporation*, 503 U. S. 258, 265–266 (1992); see also *id.*, at 266, n. 11 (citation of cases). Such an interpretation is in keeping with the vernacular understanding of the phrase. See American Heritage Dictionary 1506 (3d ed. 1992) (defining "by reason of" as "because of"). This statute should be read as requiring proximate causation as well. Respondents do not contend that their disabilities constituted the proximate cause for their exclusion. Nor could they—community placement simply is not available to those without disabilities. Continued institutional treatment of persons who, though now deemed treatable in a community placement, must wait their turn for placement does not establish that the denial of community placement occurred "by reason of" their disability. Rather, it establishes no more than the fact that petitioners have limited resources.

* * *

For the foregoing reasons, I respectfully dissent.

Report and Recommendations of the Olmstead Cabinet

A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting

OLMSTEAD
Community Integration for Every New Yorker

Andrew M. Cuomo
Governor

Roger Bearden
Special Counsel for Olmstead

"People with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights."

—Governor Andrew M. Cuomo

REPORT AND RECOMMENDATIONS OF THE OLMSTEAD CABINET

A Comprehensive Plan for Serving People with Disabilities in the Most Integrated Setting

New York State

Andrew M. Cuomo, Governor

October 2013

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Introduction

Under Governor Andrew M. Cuomo, New York is reclaiming its leadership role in serving people with disabilities. In 2011, the Governor directed a landmark redesign of the state's Medicaid program in order to improve care coordination and the delivery of cost-effective, community-based care. The Governor also established the Justice Center for the Protection of People with Special Needs (Justice Center), which provides the strongest protections from abuse and neglect for people with disabilities in the nation.

To further safeguard the rights of people with disabilities, in November 2012, Governor Cuomo issued Executive Order Number 84 to create the Olmstead Development and Implementation Cabinet (Olmstead Cabinet). The Olmstead Cabinet was charged with developing a plan consistent with New York's obligations under the United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) (Olmstead). Olmstead held that the state's services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to a person's needs.

To examine New York's compliance with Olmstead, the Olmstead Cabinet employed a broad and inclusive process. The Olmstead Cabinet received public comment through four public forums and through a dedicated page on the Governor's website. The cabinet met with over 160 stakeholder organizations and received over 100 position papers. Hundreds of state agency personnel across a dozen agencies providing services to people with disabilities participated in multiple discussions and provided data regarding New York's service systems for people with disabilities.

The results of the Olmstead Cabinet's work are contained in this report. This report identifies specific actions state agencies responsible for providing services to people with disabilities will take to serve people with disabilities in the most integrated setting. These actions will:

- Assist in transitioning people with disabilities out of segregated settings and into community settings;
- Change the way New York assesses and measures Olmstead performance;
- Enhance the integration of people in their communities; and
- Assure accountability for serving people in the most integrated setting.

Together, the actions described in this report will ensure that New York is a leader in providing services to people with disabilities in the most integrated setting, consistent with their fundamental civil rights.

Report and Recommendations

I. The Olmstead Mandate

The Olmstead decision addressed the rights of two women who had been confined in a Georgia state psychiatric hospital for five and seven years beyond the time at which they had been determined ready for community discharge. The United States Supreme Court held that the failure to provide community placement for these people constituted discrimination under the Americans with Disabilities Act. The court also held that states are required to provide community-based services to people with disabilities when: (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving disability services from the state.[1]

The Olmstead case itself concerned people in a psychiatric hospital. Subsequent cases have addressed developmental centers, board and care homes, and people at-risk of institutional care. Most recently, the Olmstead mandate has been extended to segregated employment services for people with disabilities. Given the breadth and continuing evolution of the Olmstead mandate, in order to develop its specific recommendations, the Olmstead Cabinet sought the views of a broad set of stakeholders regarding the areas in which the cabinet should focus its attention. Through this stakeholder engagement, four areas of focus emerged:

1. The need for strategies to address specific populations in unnecessarily segregated settings, including:
    a. People with intellectual and developmental disabilities in developmental centers, intermediate care facilities (ICFs), and sheltered workshops;
    b. People with serious mental illness in psychiatric centers, nursing homes, adult homes, and sheltered workshops; and
    c. People in nursing homes.
2. The need to increase opportunities for people with disabilities to live integrated lives in the community;
3. The need to develop consistent cross-systems assessments and outcomes measurements regarding how New York meets the needs and choices of people with disabilities in the most integrated setting;
4. The need for strong Olmstead accountability measures.

The following sections of this report discuss each of these areas of focus in turn.

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

II. Transitioning People with Disabilities from Segregated Settings to the Community

In collaboration with state agencies providing services to people with disabilities and a broad set of stakeholders, the Olmstead Cabinet sought to identify specific strategies to assist people with disabilities residing in segregated settings to transition to community-based settings. The specific settings and strategies are described in the sections that follow.

A. People with Intellectual and Developmental Disabilities in Developmental Centers, Intermediate Care Facilities, and Sheltered Workshops

In April 2013, Governor Cuomo announced a comprehensive transformation plan for serving people with intellectual and developmental disabilities in the most integrated setting.[2] The plan addresses the approximately 1,000 people who resided in developmental centers as of April 2013. The Office for People With Developmental Disabilities (OPWDD) closed its West Seneca Developmental Center in May 2011 and the Staten Island Multiple Disabilities Unit in June 2012, with the individuals residing at these facilities moving to community-based residential services. In addition, OPWDD will close the Monroe and Taconic developmental centers by December 2013, and the 155 people residing at those centers will move to community-based residential settings.

The transformation plan includes the closure of four additional developmental centers in the next four years: Oswald D. Heck (by March 2015); Brooklyn (by December 2015); Broome (by March 2016); and Bernard M. Fineson (by March 2017). It is projected that OPWDD will retain capacity for 150 individuals to receive short-term intensive treatment services in the remaining developmental centers. In addition, over the next few months, OPWDD will finalize its timeline for additional community transition opportunities for other people with intellectual and developmental disabilities residing in community-based ICFs and nursing homes.

OPWDD is also changing the nature of its service system by developing consistent, person-centered intake practices through its Front Door initiative, a comprehensive, person-centered needs assessment process with enhanced, person-centered planning, a fuller menu of community-based supports to better meet a person's needs in community-based settings, and quality oversight that examines individual outcomes as well as systems measures.[3]

Under its transformation plan, OPWDD will also be exploring new options for community-based housing and has begun participating in the New York State Money Follows the Person (MFP) demonstration. Within the MFP demonstration, people with intellectual and developmental disabilities will transition from institutional settings (developmental centers, community-based ICFs, and nursing homes) to community-based independent housing, supported housing, or supervised residences of four or fewer unrelated people, as appropriate. With this range of housing options and smaller residential service settings, OPWDD anticipates that the people transitioning from institutional settings will lead more integrated lives.

OPWDD's participation in the MFP demonstration began in April 2013. Over the next four years, OPWDD will assist 875 people with developmental disabilities who currently reside in institutional settings to move to community-based settings. This demonstration will require OPWDD to identify people who wish to move to the community and to work with those people to develop transition plans and identify community-based service options to meet their needs in community settings,

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[2] New York. Office for People With Developmental Disabilities. (April 2013). *Road to Reform: Putting People First*. Retrieved from http://www.opwdd.ny.gov/opwdd_about/commissioners_page/OPWDD_Road_to_Reform_April2013.

[3] Additional information about OPWDD's Front Door imitative is available at http://www.opwdd.ny.gov/welcome-front-door/home.

and to facilitate that transition. OPWDD will utilize peer outreach to identify potential MFP demonstration participants, provide accurate information and referral, and effectively address concerns of participants and family members. Contracted transition coordinators will work closely with OPWDD regional staff to transition MFP demonstration participants to the community through Home and Community-Based Services (HCBS) waiver enrollment.

OPWDD will track all participants' experiences in the MFP demonstration using the Quality of Life Survey to measure the community integration outcomes. This survey will be administered prior to MFP demonstration participants' transition to the community, at 11 months post transition, and at 24 months post transition. This survey measures key integration outcomes for people transitioning from institutional to community-based settings, including living situation, choice and control, access to personal care, respect/dignity, community integration/inclusion, overall life satisfaction, and health status.[4]

OPWDD will also promulgate regulatory amendments to align OPWDD regulations and requirements with the federal Centers for Medicare & Medicaid Services' (CMS) proposed standards for HCBS settings.[5] These requirements, which largely mirror existing OPWDD regulations, will be implemented throughout OPWDD's service delivery system and will further define the characteristics of a community-based setting that must be present wherever HCBS services are delivered. In addition to the regulations, OPWDD will adopt implementation guidelines and integrate these enhanced standards into its oversight activities.

An important goal of the transformation of the service system for people with intellectual and developmental disabilities is implementation of a self-directed approach in which MFP demonstration participants and/or their designated representatives will be given the option of self-directing by employer authority and budget authority or, at the preference of the individual, either employer authority or budget authority. As part of this effort, OPWDD will offer increased education to all stakeholders by providing a standard curriculum on self-direction to at least 1,500 people and their designated representatives per quarter beginning on April 1, 2013. As a result, OPWDD has set a goal of enabling 1,245 new people to self-direct their services by March 31, 2014.

Recognizing the need to build additional community capacity to support people with developmental disabilities and their families in the community, OPWDD is piloting the national Systemic, Therapeutic, Assessment, Respite, and Treatment (START) program model to provide emergency crisis services and limited therapeutic respite services.[6] This program will begin as a pilot in the Finger Lakes and Taconic regions, where OPWDD plans to close its developmental centers in 2013.

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[4] Additional information about the Money Follows the Person Quality of Life Survey can be found at http://apply07.grants.gov/apply/opportunities/instructions/oppCMS-1LI-13-001-cfda93.791-cidCMS-1LI-13-001-013945-instructions.pdf.

[5] State Plan Home and Community Based Services under the Act," Proposed Rulemaking. *Federal Register*, 77:86, (May 3, 2012) p. 26361.

[6] Additional information about the Systemic, Therapeutic, Assessment, Respite, and Treatment program can be found at http://www.centerforstartservices.com/community-resources/newyorkpublic.aspx.

OPWDD is also increasing integrated employment opportunities for people with developmental disabilities. On May 31, 2013, New York provided CMS with a baseline count of the number of enrollees receiving supported employment services and the number of enrollees engaged in competitive employment. As of July 1, 2013, OPWDD no longer permits new admissions to sheltered workshops. By October 1, 2013, New York will increase the number of people with developmental disabilities in competitive employment by no fewer than 250 people. Only integrated, gainful employment at minimum wage or higher will be considered competitive employment. New York submitted a draft plan to CMS for review on October 1, 2013, and will submit a final plan no later than January 1, 2014, on its transformation toward a system that better supports competitive employment for people with developmental disabilities.[7]

B. People with Serious Mental Illness in Psychiatric Centers, Nursing Homes, Adult Homes and Sheltered Workshops

The New York State Office of Mental Health (OMH) is implementing the Olmstead mandate in several ways. First, the development of behavioral health managed care will enhance community integrated health and mental health plans of care. Second, the development of Regional Centers of Excellence (RCE) will reorient OMH's state psychiatric center system to focus on high quality, intensive treatment with shorter lengths of stay and enhanced treatment and support in the community.[8] Third, the implementation of two settlement agreements will assist people in moving from nursing homes and adult homes to integrated community apartments supported by services that focus on rehabilitation, recovery, and community inclusion.

Under Medicaid redesign for managed behavioral health care, New York will create special needs Health and Recovery Plans (HARPs): distinctly qualified, specialized, and integrated managed care programs for people with significant behavioral health needs. Mainstream managed care plans may qualify as HARPs only if they meet rigorous standards or if they partner with a behavioral health organization to meet those standards.[9] HARPs will include plans of care and care coordination that are person centered and will be accountable for both in-plan benefits and non-plan services. HARPs will interface with social service systems and local governmental units to address homelessness, criminal justice, and employment related issues, and with state psychiatric centers and health homes to coordinate care. HARPs will include specialized administration and management appropriate to the populations/services, an enhanced benefit package with specialized medical and social necessity/utilization review approaches for expanded recovery-oriented benefits, integrated health and behavioral health services, additional quality metrics and incentives, enhanced access and network standards, and enhanced care coordination expectations.

To support the extension of outpatient services to people in their homes and communities, OMH will seek federal approval to provide mental health outpatient services outside of facility-based locations. Providing mobile services will increase access and effectiveness of care for people who cannot or will not access facility-based services. More accessible, consistent, and effective treatment is expected to reduce the need for inpatient care, and will instead serve people with psychiatric disabilities in the most integrated setting.

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[7] The workplan is available at: http://www.opwdd.ny.gov/opwdd_services_supports/employment_for_people_with_disabilities/draft-plan-increase-employment-opps.

[8] Additional information about the Regional Centers of Excellence is available at http://www.omh.ny.gov/omhweb/excellence/rce/.

[9] New York. Department of Health. (June 18, 2013). *MRT Behavioral Health Managed Care Update.* (PowerPoint slides). Retrieved from http://www.health.ny.gov/health_care/medicaid/redesign/docs/2013-6-18_mc_policy_planning_mtg.ppt.

Complementing its transformation of community-based services, in July 2013, OMH announced its plan to transform New York's inpatient psychiatric hospitals into regional centers of excellence (RCEs).[10] RCEs will be regionally-based networks of inpatient and community-based services, each with a specialized inpatient hospital program located at its center with geographically dispersed community service "hubs" overseeing state-operated, community-based services throughout the region. The RCE plan reduces the number of state psychiatric centers from 24 to 15, eliminating 655 inpatient beds in favor of community services. Over the next year, OMH will pursue a regional planning process to guide the development of its RCEs. This planning process will include the assessment of existing community capacity within its five state regions and recommendations for the development of additional community capacity to prevent unnecessary hospitalization and to transition people currently residing in psychiatric hospitals back to their communities. These recommendations will be prepared by December 2013.

Coupled with its community capacity evaluation, OMH will focus on transitioning long-stay patients currently residing at psychiatric hospitals back into the community. OMH has steadily reduced its inpatient psychiatric population from 43,803 in 1973 to 3,876 in 2012 by creating appropriate community placements and supports. As of July 1, 2013, the total number of non-forensic patients in New York's state psychiatric centers was 2,980, 1,328 of whom have stayed longer than one year. Over the next two years, OMH has established a goal to reduce this number of long-stay patients by 10 percent by transitioning these people to appropriate community housing and services.[11]

In addition to its inpatient psychiatric reforms, in September 2011, New York settled a federal class action lawsuit, *Joseph S. v. Hogan*, concerning people with serious mental illness discharged or at risk of discharge to nursing homes from state-operated psychiatric centers and psychiatric wards of general hospitals. All remedy class members capable of and willing to live in the community will be provided with, or otherwise obtain, community housing and community supports by November 2015. In July 2012, OMH awarded contracts for 200 units of supported housing in order to increase the housing available for qualified people transitioning out of nursing homes. An initial community transition list of remedy class members was developed in December 2012 and will continue to be revised through November 2014. In addition, New York revised its pre-admission screen and resident review process for people with serious mental illness proposed for admission to nursing homes to further prevent unnecessary admissions to these facilities.[12]

New York has also pursued a comprehensive strategy to provide community housing for people with serious mental illness residing in transitional adult homes.[13] In 2012, New York awarded contracts for 1,050 supported housing opportunities for residents of transitional adult homes. In 2012, the Department of Health (DOH) and OMH finalized regulations regarding residents of

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[10] New York. Office of Mental Health. (July 11, 2013). *OMH Regional Centers of Excellence: Today Begins a New Era in New York's Behavioral Health System*. Retrieved from http://www.omh.ny.gov/omhweb/excellence/rce/docs/rceplan.pdf.

[11] Non-forensic patients are those not on the following statuses: felony defendants found incompetent to stand trial (CPL §730); defendants found not responsible for criminal conduct due to mental disease or defect (CPL §330.20); pre-trial detainees in local correctional facilities in need of inpatient care (CL §508); inmates sentenced to state and local correctional facilities in need of inpatient care (CL §402); civil patients transferred to a forensic facility (14NYCRR §57.2); and people committed to sex offender treatment programs within a secure treatment facility (MHL Art. 10).

[12] *Joseph S. v. Hogan*. No. 06-cv-01042, ECF 232 (E.D.N.Y. Sept. 7, 2011).

[13] Transitional adult homes are defined in regulations as adult homes with a certified capacity of 80 beds or more in which 25 percent or more of the resident population are people with serious mental illness. See 18 NYCRR §487.13 for more information.

transitional adult homes to assist in their movement to more integrated settings. These regulations were based on a 2012 OMH clinical advisory, which found that such homes "are not clinically appropriate settings for the significant number of people with serious mental illness who reside in such settings, nor are they conducive to the rehabilitation or recovery of such people."[14]

In July 2013, New York reached a settlement with the plaintiffs in longstanding litigation concerning 23 adult homes in New York City serving people with serious mental illness. Over the next five years, New York will provide integrated supported housing to at least 2,000 adult home residents along with appropriate community-based services and supports. The agreement also will ensure that adult home residents have the information they need to make an informed choice about where to live. As these adult home residents choose to move to supported housing, they will participate in a person-centered, transition planning process.

Since January 2011, OMH has shifted its reliance on sheltered workshops to integrated, competitive employment for people with psychiatric disabilities who desire to work. As of December 31, 2013, all OMH funding of community-based sheltered workshops will be converted to funding of programs that support integrated and competitive employment. Agencies received technical support through New York State Rehabilitation Association and the Medicaid Infrastructure Grant to develop sound business plans to transition individuals served in sheltered workshops into integrated, competitive employment. Local government units played integral roles in developing and reviewing plans that were submitted to OMH for review and approval, and agencies operating sheltered workshops were able to reinvest this sheltered workshop funding into one of several alternatives, including assisted competitive employment, transitional employment program, affirmative business, and transitional business programs.[15]

C. People in Nursing Homes

New York has pursued a number of policies to support community living for people with disabilities residing in, or at risk of placement in, nursing homes. These include the MFP demonstration, the Nursing Home Transition and Diversion Waiver, the Traumatic Brain Injury Waiver, the Long-Term Home Health Care Plan, and the Care at Home I and II waivers. All of these alternatives provide access to community-based supports for people who meet the criteria for nursing home level of care.

Through its Medicaid redesign initiatives, over the next several years, New York will include all Medicaid-eligible nursing home residents in mandatory managed care. The mandatory "care management for all" initiative is well underway for people receiving Medicaid only, as well as for people who are dually-eligible (Medicaid and Medicare), over the age of 21, and who require at least 120 days of community-based care. New populations and benefits are expected to steadily phase in to mainstream managed care and managed long-term care over the next few years.

Building on the care management for all initiative, reforms in the 2012-2013 budget removed the financial incentives that may have encouraged nursing home placement. Previously, nursing home costs were "carved out" of managed care rates and were instead covered by the state. This policy had the potential to encourage managed care plans to pressure high-cost people served in community-based settings to enter nursing homes. Budget reforms will include the full cost of nursing home care in managed care rates, which is expected to encourage these plans to seek lower cost, community-based services.

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[14] L.I. Sederer, MD, memorandum, August 8, 2012, available at http://www.omh.ny.gov/omhweb/advisories/Clinical_Advisory_Adult.pdf.

[15] Definitions of these programs are available at http://www.omh.ny.gov/omhweb/cbr/fy09/section_30.html.

For certain people with significant disabilities, the cost of community-based care will exceed that of nursing home care. For these people, New York is developing financing structures that will permit these people to continue to reside in the community or transition from nursing home to the community, as well as avoid clustering people with significant disabilities in certain plans with preferred benefits. These financing structures will likely include the development of a funding pool to provide supplemental payment to plans serving these people to support their high-cost needs in the community.

To complement these initiatives, DOH is currently exploring mechanisms to enhance existing transition and diversion efforts for people currently residing in nursing homes. DOH will develop and adopt Olmstead performance measures which will be incorporated into its managed care contracts. These measures will evaluate the extent to which plans encourage the transition of people from nursing homes to the community; maintain people in the community; prevent nursing home placement; offer consumer-directed services as the first option for plan enrollees; support the use of assistive technologies; and encourage consumer choice and control.

Additionally, DOH has committed to reduce the long-stay population in nursing homes.[16] As of December 31, 2012, the total number of nursing home residents in New York was 119,987, of which 92,539 have stayed 90 days or more.[17] DOH has set a goal of reducing the long-stay population by 10 percent over the next five years. This target will be coupled with a home and community-based services and housing investment strategy to increase the availability of appropriate community-based housing and services.

[16] Here, long stay is defined as residence in a nursing facility for 90 days or longer, for other than a rehabilitative stay.

[17] Data were derived from the Minimum Data Set 3.0 and include all payment sources. Data include continuing care retirement communities and pediatric facilities, but excludes transitional care Units and four non-Medicaid facilities.

III. Assessment and Outcomes Strategies to Advance Community Integration

In addition to identifying strategies to transition people with disabilities from segregated to community-based settings, the Olmstead Cabinet examined the methods by which the state agencies providing services to people with disabilities understand the needs and choices of the people they serve and how those agencies measure whether those needs and choices are being met in the most integrated setting. The Olmstead Cabinet found inconsistencies in these outcome measures and recommends that state agencies providing services to people with disabilities develop or improve their assessment instruments and processes and Olmstead outcomes measures.

Over the past several years, New York has increasingly standardized its assessments of needs and choice for people with disabilities within its service systems. DOH consolidated eight separate assessment instruments previously used in its home care programs into a single instrument, called the Uniform Assessment System-New York (UAS-NY).[18] OPWDD is developing the Coordinated Assessment System-New York (CAS-NY) for all people served within its service system.[19] Significantly, the CAS-NY shares a common core of clinical items with the UAS-NY, which will permit OPWDD and DOH to assure no-wrong-door access to services and programs administered by these two agencies.

Building upon this initiative, OMH will develop an assessment for its community-based mental health system that shares a common core with both the UAS-NY and CAS-NY. OMH will then explore extending this assessment tool to its inpatient psychiatric hospitals.

Similarly, the State Office for the Aging (SOFA) will revise its Comprehensive Assessment for Aging Network Community Based Long Term Care Services (COMPASS) tool to share a common core with the UAS-NY, CAS-NY, and OMH's revised assessment tool. Currently, while the people and families served by SOFA programs are at high risk of spending down to Medicaid eligibility levels, SOFA's current assessment is not interoperable with the UAS-NY and the Minimum Data Set 3.0, used to assess residents of nursing homes. As a result, opportunities for strategic investment in non-Medicaid services to avoid institutionalization may not be readily identified. The development of consistent, cross-systems core assessments of the service needs and choices of people with disabilities of all ages will address this deficiency. Further, technological interfaces between SOFA and DOH data systems will help facilitate meeting cross-systems needs of people and enhance the ability to follow an individual through different systems and determine their progress in meeting their care plans, goals, and objectives.

The process for conducting assessments will also change. To enhance person-centered planning, New York will implement the Community First Choice Option (CFCO) as an amendment to its Medicaid State Plan. The assessment process will be expected to assess for "community first" service options as the default mechanism, so that every person with a disability is offered services in the most integrated setting and only receives services in a more restrictive setting when necessary. Under CFCO, New York will examine and revise existing assessment processes to ensure that service plans will reflect the services and supports important to the individual, identified through an assessment of functional need and preferences for the delivery of such services and

[18] For more information on the Uniform Assessment System-New York, see http://www.health.ny.gov/health_care/medicaid/redesign/uniform_assessment_system/.

[19] For more information on the Coordinated Assessment System-New York, see http://www.opwdd.ny.gov/people_first_waiver/coordinated_assessment_system/.

supports. This revised assessment process will also seek to minimize conflicts of interest by requiring the assessments be conducted independent of the service delivery system.

Building upon interoperable assessment tools and processes, the agencies providing services to people with disabilities will examine and revise their current outcome measures to incorporate Olmstead measures. To achieve community integration for people with disabilities, New York's service systems must measure whether these services maximize the opportunity for people with disabilities to lead integrated lives. These measures should include whether people with disabilities have control over their own day, whether they control where and how they live, whether they have the opportunity to be employed in non-segregated workplaces for a competitive wage, and whether they have the opportunity to make informed choices about services and supports.

Through design teams and workgroups associated with the People First Waiver, OPWDD explored the best practices for measuring the outcomes that are most important to people with developmental disabilities. After this review, OPWDD selected the Council on Quality and Leadership's Personal Outcome Measures (CQL POMs).[20] The 21 measures of the CQL POMs identify the areas of greatest importance to a person receiving supports and the support areas in which improvements may be needed.[21] OPWDD will incorporate the CQL POMs into the new managed care infrastructure for the developmental disabilities service system.

As part of the implementation of Medicaid managed care, DOH, OMH, OPWDD, and the Office of Alcoholism and Substance Abuse Services (OASAS) are establishing common quality measures across all managed care plan types. Similar to the CQL POMs, these measures will include whether people with disabilities have control over their own day, whether they control where and how they live, whether they have the opportunity to be employed in integrated workplaces for a competitive wage, and whether they have the opportunity to make informed choices about services and supports. These measures will be developed in time for the planned June 2014 implementation of the behavioral health managed care initiative.

In addition, state agencies will enhance the comprehensiveness of their assessment tools. For people with disabilities, true community integration involves the ability to access integrated housing, employment, transportation, and support services. In revising their assessment tools, state agencies will jointly identify relevant items that include these domains and incorporate these items into their assessment tools.

Reforms to New York's assessment of needs and choice and Olmstead outcomes measurement will be sustained by investments made under the federal Balancing Incentive Program (BIP).[22] Participation in the BIP will reinforce New York's ongoing efforts to improve access to home and community based long-term care services for those with physical, behavioral health, and/or

[20] Additional information about the Council on Quality and Leadership's Personal Outcome Measures is available at http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/documents/POMs_fact_Sheet_clean.

[21] In addition to personal outcomes, the CQL POMs measure community integration outcomes, such as whether the person is connected to natural support networks, has intimate relationships and friends, chooses where and with whom they live, chooses where they work, lives in integrated environments, interacts with other members of the community, performs different social roles, chooses services, chooses and realizes personal goals, and participates in the life of the community.

[22] New York received an award letter from CMS on March 15, 2013, to participate in the federal Balancing Incentive Program authorized under the Affordable Care Act. For more information about this program, see http://www.health.ny.gov/health_care/medicaid/redesign/balancing_incentive_program.htm.

intellectual and developmental disabilities throughout the state. Through improved access to information and assistance, people with disabilities will be able to make informed choices regarding services, settings, and related issues. To achieve these goals, New York will implement the three structural changes required under BIP. Specifically, New York will enhance the existing New York Connects network to assure a no wrong door/single point of entry for long-term care services and supports, implement a standardized assessment instrument, and assure conflict-free case management services.[23,24]

[23] New York Connects is currently operational in 54 counties and serves as an information and assistance system for long term care services. Additional information about New York Connects is available at www.nyconnects.ny.gov/.

[24] Conflict-free case management is defined by the Balancing Incentive Program as eligibility determination independent of service provision; case managers and evaluators not related to service recipients; robust monitoring and oversight; accessible grievance process; measurement of consumer satisfaction; and meaningful stakeholder engagement. For more information, see http://www.balancingincentiveprogram.org/resources/what-design-elements-does-conflict-free-case-management-system-include.

IV. Supporting Community Integration for People with Disabilities

The Olmstead mandate addresses not only the movement of people with disabilities from segregated to community-based settings, but also the ability of those people to lead integrated lives. Therefore, the Olmstead Cabinet's review sought to identify how New York can further support the integration of people with disabilities in their communities and worked with state agencies to develop policies that would improve community integration.

A. Housing Services

New Yorkers with disabilities need affordable, accessible housing to lead integrated lives. New York has long been a leader in the development of a continuum of housing options for people with disabilities, which include congregate and scattered-site supportive housing, tenant-based rental assistance that enables people with disabilities to lease housing in integrated developments, and apartments specifically set aside for people with various disabilities in mainstream, multi-family housing developments. New York invests over $900 million annually in supportive housing initiatives, and in the past two years, New York has invested an additional $161 million in supportive housing as part of Medicaid redesign.

The Medicaid Redesign Team Affordable Housing Work Group is a cross-agency body composed of representatives from multiple state agencies administering and/or funding supportive housing programs, including OMH, OPWDD, OASAS, DOH, Homes and Community Renewal (HCR), and the Office of Temporary and Disability Assistance (OTDA).[25] This work group has achieved $161 million in supportive housing investments over the last two years for high-cost Medicaid recipients. The work group will reconvene in October 2013 to consider further collaborations to increase the number of available and affordable housing options and community supports to increase the availability of integrated housing.

HCR facilitates the availability of community-based supportive housing for people with disabilities through early decision, scoring, and financing incentives for multi-family housing projects. Housing projects may be jointly funded by HCR and a state human service agency, such as OPWDD, OMH, or OASAS. In 2013 (as in past years) early decision incentives are available for multi-family, supportive housing projects that set aside a percentage of units for low-income veterans with special needs and people with intellectual and developmental disabilities. Project developers must also show that they have entered into agreements with human service providers to operate and fund community-based support services. HCR also awards developers applying for New York State low-income housing tax credits additional points in its scoring system for projects which reserve a percentage of units for people with mobility and sensory impairments, and for those that give preference in tenant selection for people with special needs. Additional tax credits, tax-exempt bond financing, and funding in excess of usual program limits are also available for multi-family housing projects with units set aside for special needs populations, depending on ownership and financing circumstances. Beginning in its 2013 annual funding round, HCR will examine new project applications to assess whether new developments are consistent with Olmstead principles.[26]

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[25] For more information about the Medicaid Redesign Team Affordable Housing Work Group, see http://www.health.ny.gov/health_care/medicaid/redesign/affordable_housing_workgroup.htm.

[26] For more information on the Homes and Community Renewal Annual Funding Round RFP, see http://www.nyshcr.org/Funding/UnifiedFundingMaterials/2013/RFP_MultiFamilyPrograms.pdf.

As part of its monitoring of completed projects, HCR verifies that project units set aside for people with disabilities are occupied by the special needs population intended, as provided for in the developer's regulatory agreement and affirmative marketing plan. In instances where a service provider is unable to provide qualified applicants or has discontinued operations, HCR requires that an acceptable replacement provider be identified and may allow a different special needs population to be targeted.

OTDA engages in a variety of housing initiatives to support the state's implementation of its Olmstead Plan. The agency's Bureau of Housing and Support Services (BHSS) administers both capital and housing programs that are focused on providing supportive housing for homeless people with disabilities and their families in the least restrictive environment possible. OTDA's Homeless Housing and Assistance Program (HHAP), created in 1983, was the first state-funded program in the country to develop supportive housing units for homeless people with disabilities and their families. Among those for whom such housing is provided are homeless people with serious and persistent mental illness, including those with co-occurring substance abuse disorders; people living with HIV/AIDS; people with cognitive impairments such as those caused by traumatic brain injury; and people with other mental and/or physical disabilities. In addition, OTDA's New York State Supportive Housing Program (NYSHHP) provides funding for housing retention services and other supports for formerly homeless people with disabilities who are living in supportive housing programs throughout the state. Many of these supportive housing programs are located in "mixed use" apartment buildings which house people with disabilities along with other community members. Finally, OTDA's Solutions to End Homelessness Program (STEHP) contracts with local not-for-profit agencies to provide eviction prevention services to prevent people at risk of homelessness, including those with disabilities, from losing their housing. STEHP also provides short-term rental assistance and other supports to homeless individuals, including those with disabilities and their families in order to obtain housing available in the general rental market. All of OTDA's housing efforts are aimed at assisting homeless people, including those with disabilities, to obtain and retain housing of their own choosing within the community.

In addition to these programs and incentives, the Olmstead Cabinet examined opportunities for expansion of integrated housing models that will support people with disabilities leaving institutions or at serious risk of institutional care. The Frank Melville Supportive Housing Investment Act of 2010 authorized Section 811 Project Rental Assistance (PRA), specifically designed to support Olmstead implementation efforts by funding developments and subsidizing rental housing with the availability of supportive services for very low income people with disabilities.[27] State-level housing (i.e., HCR) and health and human services agencies (e.g., OPWDD, OMH, DOH) partner to meet the housing and support needs of the target population. The health care agency develops a policy for referrals, tenant selection, and service delivery to ensure that this highly-integrated housing is targeted to a population most in need. Through an interagency partnership, New York will develop and submit an application for PRA when the request for proposals (RFP) is released. Subject to the RFP's guidance, this application will target low income people with disabilities transitioning from institutions or at serious risk of institutional placement.

Additionally, New York has expanded the information available to people with disabilities through the www.NYHousingSearch.gov website. HCR maintains this website as a free service to list and find affordable, accessible housing in New York. To expand the listings of affordable housing, HCR requires that owners and managers of multi-family projects developed since 2006 list all adaptable and adapted apartments, as well all special needs/supportive services apartments. Further, HCR requires developers of new multi-family projects to list all units adapted or set aside for people with

[27] For more information about Section 811 Project Rental Assistance, see http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/progdesc/disab811.

disabilities when advertising new units or accepting tenant applications.

B. Employment Services

The continued strengthening of New York's economic development strategies will help to assure an adequate supply and breadth of jobs available to people with disabilities. Certain reforms implemented under Governor Cuomo's Spending and Government Efficiency (SAGE) Commission have aligned workforce development programs more closely with the New York's economic development efforts. The Department of Labor (DOL) will build upon these reforms for people with disabilities by coordinating disability workforce strategies and assuring that these initiatives are aligned with New York's economic development strategies, such as Regional Economic Development Council priorities.[28]

DOL will coordinate with state agencies serving people with disabilities (e.g., OMH, OPWDD, OASAS, State Education Department's Adult Career Continuing Education Services – Vocational Rehabilitation (ACCES-VR), and New York State Commission for the Blind (NYSCB)), to better align DOL's disability workforce strategies with the vocational rehabilitation and employment programs administered by those agencies. DOL will increase coordination of disability workforce initiatives by establishing a stronger linkage between disability resource coordination (DRC) activities at One-Stop Career Centers and ACCES-VR. Specifically, DOL regional business services teams, responsible for coordinating One-Stop Career Center business services with regional business strategies and regional labor market information, will include ACCES-VR services in its coordination activities.[29] Further, DOL will use disability resource coordinators, established under a federal Disability Employment Initiative pilot program, to provide specialized services designed to increase employment opportunities for people with disabilities through skills upgrading (e.g., on-the-job training, obtaining industry-recognized credentials, entrepreneurial training, and customized training) and community partnerships with agencies that support people in employment, life coaching, and asset development.[30]

This increased employment coordination will build upon the comprehensive employment supports coordination and data system called the New York Employment Services System (NYESS).[31] NYESS provides New Yorkers of all abilities with a central point of access to all employment-related services and supports offered by DOL, ACCES-VR, NYSCB, OMH, OPWDD, OASAS, and SOFA. This system connects to the New York State Job Bank, where approximately 90,000 job openings are currently listed each month by employers. Increasing the number of providers and customers in NYESS will allow for comprehensive data analysis of the talent pipeline of people with disabilities. This analysis will include the educational attainment, employment status, and career sectors in which people with disabilities are represented, which will better enable New York to strategically implement effective policy around employment services for people with disabilities.

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[28] For more information about New York's 10 Regional Economic Development Council priorities, see http://regionalcouncils.ny.gov/.

[29] For more information about the Department of Labor regional business services teams, see http://www.labor.ny.gov/workforcenypartners/ta/ta10-12.pdf.

[30] For more information about the federally-funded Disability Employment Initiative in New York, see http://www.labor.ny.gov/workforcenypartners/dpn_dei.shtm.

[31] For more information about the New York Employment Services System, see http://www.nyess.ny.gov/.

DOL and other partner staff will continue to engage Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI) beneficiaries with benefits advisement and work incentive counseling in an effort to increase the assignment of tickets to the state under the Social Security Administration's (SSA) Ticket to Work (TTW) program. For people eligible for the TTW program, DOL, ACCES-VR, OPWDD, OMH, and NYSCB will develop a cross-systems assessment protocol to assess each individual's vocational rehabilitation and employment service needs. This protocol will assure that an individual's ticket assignment options are based on individual needs to achieve competitive employment, consistent with the unique strengths, abilities, interests, and informed choice of the individual. This cooperative approach will provide a broad range of employment and career services options for people with disabilities.

Engaging community employers around the benefits of hiring people with disabilities would also improve the opportunities for competitive, integrated employment. Efforts such as the "Think Beyond the Label" advertising campaign help to raise awareness among employers across the state about the benefits of hiring people with disabilities. New York will market various tax credits and incentives, such as the Workers with Disabilities Tax Credit and the Work Opportunity Tax Credit to encourage community employers to hire people with disabilities.

C. Transportation Services

In addition to New York's housing and employment services, transportation services are also fundamental to community living for people with disabilities. New York has conducted a variety of self-evaluation exercises to review its disability transportation strategies (e.g., assessments conducted by the Department of Transportation, Most Integrated Setting Coordinating Council (MISCC), and New York Makes Work Pay[32,33,34]) in recent years. These reports, and the Olmstead Cabinet's review, show a continued need for coordination of disability transportation services.

A federal executive order was issued in 2004 supporting coordinated transportation planning.[35] A cornerstone of such efforts is the establishment of mobility management, a strategic approach to service coordination and customer service to enhance the ease of use and accessibility of transportation networks. Mobility management meets the unique set of transportation needs in each local area by acting as a functional point of coordination for each community's public and private human services organizations and public transportation providers. Mobility management forms and sustains effective partnerships among transportation providers in a community by providing a single, localized source for coordinating and dispatching the full range of available transportation resources to customers. The partnerships formed by mobility management are meant to increase the available travel services for riders and create resource and service efficiencies for transportation providers.

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[32] For more information about the Department of Transportation review of transportation services, see https://www.dot.ny.gov/programs/adamanagement/ada-management-plan/appendix.

[33] For more information about the Most Integrated Setting Coordinating Council review of transportation services, see http://www.opwdd.ny.gov/node/784.

[34] To access the New York Makes Work Pay report, see http://www.nymakesworkpay.org/docs/Transportation_PWDs_NYS_032010.pdf.

[35] Exec. Order No. 13330. 69 FR 9185-9187. (2004). Retrieved from http://www.gpo.gov/fdsys/pkg/FR-2004-02-26/pdf/04-4451.pdf.

Under Medicaid redesign, New York implemented a transportation management system, through state-managed contracts, to improve coordination and cost effectiveness for non-emergency Medicaid transportation.[36] Non-emergency Medicaid transportation is only available to access medical care covered by Medicaid. Therefore, there remains a need for enhanced coordination of transportation resources to assure the availability of services for people with disabilities who need transportation to work or engage in other non-medical activities.

Prior to Medicaid redesign, a number of local transportation providers had begun to implement mobility management programs for both non-emergency Medicaid and non-medical transportation. New York will review the impacts of Medicaid redesign on these local mobility management efforts. This review will evaluate the cost effectiveness and availability of non-emergency Medicaid and non-medical transportation resources for people with disabilities. Based upon this analysis, New York will consider a pilot program to expand the existing Medicaid transportation management system to non-medical trips.

D. Children's Services

Children with disabilities in residential care and those at risk of placement require strategies capable of specifically addressing their personal, familial, and educational resource needs. New York has long recognized the unique relationships between children and families, the roles of multiple agencies in addressing children's needs, and the need to plan for transitions from childhood to adulthood.

The decision that a student needs out-of-home placement in a residential school must be based on the Committee on Special Education's determination that there is no appropriate alternative available to meet the educational needs of the student. New York adopted Chapter 600 of the Laws of 1994, which was intended to discourage unnecessary out-of-home placements by increasing the connection between families and children at risk of placement with local support services.[37] Recognizing that a single system cannot meet all the needs of children with disabilities and their families, CSE membership includes, with the consent of the parent (or student if age 18 or older), representatives from local social service departments, state agencies (e.g., OMH, OPWDD), and local school districts. CSEs provide families with information about in-home and community support services available as alternatives to out-of-home placement to address the unique needs of the child and family. CSEs also consider post-secondary goals and transition services for older students. In 2011, the State Department of Education strengthened its review of proposed out-of-state educational placements to assure adherence with the law.[38]

The Coordinated Children's Services Initiative (CCSI) is another mechanism for serving children with disabilities in the most integrated setting. This initiative began in the 1990s and is currently operated by the Council on Children and Families. CCSI is an approach to developing individual/family-, county- and state-level mechanisms to identify individual and family needs, coordinate multiple service systems, address barriers to coordinated service delivery, and assure that funding is available to prevent out-of-home placement of children with disabilities.[39]

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[36] For more information about the Medicaid transportation management initiative, see http://www.health.ny.gov/funding/rfp/inactive/1103250338/.

[37] For more information about the changes to New York's Social Services and Education Law as a result of Chapter 600, see http://www.p12.nysed.gov/specialed/publications/policy/chap600.pdf.

[38] For more information about the updated procedures, forms, and policy regarding a school district's responsibilities under Chapter 600 of the Laws of 1994, see http://www.p12.nysed.gov/specialed/publications/outofstateplacementsEIP.htm.

[39] For more information about the Coordinated Children's Services Initiative, see http://ccf.ny.gov/CCSI/index.cfm.

Recent Medicaid redesign initiatives have further sought to coordinate the unique service needs of children with disabilities and their families to prevent out-of-home placements. In 2011, the Medicaid Redesign Team Children's Work Group was created to redesign behavioral health services for children. This work group focused on early identification of trauma and behavioral health needs via primary care, collaborative, multi-system care models of treatment, specialty care treatment capacity (including clinical and wrap-around services), family engagement, cross-systems care coordination, and funding and administrative alignment.

The children's work group determined that the Medicaid Children's Behavioral Health Care system, currently funded through Medicaid fee-for-service, should be transitioned to Medicaid managed care. Under Medicaid managed care, physical health, behavioral health, and community support services will be coordinated through person- and family-centered care plans. Olmstead outcome measures will be incorporated into managed care plans, and will seek to ascertain whether services for children maximize the opportunity for children with disabilities to lead integrated lives. The transition to this reformed children's managed care system is planned for January 2016.

E. Aging Services

In addition to the Medicaid redesign initiatives to assist people with disabilities residing or at risk of placement in nursing homes, the Olmstead Cabinet reviewed non-Medicaid services for older adults that may delay or prevent institutionalization, hospital utilization, and Medicaid spend down. Federal, state, and local funds sustain a variety of non-medical, long-term services and supports targeted at older people at risk of nursing home placement and Medicaid spend-down, with the goal of avoiding higher levels of care and public financing of such care. In particular, the Expanded In-home Services for the Elderly Program provides case management and non-medical, in-home and ancillary services for people who need assistance with activities of daily living and instrumental activities of daily living.[40,41,42] Other services, such as congregate and home delivered meals, transportation, and caregiver services, supported through federal, state, and local funds, also assist older New Yorkers to remain in their homes and communities.

As previously noted, SOFA will revise its COMPASS tool to share a common core with the UAS-NY, CAS-NY, and OMH's revised assessment. This revision will help identify opportunities for strategic investment in non-Medicaid services to avoid institutionalization. Further, technological interfaces between SOFA and DOH data systems will help meet cross-systems needs of people with disabilities and enhance the ability to follow a person through different service systems and determine his/her progress in meeting care plan goals and objectives.

SOFA also administers New York Connects, the state's federally-designated Aging and Disability Resource Center to serve as a no wrong door/single point of entry to long-term supports and services for people of all ages with disabilities.[43] Using BIP funds, New York Connects will be strengthened to provide better information to people with disabilities and older adults about both private and public community-based services and supports available to meet their needs. This resource center will also provide options counseling to assist with decision making. These services

[40] For more information about the Expanded In-home Services for the Elderly Program, see http://www.health.ny.gov/health_care/medicaid/program/longterm/expand.htm.

[41] Self-care activities are activities that a person tends to do every day, including feeding, bathing, toileting, dressing, and grooming.

[42] In addition to activities of daily living, a person must be able to perform instrumental activities in order to live independently, including shopping, transportation, and housekeeping.

[43] For more information about New York Connects, see http://www.nyconnects.ny.gov/nyprovider/consumer/indexNY.do.

are expected to enhance a person's ability to receive the right service at the right time in the right setting for the right cost.

Further, SOFA will strengthen its Long-Term Care Ombudsman Program to assist residents of nursing homes and adult homes to transition to community-based services and supports.[44] Ombudsmen currently help residents understand and exercise their rights in facilities and work to resolve problems between residents and facility staff/administrators. Ombudsmen will be trained to assist nursing home and adult home residents to exercise their rights to community placement and to facilitate linkages to community resources, consistent with proposed federal guidelines regarding long-term care ombudsmen.[45]

F. Criminal Justice

The Olmstead Cabinet examined two criminal justice issues concerning people with disabilities and the Olmstead mandate. First, the cabinet sought to assure that people with disabilities who leave correctional facilities are able to access needed community-based services. Second, the cabinet reviewed current state policies to assure that people with disabilities are not unnecessarily incarcerated for minor offenses that are a result of their disability.

Under Medicaid redesign, New York has enhanced its ability to voluntarily engage people with significant behavioral health needs in services and provide strong follow-up upon discharge from institutional settings. For the limited number of people who do not voluntarily access services, the New York Secure Ammunition and Firearms Enforcement (SAFE) Act strengthened assisted outpatient treatment.[46]

OMH works closely with the Department of Corrections and Community Supervision to implement robust statewide policies for screening people in prisons for mental illness, provide mental health services in prisons, and facilitate reentry from prisons to the community. OMH also offers in-reach services to link prisoners with community-based services and employs pre-release coordinators in prisons throughout the state. These coordinators link mentally ill prisoners with appropriate services in the community and assist, where appropriate, in applying for entitlements such as Medicaid and SSI/SSDI.[47]

County-based services for mentally ill jail inmates are supplemented with state funding through the Medication Grant Program to pay for psychotropic medications for released inmates while their Medicaid application is pending. In addition, OMH provides over $4 million annually to support transition programming in local jails.

The majority of services to divert people with disabilities from the criminal justice system and transition mentally ill inmates back into the community, however, are administered at a local level.

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[44] For more information about the Long-Term Care Ombudsman program, see http://www.ltcombudsman.ny.gov/.

[45] "State Long-Term Care Ombudsman Program, Proposed Rules." *Federal Register*, 78:117. (June 18, 2013) p. 36449-36469. Retrieved from http://www.gpo.gov/fdsys/pkg/FR-2013-06-18/html/2013-14325.htm.

[46] Information about the impact of the New York Secure Ammunition and Firearms Enforcement Act on mental health services can be found at http://www.omh.ny.gov/omhweb/safe_act/.

[47] Recipients of services at OMH forensic facilities are almost always discharged to an OMH civil psychiatric center prior to transitioning back to the community. Residents in OMH secure treatment facilities are transitioned back into the community through the Strict and Intensive Supervision and Treatment program, established by MHL Art. 10.

These local services include law enforcement, courts, jails, and community supervision. Examples of pre-arrest diversion programs that exist across the state are crisis intervention teams, emotionally disturbed people response teams, and mobile crisis teams. In addition, there are currently 28 mental health courts throughout the state, and the Mental Health Connections program shares current mental health court resources with counties that do not have an established mental health court.

A number of recent reforms will further support the diversion of people with disabilities from the criminal justice system and facilitate reentry from the criminal justice system. Notably, OMH has significantly increased the number of supported housing units for parolees with serious mental illness. It also has partnered with the Center for Urban Community Services (CUCS) to develop the Reentry Coordination System in New York City, which operates as a forensic single point of entry for services, including housing, intensive case management, assertive community treatment, and outpatient clinic services. In addition, OMH has collaborated with the New York City Department of Health and Mental Hygiene and with CUCS to establish the Academy for Justice-Informed Practice to cross-train mental health and criminal justice practitioners on best practices for working with justice-involved, mental health service recipients.[48]

The Division of Criminal Justice Services (DCJS) oversees the operation of 19 county reentry task forces and provides $3 million annually through performance-based contracts with localities to support the reentry of people returning from state prisons. DCJS also provides specialized training to police officers to address the needs of people with mental illness.

DCJS was recently awarded a grant from the Bureau of Justice Assistance to provide training and technical assistance to up to 10 localities with high crime rates and high per member per month Medicaid spending to address the needs of people with serious mental illness in the criminal justice system and coordinate with community-based treatment and supports. Using the Sequential Intercept Model, DCJS will work collaboratively with OMH to assist localities in conducting countywide mapping of mental health and criminal justice resources for planning purposes.[49] DCJS and OMH also will provide training and technical assistance to identify local service gaps and develop strategies to address unmet need at each interception point. These strategies will help counties address the needs of people with serious mental illness involved in the criminal justice system and connect them to community-based treatment and supports, which is expected to decrease crime rates and the burden on local jails while improving mental health outcomes for the people served. Initial outcome measures for this initiative will seek to identify probationers screened for mental illness, probationers supervised through the joint probation/mental health case management model, probationers with mental illness successfully completing probation supervision, the number of jail admissions screened for mental illness, and the number of police officers completing crisis intervention training.

G. Legal Reform

To promote the full integration of people with disabilities in the community, the Olmstead Cabinet examined legal and regulatory barriers that impact the ability of people with disabilities to achieve

[48] For more information about the Center for Urban Community Services and the Academy for Justice-Informed Practice, see http://www.cucs.org/training-and-consulting/training/nyc-training-program.

[49] The Sequential Intercept Model, developed by SAMHSA's GAINS Center for Behavioral Health and Justice Transformation, identifies five key points within the criminal justice system where people with serious mental illness can be intercepted and diverted to community-based alternatives: (1) law enforcement, (2) initial detention/initial court hearings, (3) jails/courts, (4) re-entry, and (5) community corrections. For more information, see http://gainscenter.samhsa.gov/pdfs/integrating/GAINS_Sequential_Intercept.pdf.

community integration. The Olmstead Cabinet identified two issues requiring legal reform: access to health-related task assistance in community settings and guardianship laws for people with intellectual and developmental disabilities.

A barrier to community integration for many people with disabilities is their ability to access community-based assistance with health-related tasks, including medication management, medication administration, and other home health treatments. Recognizing these barriers, current law authorizes people with disabilities served by certain programs to receive assistance with these tasks from non-nursing personnel. People receiving home care services under the Consumer Directed Personal Assistance Program (CDPAP) may direct another individual to provide them with health-related task assistance.[50] Additionally, people with intellectual and developmental disabilities residing in OPWDD certified residences can utilized trained and certified direct care staff for medication, tube feedings, and insulin administration, as well as for other health-related tasks under the supervision of a registered professional nurse.[51]

However, for people with disabilities not served by these programs, facility-based care is often the only option for receiving needed assistance with these health-related tasks. For example, while a person with a developmental disability residing in a group home certified by OPWDD may receive assistance with medication administration by an unlicensed direct care staff member, the same person could not receive this level of assistance in an independent apartment. Likewise, people with physical disabilities enrolled in the CDPAP program can receive the assistance of an unlicensed aide in their own homes if they or a designee assumes full responsibility for hiring, training, supervising, terminating the employment of people providing the services, but could not make use of an unlicensed aide if they wish to direct another in the provision of health-related task assistance, but do not wish to assume all responsibilities associated with the CDPAP program. Similar barriers exist for other people with disabilities who need assistance with health-related tasks to live successfully in the community.

In order to fully support community integration for people with disabilities, current restrictions on community-based health-related task assistance require reform. A broader application of the current self-direction exemption of the Nurse Practice Act for CDPAP enrollees should be explored to cover all people with disabilities who are capable of directing others to provide health-related task assistance. For people not capable of directing others to provide this assistance, a broader application of the exemption within the Nurse Practice Act for certified settings, as currently implemented by OPWDD, should be explored to cover all integrated, community-based housing for people with disabilities.

The Olmstead Cabinet also recommends reform to law governing guardianship over people with developmental disabilities. Community integration includes the ability of people with disabilities to make their own choices to the maximum extent possible. Guardianship removes the legal decision-making authority of an individual with a disability and should, consistent with Olmstead, only be imposed if necessary and in the least restrictive manner. New York maintains two separate systems of guardianship for people with disabilities. Article 17A of the Surrogate Court's Procedure Act, adopted in 1969, applies to people with developmental disabilities. Article 81 of Mental Hygiene Law, adopted in 1987, applies to all other people with disabilities.

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[50] For more information about Consumer Directed Personal Assistance Program requirements, see http://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap.htm.

[51] To access the Office for Mental Retardation and Developmental Disabilities and State Education Department's joint Memorandum of Understanding #2003-01 for registered nursing supervision of unlicensed direct care staff in certified residential facilities, see http://www.op.nysed.gov/prof/nurse/nurse-omrddadminmemo2003-1.htm.

Under Article 17A, the basis for appointing a guardian is diagnosis driven and is not based upon the functional capacity of the person with disability. A hearing is not required, but if a hearing is held, Article 17A does not require the presence of the person for whom the guardianship is sought. Additionally, Article 17A does not limit guardianship rights to the individual's specific incapacities, which is inconsistent with the least-restrictive philosophy of Olmstead. Once guardianship is granted, Article 17A instructs the guardian to make decisions based upon the "best interests" of the person with a disability and does not require the guardian to examine the choice and preference of the person with a disability.

In contrast, Article 81 imposes guardianship based upon a functional analysis of a person's disability, requires a hearing, requires the presence of the person over whom guardianship is sought at the hearing, requires guardianship to be tailored to the person's functional incapacities, and requires the guardian to consider the person's choice and preference in making decisions. The Olmstead Cabinet recommends that Article 17A be modernized in light of the Olmstead mandate to mirror the more recent Article 81 with respect to appointment, hearings, functional capacity, and consideration of choice and preference in decision making.

In addition to reforming guardianship law, New York should build upon current OPWDD regulations that recognize certain actively involved family members as surrogates for people who cannot provide their own consent.[52] By extending the authority of these people, OPWDD has minimized those instances in which guardianship is pursued. This outcome could be beneficial to all other people with disabilities to support decision-making activities without pursuing guardianship.

[52] Among other things, actively-involved family members may give informed consent for major medical procedures on behalf of individuals residing in OPWDD facilities who lack the "capacity to understand appropriate disclosures regarding proposed professional medical treatment" (14 NYCRR 633.11(a)(1)(iii)(a) and (b)), may approve service plans (14 NYCRR 681.13), object to OPWDD-related services on behalf of such individuals (14 NYCRR 633.12), may provide informed consent for behavior support plans that include restrictive/intrusive interventions (14 NYCRR 633.16(g)(6)(i)and (iii)), and make end-of-life decisions on behalf of individuals with developmental disabilities. (Surrogate's Court Procedure Act § 1750-b [1] [a]; see also 14 NYCRR 633.10 [a] [7] [iv]).

V. Ensuring Accountability for Community Integration

Although this report provides the foundation for New York's compliance with the Olmstead mandate, effective oversight is required in order to protect the rights of person with disabilities to live in the community on an ongoing basis.

Since 2011, New York has undertaken significant initiatives to ensure the protection of people with disabilities and other special needs. In June 2013, Governor Cuomo established the Justice Center to investigate and prosecute cases of abuse and neglect against people with disabilities and to provide oversight and monitoring of the systems of care serving these people. Governor Cuomo also designated Disability Rights New York as the state's federally-funded Protection and Advocacy and Client Assistance Program to provide independent oversight of these systems. Additionally, New York initiated independent ombudsman functions through Medicaid redesign to assist people with disabilities served in the Medicaid managed care system. Finally, the Governor created the Olmstead Development and Implementation Cabinet and designated a representative of the Governor's Office to direct its activities. Together, these measures strengthen the oversight of providers and service systems and provide access to independent advocacy to protect the rights of people with disabilities to live in the community.

New York's sustained attention to serving people with disabilities in the community requires continued leadership from the Governor's Office. The legislature created the MISCC in 2002 as the statutory body intended to develop New York's Olmstead plan and hold state agencies accountable.[53] As designed, MISCC had a rotating chairmanship among the commissioners of four state agencies. This model has proved challenging because one state agency commissioner does not have the authority to command other state agency commissioners. The creation of the Olmstead Cabinet, with a chair from the Governor's Office, was intended to provide leadership from the Governor's Office in the development of a plan for Olmstead compliance. To sustain this leadership over time and to hold state agencies accountable for Olmstead compliance, a representative of the Governor's Office will continue to provide leadership to the MISCC. MISCC meetings will be a continuing means of public accountability for the state's accomplishment of Olmstead goals.

In addition, the Governor's Office will develop and maintain a dashboard to monitor Olmstead compliance. This dashboard will contain key agency Olmstead initiatives and metrics to measure New York's progress in serving people with disabilities in the most integrated setting. The Governor's Office will also maintain a dedicated website, http://www.governor.ny.gov/olmstead/home. This website will provide relevant information regarding New York's implementation of Olmstead and a mechanism for the public to provide feedback regarding New York's Olmstead Plan.

[53] Additional information about past MISCC Olmstead proceedings is available at http://www.opwdd.ny.gov/opwdd_community_connections/miscc/press_releases_and_important_documents.

Conclusion

This report and recommendations, developed by the Olmstead Cabinet, provide the framework for New York to serve people with disabilities in the most integrated setting appropriate to their needs and desires. Through implementation of these recommendations, New York will:

- Assist in transitioning people with disabilities into the community from developmental centers, ICFs, sheltered workshops, psychiatric centers, adult homes, and nursing homes;
- Reform the assessment of the needs and choices of people with disabilities;
- Adopt new Olmstead outcome measures for people with disabilities;
- Enhance integrated housing, employment, and transportation services available to people with disabilities;
- Improve services to children, seniors, and people with disabilities involved with the criminal justice system;
- Remove legal barriers to community integration; and
- Assure continuing accountability for serving people with disabilities in the most integrated setting.

The effective implementation of these recommendations will safeguard the fundamental civil rights of New Yorkers with disabilities to lead integrated lives.

www.governor.ny.gov/olmsteadplan

WILLOWBROOK PERMANENT INJUNCTION

UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF NEW YORK

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, BENEVOLENT SOCIETY FOR RETARDED CHILDREN, et al.,	:	
Plaintiffs,	:	PERMANENT INJUNCTION
-against-	:	72 Civ. 356, 357
MARIO CUOMO, et al.,	:	
Defendants.	:	

WHEREAS, plaintiffs and defendants entered into a Consent Judgment which was approved by the Court on May 5, 1975, 393 F. Supp. 715 (EDNY), requiring defendants to provide a range of individualized services to the plaintiff class of persons with mental retardation ("class member") and to place them in appropriate, less restrictive, normalizing residences in the community, and

WHEREAS, this Court has actively monitored and supervised, through regularly scheduled status conferences and hearings on various motions of the parties, the provision of services and community residential placements provided to class members pursuant to the Consent Judgment and subsequent orders of the Court, and

WHEREAS, on February 25, 1987, after several years of negotiations between the parties, this Court approved a settlement agreement which, inter alia, imposed the obligation on

defendants to place and maintain plaintiff class members in community residential facilities, placed specific limits on the size of such facilities, established timelines for the completion of all such placements, and provided for the entry of a permanent injunction upon satisfaction of defendants' service and placement obligations ("1987 Stipulation"), and

WHEREAS, defendants have achieved most of their quantitative placement obligations for class members, but will not be able to complete their remaining obligations within the December 31, 1992, timeline set by the 1987 Stipulation, and

WHEREAS, plaintiffs seek to protect the rights and ensure the quality of the residential placements and treatment services of those class members who will not be placed on or before December 31, 1992, and

WHEREAS, in order to prevent the recurrence of the tragic conditions which led to the filing of this litigation in 1972 and the entry of the Consent Judgment in 1975, both plaintiffs and defendants agree that the members of the plaintiff class must continue to receive high quality services in appropriate community residential settings for the rest of their lives, after the removal of this case from the active docket of the Court, and

WHEREAS, as a result thereof, and pursuant to the provisions of paragraph 11 of the 1987 Stipulation, the parties have agreed to the terms and provisions of a permanent injunction which assures that defendants will continue to provide appropriate community residential and habilitative services to the members of

the plaintiff class, replaces the Consent Judgment and subsequent orders of the Court, removes this case from the active docket and active supervision of the Court, and, if adhered to by Defendants, will hereafter assure that the class members continue to receive the high level of habilitation services and appropriate community residential options which have been the objectives of this litigation since its inception, and which have been the obligations required of Defendants by the orders of this Court, and

NOW, THEREFORE, for these findings and reasons, plaintiffs and defendants herein, through their respective counsel, stipulate and agree to the following provisions of this permanent injunction:

1. This permanent injunction supplants and replaces the Consent Judgment and all subsequent orders of this Court in this matter, except as specifically referenced herein. All such judgments and orders are hereby vacated and dissolved, subject however to the exceptions and reservations herein set forth. The Office of the Special Master shall terminate at the close of business on March 31, 1993. Any motions to enforce the rights of the plaintiff class shall be brought before this Court pursuant to the permanent injunction. The action shall otherwise be terminated, and the case shall be removed from the active docket.

Richmond Complex.

2. Defendants may, but are not required to, operate and maintain on the grounds of Willowbrook residential facilities which, in the aggregate, do not exceed a capacity for 150 persons. For purposes of this paragraph, "Willowbrook" shall be defined as set forth in paragraph 2(a) of the 1987 Stipulation, which definition is specifically retained and incorporated herein. (See Appendix A attached hereto)

3. Defendants shall render high quality and appropriate medical and habilitative services, shelter, food and clothing to the residents of the Richmond Complex. At a minimum these services shall conform to applicable state and federal requirements and all other requirements of this permanent injunction. For purposes of this paragraph, the "Richmond Complex" shall be defined as set forth in paragraph 3(a) of the 1987 Stipulation, as that definition incorporates paragraph 2(a) of the 1987 Stipulation, which definitions are specifically retained and incorporated herein. (See Appendix B attached hereto)

4. Defendants shall continue to prepare the residents of the Richmond Complex for placement in small community residential settings of 10 beds or less, to the extent warranted by interdisciplinary team recommendations. At the time the permanent injunction is entered, defendants shall provide plaintiffs a list of the names of every class member residing at the Richmond Complex on that date. A copy of that list shall be

attached to this permanent injunction. (See Appendix C attached hereto) No later than two years after the entry of this permanent injunction, defendants shall provide plaintiffs' counsel with the current address of each individual listed on Appendix C, the residential capacity of the facility where he or she resides, the name and address of the provider of residential services for each resident of the Richmond Complex who resided there on the entry of this permanent injunction, and placement plans for those residents who still remain at the Richmond Complex at that time. For those residents whose interdisciplinary team has recommended they should continue to remain at the Richmond Complex, defendants shall also provide plaintiffs' counsel with all data and reports in its possession which support, and which do not support, such recommendations.

5. Placements.

(a). With the exception of the class members listed on Attachment 1 to this permanent injunction, defendants have satisfied their quantitative placement obligations under the 1987 Stipulation, including Attachment A to the 1987 Stipulation. (A copy of Attachment A and a list of the other Willowbrook class members placed pursuant to the Willowbrook Consent Judgment is attached hereto as Attachment 2.)

(b). All class members who have not been placed in a community or qualifying facility by December 31, 1992 shall be placed on Attachment 1 to the permanent injunction. Before being included on Attachment 1, each class member must have a complete

placement plan which has been reviewed and approved by the Special Master and plaintiffs' attorneys.

(c). OMRDD shall place all class members listed on Attachment 1 into appropriate community residential facilities as defined in paragraph 4(d) of the 1987 Stipulation, see Appendix B, no later than August 31, 1993, however this deadline may be extended upon consent of plaintiffs and defendants, where appropriate to meet the needs of an individual class member. Appendix A to the Consent Judgment and subsequent orders of the Court shall continue to be applicable to these individuals until six months after each person on Attachment 1 has been placed in an appropriate community facility or, in the case of an individual who has been returned to a developmental center or otherwise placed in a non-qualifying facility as defined in paragraph 2(c) of the 1987 Stipulation, until the individual has lived continuously in an appropriate community facility for six months.

(d). Plaintiffs' counsel and defendants have agreed upon an independent evaluator who will closely monitor the individuals listed on Attachment 1 to ensure that they receive the services required in paragraph 1(c) above and verify the continued appropriateness of their placement plans. With regard to these individuals only, the independent evaluator shall have the same powers granted to the Special Master pursuant to paragraphs 5, 6, 8, 9, 10, 13, and 16 of the Order of Referral, dated July 13, 1982, including but not limited to monitoring,

providing technical assistance, and issuing formal recommendations. Defendants shall provide adequate funds to permit the independent evaluator to perform his or her duties under this permanent injunction. (See Appendix D attached hereto, setting forth the powers and duties of the independent evaluator).

(e). Defendants shall report regularly to both plaintiffs and the independent evaluator on the progress of their efforts to place individuals listed on Attachment 1. The independent evaluator shall certify to the court and the parties no later than September 30, 1993 whether defendants' placement obligations have been met under Attachment 1 and the individuals listed on Attachment 1 are receiving services consistent with Appendix A to the Consent Judgment and subsequent orders of the Court, as provided in paragraph 5 (c) above. Because these individuals are among the most difficult to place and maintain in the community, the independent evaluator shall continue to monitor their progress in the community for six months following their placement into a community facility.

6. Maintenance of Size of Community Residences.

Defendants shall maintain class members in the community residential facility in which they live at the time of the entry of this permanent injunction, or in such community residential facilities with equal or smaller residential capacities as are appropriate for the class member, except:

(a). in the event of an emergency as described in paragraph 8 (b) of the 1987 Stipulation (See Appendix E attached hereto);

(b). where the class members' medical needs require movement pursuant to the criteria for inclusion in Attachment A to the 1987 Stipulation which are described in paragraph five of said Stipulation and certain documents developed by the Special Master and which are specifically retained and incorporated herein (See Appendix F attached hereto);

(c). where the class member's interdisciplinary team recommends a residential movement for the purpose of providing treatment and services which are more appropriate to the class member's needs and which cannot be provided in the same or a smaller facility, subject to:

(i). the consent of the class member, if the class member has capacity; or, if the class member lacks capacity, the class member's correspondent or, in the case of noncorrespondents, the Consumer Advisory Board. However, consent shall not unreasonably be withheld if the class member is endangering other residents at the facility where the class member resides or is substantially interfering with the operation of the residential program; and

(ii). the considerations set forth in paragraph 6 of the 1987 Stipulation, which is specifically retained and incorporated herein. (See Appendix G attached hereto)

(d). where a class member with capacity requests a move to another facility;

(e). upon consent of plaintiffs' counsel.

7. Consumer Advisory Board.

Defendants shall comply with the Stipulation and Order of January 3, 1992, which shall remain in effect, and is specifically retained and incorporated herein. (See Appendix H attached hereto). For purposes of this permanent injunction and the Stipulation and Order of January 3, 1992, the parties agree that the term "noncorrespondent class member" shall mean any class member who does not receive active representation, as defined in Appendix H, attached hereto. Defendants shall refer for Consumer Advisory Board representation or co-representation those class members who lack active representation, as defined in Appendix H attached hereto. With the consent of a class member with capacity or his or her correspondent, the Consumer Advisory Board may also act as co-representative or advocate for those members of the plaintiff class who are not noncorrespondent class members. The Consumer Advisory Board shall continue to have the responsibility to evaluate alleged dehumanizing practices and violations of individual or legal rights with regard to any and all members of the plaintiff class.

8. Case Management.

Defendants shall continue to provide plaintiff class members with case management services, as defined in Appendix I, at a ratio of no less than one case manager to every 20 persons. No

later than the first day of January and the first day of July of each calendar year, so long as any plaintiff class member lives, defendants shall provide to plaintiffs' counsel, or their designated representative, and the Consumer Advisory Board a report detailing the current status of defendants' compliance with their case management obligations and listing the name and caseload of every case manager providing services for a member of the plaintiff class and the name and address of any class member who is not receiving case management services in accordance with this paragraph.

9. Access to Class Members and Records; Plaintiffs' Access to Commissioner of OMRDD.

(a). For so long as any class member lives, defendants shall provide plaintiffs' counsel, the Consumer Advisory Board and Mental Hygiene Legal Service ("MHLS"), to the extent it represents a class member, with the following rights of reasonable, unrestricted access to:

(1). all class members; and

(2). all records relating to class members maintained by or in the possession of defendants, or maintained by any provider of services to the class member upon reasonable advance request to the OMRDD Defendants, including but not limited to individual developmental plans and incident reports; and

(3). all facilities where class members reside or receive habilitation, treatment or other services; and

(4). copies of all residential or program surveys and audits for facilities where class members receive services upon reasonable advance request to the OMRDD Defendants. For purposes of this paragraph, surveys and audits shall include, but not be limited to, those completed by the New York State Commission on Quality of Care, and the OMRDD Quality Assurance Division, and/or any successor to either agency.

(b). For so long as a correspondent shall represent a class member, defendants shall provide each correspondent the right of reasonable, unrestricted access to each class member the correspondent represents and all records and facilities listed in paragraph 9 (a)(2), (3) and (4) above.

(c). Plaintiffs and plaintiffs' counsel shall continue to have reasonable access to the Commissioner of the Office of Mental Retardation and Developmental Disabilities ("OMRDD") to discuss matters of concern to members of the plaintiff class through telephone calls and informal meetings at mutually convenient times and places.

10. Programming.

(a). Defendants shall provide all class members with meaningful, full day habilitative programming and services appropriate to their individual needs each day during week days and meaningful, appropriate recreation and community integration each day during evenings and weekends for the remainder of their lives. Such habilitative programming and services, recreation and community integration shall include, but not be limited to,

compliance with applicable contemporary habilitation standards and contemporary federal and state regulatory standards. Class members with capacity have a right to refuse to partake in such programming.

(b). Defendants shall ensure that each class member's developmental plan is reviewed by the class member's interdisciplinary treatment team at least annually, and quarterly if the class member, correspondent, Consumer Advisory Board or MHLS, to the extent it represents a class member, so requests. The class member if he or she has capacity, the class member's correspondent or the Consumer Advisory Board, and MHLS, to the extent it represents a class member, shall be invited to attend such reviews and kept informed of the class member's educational, vocational and living skills, progress, medical condition and other matters relevant to his or her care, treatment and development. Defendants shall maintain current, appropriate professional assessments of each class member's needs, including where applicable, but not limited to, medical, psycho-social, habilitative, psychological, speech therapy, food and nutrition, physical therapy, and occupational therapy.

(c). In addition to the above, the notice to the class described in paragraph 18 below shall include the following notice of the following right of each class member under the permanent injunction:

> "Class members presently are entitled to receive active treatment and full day programs and it is the defendants' intention to continue these programs. If any aspect of the day program that the class member was entitled to under the

Consent Judgment is proposed to be changed, including but not limited to the nature or duration of the program, you will be given notice of the proposed change and will have an opportunity to discuss the proposal and object to it if you are not satisfied. You will be entitled to administrative and judicial review of the proposal if you object. Any future change in the program to which the class member was entitled under the Willowbrook Consent Judgment shall be permitted only on a showing that it provides a greater opportunity for the class member's growth and development and is based on an individualized assessment of the class member's current needs made by the individual's treatment team, including, where applicable, the individual's medical psycho-social, habilitative and psychological needs, in the exercise of its professional judgment. Appropriate changes in the individual developmental plan may be made where a class member is unable to participate fully in programming because of a medical condition or advanced age and such assessment is based upon a full individualized assessment of the class member's current needs in the manner described above. In the case of a class member incapacitated by a medical condition, prior programming shall be restored as soon as the individual is no longer incapacitated."

11. Safety and Physical Environment.

Defendants shall assure each class member protection from harm and a safe, clean and appropriate physical environment.

12. Staffing.

Defendants shall assure that there is sufficient staff present and on duty to protect each class member from harm; provide a safe, clean and appropriate physical environment; provide meaningful, full day habilitative programming and services appropriate to the individual's needs during week days and meaningful, appropriate recreation and community integration each day during evenings and weekends for the rest of their lives; and satisfy defendants' other obligations under this permanent injunction.

13. Behavior Modification, Research, and Hazardous or Experimental Treatment.

Paragraph P, subparagraphs (2), (3) and (4) of Appendix A to the Willowbrook Consent Judgment, attached hereto as Appendix J, is specifically retained in the permanent injunction, except that in subparagraph (2)(c) plaintiffs' attorneys shall designate the individual formerly designated by the Professional Advisory Board.

14. Names and Locations of Class Members.

Defendants shall provide plaintiffs' counsel and CAB with a list of the names and locations of all class members at the time the permanent injunction is entered and at six month intervals thereafter, so long as any class member lives.

15. Due Process Notices.

Except in emergencies as defined in Appendix K, defendants shall provide notice at least 30 days prior to the transfer of any class member from any residential facility or building in which he or she resides, to:

(a) the Consumer Advisory Board, so long as any class member remains alive;

(b) to plaintiffs' counsel for at least five years from the date of entry of this permanent injunction; and

(c) MHLS, to the extent it represents a class member.

In an emergency, as defined in Appendix K, one day's notice shall suffice unless circumstances are such that it is impossible to provide notice prior to the transfer, for example

in the event of a fire or other natural disaster. In such cases notice shall be provided as soon as practicable. Notice shall be provided through due process forms, a copy of which is attached hereto as Appendix L. Unless the parties expressly agree otherwise in writing, defendants' obligation to provide: 1) a hearing before an independent factfinder and the other rights presently afforded at such a hearing, as described in Appendix L; and 2) full, written notice of such rights 30 days prior to the proposed transfer, as described in Appendix L, shall remain in effect for so long as any class member is alive, regardless of any change in the form or content of defendants' due process notices.

16. Appropriate Services.

Defendants shall continue to provide each class member with residential, habilitative and programming services that are reasonably unrestrictive and appropriate to his or her individual needs.

17. Notice of Rights.

The OMRDD defendants shall place the following information describing the rights and entitlements under the permanent injunction in the permanent record of each class member, shall retain such information on record for so long as the class member is alive, and shall enter such information in the class member's file maintained by all providers of residential and habilitative services to class members:

(a). designation of membership in the Willowbrook class;

(b). notation that class membership results in rights and services guaranteed by this permanent injunction issued by the United States District Court, Eastern District, and a summary o those rights; and

(c). the name, address and telephone number of plaintiffs' counsel, MHLS and the Consumer Advisory Board.

18. Notice of entry of Permanent Injunction.

Defendants shall provide one time notice to all correspondents and class members of their rights and entitlemen under the permanent injunction. Within three (3) months of the entry of the permanent injunction, defendants shall mail the Notice to Correspondents, which is attached hereto as Appendix I to the Consumer Advisory Board, MHLS and all class members with capacity and each and every class member's correspondent at the last known address.

19. Commissioner's Task Force.

Defendants shall create a Commissioner's Task Force which shall meet quarterly and be comprised of parents, advocates, consumers, members and staff of the Consumer Advisory Board, OMRDD, other professionals in the field and plaintiffs' counsel. The Task Force shall, inter alia, review information from the monitoring provided in paragraph 21 below and advise the Commissioner on both the dissemination to other facilities of better practices at facilities found to be exemplary and on possible plans of corrective action where deficiencies are identified. The Task Force shall also identify and address

systemic problems, review the progress in implementing the systemic plans identified in paragraph 20 below, and advise the Commissioner regarding these and other matters concerning the plaintiff class. In addition to the monitoring reports described in paragraph 21 below, the Task Force shall receive quarterly reports of case management ratios and use other sources of information including but not limited to parents, consumers, the New York State Commission on Quality of Care, and the OMRDD Division of Quality Assurance. Plaintiffs and defendants have agreed upon the members of the Task Force. The Task Force shall operate until the 350 audits described in paragraph 21(d) below have been completed and reviewed by the Task Force. Thereafter, the Task Force, plaintiffs' counsel and the Commissioner shall evaluate the continuing need for the Task Force. The Task Force shall not be discontinued without the consent of plaintiffs' counsel and defendants.

20. Systemic Issues

(a). Defendants and plaintiffs agree that the continued delivery by defendants of high quality residential and habilitation services to class members is linked to the successful management of key professional interventions or services. The professional interventions and services which the parties have identified as critical to the successful implementation of this permanent injunction are: vocational and day programming, medical services, respite care, behavior management, case management, residential and integrative services, and incident review. The

items enumerated herein are not intended to be exclusive. Rather, defendants have agreed to continue to identify other professional interventions and services which are key to their obligation to successfully comply with the provisions of this permanent injunction.

(b). Defendants, while maintaining that the professional interventions and services set forth in paragraph 20 (a) above are currently being provided, have also agreed to take the steps necessary and required to improve these services. To that end, defendants and the Special Master will develop a master plan of action for each systemic issue in the areas set forth in paragraph 20(a), above. Plaintiffs and defendants have agreed upon and submitted to the Court the master plan and a plan for specific action during fiscal year 1993-94. Defendants will submit these plans to The Commissioner's Task Force, which will review the progress and problems related to these systemic issues and make recommendations to the Commissioner. Defendants will conduct individual audits of class members to determine how well their systemic solutions are improving the quality of services provided to class members, as provided in paragraph 21 below.

(c). For purposes of monitoring the development and implementation of the plans required by this paragraph, defendants agree to provide plaintiffs' counsel, if plaintiffs shall so request, information sessions to be attended by plaintiffs' counsel, any experts retained by plaintiffs' counsel and designees of the defendants, who are responsible for

designing and implementing the plans. The purpose of the meetings shall be to inform plaintiffs' counsel of their progress in developing and implementing the plans and to provide defendants with input and suggestions from plaintiffs' counsel, and to provide plaintiffs' counsel with status reports regarding the implementation of the plan.

21. Monitoring.

In order to ensure that class members are receiving the services required by this permanent injunction, defendants shall monitor class members' residential and day programs as described below. The parties agree that the audit instruments and methodology contained in Appendix N, attached hereto, measure compliance with the permanent injunction. Defendants agree to hire three staff members from the Office of the Special Master to monitor compliance with the permanent injunction and to perform the audits and related work described in paragraph 21(b), (c), (d), and (e), below.

(a). The Special Master shall complete approximately 700 validated full audits by March 31, 1993. Defendants shall take prompt action to correct any deficiencies cited in the audits.

(b). Within 24 months following entry of the permanent injunction, or longer on consent of the plaintiffs, defendants, together with staff from the Special Master's Office, shall complete surveys of each class member who was not fully audited by the Special Master as provided in paragraph 21(a) above, using

the short form audit instrument set forth in Appendix N attached hereto. Any class member whose compliance level is below 80% shall promptly be re-audited using the full audit instrument contained in Appendix N. Defendants shall promptly correct any deficiencies cited in the audits.

(c). Surveys, as required by state and federal law, will be conducted by the OMRDD defendants or the New York State Department of Health for every facility in which a class member resides and the results will be matched against the Willowbrook key indicators contained in Appendix N, attached hereto.

(d). In 1995, or at the completion of the process described in paragraph 21(b) above, whichever is later, defendants shall conduct a random sample audit of 350 class members at 350 different sites using the full audit instrument in Appendix N attached hereto, in order to determine whether class members are receiving the services required under the permanent injunction and whether the systemic problems identified in paragraph 20 have been corrected. Defendants shall devise a plan of correction for any deficiencies revealed by the audit.

(e). Defendants, together with the staff from the Special Master's Office described in paragraph 21(g) below, shall promptly devise and implement plans of correction for those individuals who are not receiving appropriate services as disclosed by the audits and surveys described above or other sources of information supplied to OMRDD.

(f). Plaintiffs may select independent consultants to review and validate the survey findings and corrective actions described above and report quarterly their findings to OMRDD, plaintiffs and the Commissioner's Task Force. OMRDD will furnish the survey findings, and raw data if requested, to plaintiffs, the Consumer Advisory Board, and the Commissioner's Task Force.

(g). Three members of the professional staff of the Special Master's Office shall continue their work, but under the direct supervision of the OMRDD Internal Audit Unit, and shall serve as staff to the Commissioner's Task Force and shall conduct the audits of class members after March 31, 1993. Defendants shall continue to employ these individuals in such capacity until one month after the completion and validation of the audits and corrective actions described in paragraph 21(b), (d) and (e) above, or December 31, 1995, whichever occurs later. In the event any staff member of the Special Master's Office does not remain until the completion and validation of the audits and corrective actions described above, he or she shall be replaced by an individual agreed upon by plaintiffs' counsel and defendants.

22. The court retains jurisdiction to enforce the provisions of this permanent injunction and for purposes of requests for attorney's fees and costs related to the monitoring and enforcement of the permanent injunction, except that after December 31, 1995, or two months after the completion and validation of the audits and corrections described in paragraph

21 above, whichever is later, plaintiffs may not seek attorney's fees for monitoring unrelated to a motion to enforce this permanent injunction.

23. Plaintiffs and defendants agree that the primary purpose of this permanent injunction is to guarantee members of the Willowbrook class certain basic, enumerated rights, high quality community residential and treatment services, high quality case management and advocacy services and the representation of noncorrespondent class members by the Consumer Advisory Board.

Dated: New York, New York
March 11, 1993

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Attorneys for Defendants

SO ORDERED:

JOHN R. BARTELS
United States District Judge

WILLOWBROOK

"Willowbrook" shall refer to the grounds of the former Willowbrook Developmental Center and the Institute for Basic Research, including the Staten Island Developmental Center, the Karl D. Warner Center, the Richmond Complex, and any subsequent structures.

Appendix A

RICHMOND COMPLEX

Defendants may operate on the grounds of Willowbrook and the Institute for Basic Research a residential facility to be known as the Richmond Complex, which shall be an institution of 150 or fewer beds. The number of residential beds at Willowbrook shall be 150 or less and shall not exceed 150 at any time.

Appendix B

POWERS OF INDEPENDENT EVALUATOR

1. The independent evaluator shall be allowed full access to all information, records (including budget records), buildings and areas covered by the preliminary injunction and shall be permitted to interview any member of the class or any employee of defendants, at reasonable times and places, to the extent necessary to the discharge of his duties.

2. Any interference with the independent evaluator in connection with his or her performance of the duties described herein, by any person having notice of the contents of this Order, may be punishable as contempt of court and subject to other sanctions provided by law.

3. In addition to those powers described above, the independent evaluator shall have the authority to:

(a) Require the defendants or their agents or any person who provides services to class members to submit any reports necessary to assist the independent evaluator in performing his or her duties, including programs, records and evaluations of individuals, and to assist in accomplishment of the community placement provisions of the Permanent Injunction;

(b) Provide advice and assistance to the parties in implementing the Permanent Injunction;

(c) Issue such reports to the parties and the Court as he or she deems useful in performing his or her duties;

(d) Consult with all parties and interested persons and bodies concerning implementation of the Permanent Injunction;

(e) Identify specifically any terms of the Permanent Injunction with which defendants are not in compliance. He or she may recommend a resolution of any disagreements which arise concerning compliance with the terms of the Permanent Injunction. Such recommendations shall be communicated in writing to the following: defendants, counsel for defendants, counsel for plaintiffs, and such other persons as the independent evaluator deems appropriate.

4. All parties shall be bound by the recommendations of the independent evaluator issued pursuant hereto, unless within 15 business days following receipt of such recommendations they serve on all other parties and file with the independent evaluator written objection to such recommendations. The filing of such an objection by any party shall automatically stay the effect of any such recommendation until further order of the Court. Within ten

(10) days of receipt of written objections, the independent evaluator or any other party, may apply to the Court for a hearing to determine whether the recommendations to which objection has been made should be adopted. Such applications shall be upon prior written notice to all parties and to the independent evaluator.

5. In order to achieve the goal of compliance with and enforcement of the Permanent Injunction, information investigations by the independent evaluator may be conducted as informal working sessions. Informal private consultations without the presence of counsel are permitted but the fact that such meetings were held shall be made known to all counsel by the independent evaluator keeping a record of them and making the record available.

6. The independent evaluator shall have no authority to exercise any control or management over the operation of any facility operated or licensed by the State of New York, but shall have authority to monitor the location and acquisition of community placement facilities in order to meet the placement goals of the Permanent Injunction and to make a report to the parties with respect thereto.

7. Defendants and all of their agents, as well as public agencies of the State of New York, will cooperate fully with the independent evaluator in order to accomplish the purposes of this order.

EMERGENCY FOR INCREASED BED SIZE

For purposes of this paragraph, an emergency situation shall be limited to the revocation, suspension or precipitous surrender of the operating certificate of a community or qualifying facility in which class members reside.

Appendix E

ATTACHMENT A CRITERIA

Defendants may place in appropriate long-term care facilities those class members who require extended intensive medical care at a more service-intensive level than that which is provided in an Intermediate Care Facility for the Mentally Retarded ("ICF/MR"), as defined in the Social Security Act, §1905(c) and (d) and 42 C.F.R. §§442.400 et seq.

PARAGRAPH 6 OF THE 1987 STIPULATION

Defendants shall continue to provide class members placed in facilities pursuant to paragraphs 4 and 5, above, with the least restrictive and most normal living conditions possible, consistent with the provisions of Appendix A, §§(1) and (2) of the Consent Judgment. Any placement pursuant to this Stipulation shall be appropriate to the individual needs of the class member and consistent with the provisions of Appendix A to the Consent Judgment.

JANUARY 3, 1992 ORDER RE: CAB

Active Representation

Active representation is generally defined as participation with the interdisciplinary team in planning and evaluating the individual development plan and/or visits between the correspondent and the individual class member at least annually. Merely signing consent forms sent through the mail or receiving phone calls initiated by facility staff with no other involvement does not constitute active representation.

UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF NEW YORK

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, et al., Plaintiffs, -against- MARIO CUOMO, et al., Defendants.	72 Civ. 356, 357 STIPULATION AND ORDER (J.R.B.)

WHEREAS, the Consumer Advisory Board was established pursuant to the provisions of §§ S and W of Appendix A to the Final Judgment entered on May 5, 1975 [393 F.Supp. 715 (EDNY)], and

WHEREAS, in paragraph 11a of the stipulation and order dated February 24, 1987, the defendants agreed to assure that necessary and appropriate representation and advocacy services were provided to noncorrespondent class members after the entry of a permanent injunction in this litigation,

NOW, IT IS HEREBY STIPULATED AND AGREED, by and between the parties, that the permanent injunction referred to in paragraph 11 of the stipulation and order dated February 24, 1987, shall contain the following paragraphs:

1. The seven member Consumer Advisory Board, as nominated and appointed pursuant to the provisions of § S (2) of Appendix A to the Final Judgment entered on May 5, 1975 [393 F.Supp. 715 (EDNY)] ("Consent Judgment") and paragraph 9 of the stipulation

and order dated February 24, 1987, shall continue to provide necessary and appropriate representation and advocacy services on an individual basis to all noncorrespondent former Willowbrook class members as long as any such class member shall live. The term "necessary and appropriate representation and advocacy services" shall include, but not be limited to, those representation and advocacy services which the Consumer Advisory Board has provided on an individual basis to noncorrespondent members of the Willowbrook class prior to the entry of this injunction.

2. The Consumer Advisory Board shall have direct access to all living areas and program areas used by noncorrespondent former Willowbrook class members and to all records relating to the care of any noncorrespondent former Willowbrook class member.

3. If necessary, or advisable, the Consumer Advisory Board may apply to an appropriate court for authority to exercise directly, or through its designees, the function of a guardian, for the purpose of providing necessary representation and advocacy services for a former Willowbrook class member. In general the defendants shall support such applications but reserve the right to oppose the particular person or persons nominated to serve as such guardian.

4. Defendants shall provide sufficient funds to ensure that the Consumer Advisory Board continues to be staffed with an executive director, two secretaries and program staff at a ratio of one (1) staff member for every 75 noncorrespondent clients

upstate and one (1) staff member for every 100 noncorrespondent clients in the New York City metropolitan area.

Dated: New York, New York
December 2, 1991

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Attorney for Defendants

SO ORDERED:

U.S.D.J.

January 3, 1992

Willowbrook Case Management

I. Definition of Case Management

A case manager is a qualified mental retardation professional (QMRP) who is either a state employee, or an employee of a voluntary agency that does not provide residential or day services to the class member. A class member or the class member's correspondent may choose a functionally independent case manager employed by the same agency that provides residential or day services if such a person is available. The case manager:

1. Promotes self-advocacy, self direction and choice;

2. Advocates and arranges for services that are accessible, community-based, comprehensive, and culturally appropriate;

3. Monitors the quality of services and programs provided to the consumer through measures of consumer satisfaction; and,

4. Monitors compliance of the services and programs with Willowbrook class requirements and entitlements and with state and federal laws and regulations.

II. Case Management Functions

The case manager shall perform the following functions on behalf of class members:

1. Advocacy

   a. The case manager shall protect and uphold the rights and entitlements of the class member in the residential program, in the day or work program, and in all spheres of the class member's life. These rights and entitlements are established by federal and state laws and regulations and by class membership under the permanent injunction. The case manager shall ensure that procedural and substantive due process requirements are met with regard to the class members and the class member's representatives.

b. The case manager shall ensure active representation, either by the class member or by a correspondent or Consumer Advisory Board ("CAB") representative.

c. The case manager shall display an appropriate long-term view for the class member that assures appropriately high, but realistic, expectations for growth, movement and independence.

2. Assessment

a. Through an interdisciplinary treatment team, appropriately constituted based on the needs of the individual, the case manager shall ascertain a class member's developmental level and specific needs for services.

b. The case manager shall ensure that all assessments for the class member including, where applicable but not limited to, medical, psycho-social, habilitative, psychological, speech therapy, food and nutrition, physical therapy, and occupational therapy, have been either completed or scheduled and the case manager shall request appropriate documentation of such.

3. Program Plan Development

a. The case manager shall make every effort to ensure that all appropriate parties, including the class member, the correspondent, the Mental Hygiene Legal Services ("MHLS") and the CAB representatives to the extent it represents a class member, are invited and in attendance at interdisciplinary treatment team meetings.

b. The case manager shall ensure development of a plan of needs and services for the class member.

c. The case manager shall ensure that each class member's developmental plan is reviewed by the class member's interdisciplinary treatment team at least annually or more frequently when required by the class member's individual needs. A class member's development plan shall be reviewed by the

interdisciplinary treatment team on a semi annual or quarterly basis if the class member, the correspondent, Consumer Advisory Board, or MHLS, to the extent it represents a class member, so requests.

4. Recordkeeping

a. The case manager shall ensure that the individual's record is maintained including the individual's plan for needs and services, persons responsible, and plans for data maintenance and monitoring.

b. The case manager shall prepare monthly case notes reflecting visits and progress.

c. The case manager shall ensure written notifications to the class member and correspondent as required by OMRDD's Client Placement Procedures.

5. Coordination

a. The case manager shall serve as a focal point for services.

b. The case manager shall coordinate among the diverse providers of service required by the class member, including their day and residential programs.

6. Linking

a. The case manager shall ensure that the class member is linked to new services, as needed. In doing so, the case manager shall, as needed, make referrals for the new services, arrange services at generic agencies, accompany the class member to agencies providing services or arrange for a person familiar with the class member and his or her needs to do so, assist in completing forms and applications, and perform other related duties.

7. Support

a. The case manager shall assist the class member and/or their family with unanticipated crisis intervention.

8. Monitoring/Follow-Up

a. The case manager shall assure that the class member is receiving appropriate services in accordance with their plans of needs and goals, and periodic reassessment of the class member's progress.

b. The case manager shall ensure that the class member's correspondent or CAB and MHLS representatives are kept informed of the class member's educational, vocational and living skills, progress, medical condition and other matters relevant to his or her care, treatment and development.

c. The case manager shall ensure reporting, investigation, implementation of preventive actions, and other needed follow-up on incidents which pose a risk to the health and safety of the class member or to others in the class member's immediate environment.

9. Discharge

a. The case manager shall coordinate the termination of services which are no longer needed by the class member or for which the class member is no longer eligible.

10. Case Manager Reporting

a. Case managers shall keep a list of dates of monthly contact with the class members and dates of attendance at team meetings, which shall be available to the plaintiffs and CAB upon request.

b. The DDSO shall monitor and evaluate case management services provided by voluntary agencies in order to ensure that all class members receive services in accordance with Appendix I.

PARAGRAPH P(2),(3), and (4) FROM THE CONSENT DECREE

P. Behavior Modification, Research, and Hazardous or Experimental Treatment

2. The use of aversive conditioning shall be permitted only after positive reinforcement procedures and other less drastic alternatives have been explored and approval has been obtained:

A. from the resident, if he or she is capable of giving informed consent, or

B. from the parent, relative or guardian if the resident can not give informed consent and the parent, relative or guardian can give informed consent, and

C. from a three person special committee on aversive conditioning, designated by the Director, which shall include at least one designee each from the Consumer Advisory Board and Professional Advisory Board.

The Deputy Commissioner for Mental Retardation, and the New York City Regional Director of the Department, shall be advised when a decision has been reached and approved to utilize such aversive conditioning. Aversive conditioning techniques shall be employed only under the supervision of and in the presence of a psychiatrist or psychologist licensed to practice in the State of New York who has had proper training in the use of such techniques, and who is specifically authorized by the Director to conduct such aversive conditioning.

3. Behavioral research or experimentation shall be conducted only after approval has been obtained as set forth in paragraph 2(A)-(C) above.

4. Because of the necessity to concentrate on the basic programmatic needs of Willowbrook residents and the history of experimentation at Willowbrook, no physically intrusive, chemical, or bio-medical research or experimentation shall be performed at Willowbrook or upon members of the plaintiff class. This standard, however, recognizes the possibility that such research or experimentation, under proper safeguards, may be appropriate for persons who are not members of the class, in other facilities or programs.

EMERGENCY MOVE

The immediate and unplanned change of residence of a person due to a sudden and acute medical or psychotic episode, behavior constituting an imminent danger of serious harm to the resident or others, or any other circumstance necessitating the immediate change of residence of a person.

SAMPLE - PLACEMENT NOTIFICATION LETTER TO CORRESPONDENT

This letter is to be adapted to suit the recipient and situation,
but must contain all the information herein

Date _____

Dear _____(correspondent)_____:

We are planning to move _____ from _____ (with a certified capacity of ___) to a _____(specify ICF/DD, CR, Family Care Home, DC, or any other placement)_____ operated by _____ and _____ located at _____ (with a certified bed capacity of ___) on or about _____.

This move has been planned because it has been determined that the proposed placement would offer him/her better services, a greater opportunity for personal development, and a more suitable living environment.

The staff of this facility/agency have considered whether the proposed placement complies with statutory, regulatory and other legal requirements and whether it is the least restrictive and most normal setting available and appropriate to _____'s needs. Since we believe this proposed move meets these conditions and is in _____'s best interest, we are requesting your agreement. Although we are including a copy of the Community Service Plan, you are invited to inspect the complete record on which the proposed placement is based.

You are also invited to visit both the residential placement site and proposed day program site. If you wish to do so, please contact me so I can make the arrangements, or you may contact the following parties directly:

Contact	(Name of Residential Placement Site Contact Address Telephone Number)	(Name of Day Program Address Telephone Number)

Please indicate on the enclosed form as to whether you agree or disagree with the proposed placement. If you do not agree, you have the right to request a hearing at which you may present your objections (see attached " Summary of Procedures for Responding to Placement Proposals").

If you, as correspondent, do not complete and return the enclosed "Proposed Placement Response" form within 30 days of receipt of this notice, the Consumer Advisory Board for the Willowbrook Class will be designated to advocate for the Class member, to review the proposed placement, and to make recommendations.

If you have any questions, including how to complete the attached "Proposed Placement Response" form, please contact me at _____(Phone number)_____.

Sincerely yours,

Attachments: Proposed Placement Agreement Response Form
Summary of Procedures for Objecting to Placement Proposals
Community Services Plan (IPP-70) (or equivalent)

cc: Person for whom Placement is Proposed
Mental Hygiene Legal Service (MHLS)
Consumer Advisory Board
Plaintiffs' Attorney
Receiving Facility (send to staff member named as contact)
Day Program (send to staff member named as contact)
B/DDSO

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229-0001

ELIN M. HOWE
Commissioner

THOMAS A. MAUL
Executive Deputy Commissioner

M E M O R A N D U M

March 12, 1993

To: All Willowbrook class members
All Willowbrook correspondents
Consumer Advisory Board
Mental Hygiene Legal Service

From: Alan M. Adler
Deputy Counsel

Subject: Notice of entry of Permanent Injunction

On March 11, 1993, Judge Bartels approved the entry of the Willowbrook permanent injunction which replaces the Willowbrook Consent Decree and all other orders in the Willowbrook litigation. Pursuant to the terms of the permanent injunction, you are to receive notice of class member rights and entitlements under the permanent injunction. The attached notice of rights will be placed in every class members' permanent record and will also serve as your notice.

In addition to the notice placed in the class members' permanent record, we are also notifying you that class members presently are entitled to receive active treatment and full day programs and it is the defendants' intention to continue these programs. If any aspect of the day program that the class member was entitled to under the Consent Judgment is proposed to be changed, including but not limited to the nature or duration of the program, you will be given notice of the proposed change and will have an opportunity to discuss the proposal and object to it if you are not satisfied. You will be entitled to

Right at home. Right in the neighborhood.

administrative and judicial review of the proposal if you object. Any future change in the program to which the class member was entitled under the Willowbrook Consent Judgment shall be permitted only on a showing that it provides a greater opportunity for the class member's growth and development and is based on an individualized assessment of the class member's current needs made by the individual's treatment team, including, where applicable, the individual's medical psycho-social, habilitative and psychological needs, in the exercise of its professional judgment. Appropriate changes in the individual developmental plan may be made where a class member is unable to participate fully in programming because of a medical condition or advanced age and such assessment is based upon a full individualized assessment of the class member's current needs in the manner described above. In the case of a class member incapacitated by a medical condition, prior programming shall be restored as soon as the individual is no longer incapacitated.

NOTICE OF RIGHTS

_____ was a member of the Willowbrook class and as such is entitled to certain rights and services which are guaranteed by a permanent injunction. This injunction was issued by the United States District Court for the Eastern District of New York on March 11, 1993 in the case of New York State Association for Retarded Children, et al., v. Cuomo, et al., 72 Civ. 356, 357.

This notice of rights must be placed in the consumer's files maintained by all providers of residential and habilitative services.

The consumer is represented by Rob Levy, an attorney with the New York Civil Liberties Union located at 132 West 43rd Street, New York, New York 11036. The telephone number of the NYCLU is 212 382-0557. The consumer may also be entitled to be represented by the Consumer Advisory Board, an advocacy group, located at 1150 Forest Hill Rd., Staten Island, New York 10314. The CAB's phone number is 718 983-5205. In addition to this special representation by the NYCLU and the CAB, the consumer may also be entitled to representation, like all other consumers, by the local office of the Mental Hygiene Legal Service (MHLS). If any problems arise concerning the consumer's rights under the permanent injunction, the NYCLU, CAB, and MHLS should be notified.

The following is a summary of the consumer's rights under the permanent injunction:

1. If the consumer is a resident of the Richmond Complex on Staten Island, the consumer has the right to high quality and appropriate medical and habilitative services, shelter, food and clothing which at a minimum conforms to state and federal regulations. Consumers at the Richmond Complex also have the right to be prepared for placement in a small community residence of 10 beds or less. The NYCLU will be notified of placement plans for consumers residing at the Richmond Complex by February 26, 1995.

2. If the consumer is not a resident of the Richmond Complex and is awaiting placement on February 26, 1993, the consumer is entitled to be placed pursuant to the approved placement plan by August 31, 1993. The placement will be monitored by Ms. Ronnie Cohn, an independent evaluator, pursuant to the permanent injunction.

3. Consumers who reside in community residential facilities on February 26, 1993 have the right to be maintained in that facility or another facility of equal or smaller residential capacity. The consumer can only be moved to a larger facility if a) medical or treatment needs require it, or b) if the consumer requests such a move, or c) the consumer is endangering other residents at the facility or is substantially interfering with the

operation of the facility, or d) in the event of an emergency as defined in the permanent injunction.

4. If the consumer does not have an active family member or friend to act as a correspondent, the consumer is entitled to be represented by the Consumer Advisory Board.

5. The consumer is entitled to case management services from a case manager who has a case load of no more than 20 consumers.

6. The NYCLU, CAB, and MHLS to the extent they represent the consumer, have access to the consumer, his or her records, and all facilities where the consumer receives residential or habilitative services.

7. The consumer has the right to a meaningful, full day habilitative program and services appropriate to his or her individual needs week days and meaningful, appropriate recreation and community integration weekday evenings and weekends. These habilitative services and recreation shall meet applicable regulatory standards. Consumers with capacity have the right to refuse such services and recreation.

8. The consumer's developmental plan shall be reviewed at least annually by the consumer's program planning team. More frequent reviews may be requested where appropriate. The consumer, if he or she has capacity, the consumer's correspondent or CAB representative, and the MHLS to the extent it represents the consumer, shall be invited to attend such reviews. Current professional assessments of the consumer's needs shall be maintained in the consumer's files.

9. The consumer is entitled to be protected from harm and is also entitled to a safe, clean, and appropriate physical environment.

10. The consumer is entitled to have sufficient staff members present to provide protection from harm and the habilitative and recreational services required by the permanent injunction.

11. Aversive conditioning, behavioral research, or experimentation may only be conducted after approval by a three person special committee.

12. Except in emergencies, the consumer, the CAB, the NYCLU until February 26, 1998, and the MHLS to the extent it represents the consumer, shall be given 30 days notice of any proposed transfer from the consumer's present residence. In addition, the consumer has the right to a hearing before an independent factfinder. These rights are the same as are afforded to all consumers on February 26, 1993. However, these rights must be afforded to this consumer for life regardless of changes that may be made that affect other consumers not subject to the permanent

injunction.

13. The consumer is entitled to continued residential, habilitative, and programming services that are reasonably unrestrictive and appropriate to his or her individual needs.

If anyone has any questions concerning this notice or the permanent injunction, please contact the attorneys for the plaintiffs or defendants:

Rob Levy
Senior Staff Attorney
NYCLU
132 W 43 St
New York, NY 10036
212 382-0557

Alan M. Adler
Deputy Counsel
OMRDD
44 Holland Ave.
Albany, NY 12229
518 474-7700

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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ELIN M. HOWE
Commissioner

(518) 474-7700
Fax: (518) 474-7382

THOMAS A. MAUL
Executive Deputy Commissioner

March 11, 1993

Robert Levy, Esq.
New York Civil Liberties Union
132 West 43rd St.
New York, New York 10036

Re: Willowbrook Permanent Injunction

Dear Rob,

This "side letter" will serve to confirm some of our understandings concerning the permanent injunction.

With regard to paragraph 5(a)'s Attachment 2, we have accounted for the 5,343 class members as best as humanly possible. If a class member whose present address is unknown should turn up at a later date, we will provide services and a placement. Likewise, if what appears to be a valid community placement turns out to be a nonqualifying facility, we will also be responsible for finding a placement in a qualifying facility. If there are any disputes as to whether an individual is entitled to a placement, the independent evaluator will resolve the dispute. If a class member is entitled to a placement, they will also be entitled to consent judgment services while awaiting placement.

With regard to paragraph 5(d), we have agreed that Ronnie Cohn will serve as the independent evaluator. While we do not expect that Ronnie will need the services of consultants, in the extraordinary circumstance that she does, she can request them from the defendants. Defendants will make sure that Ronnie has access to whatever technical assistance is necessary for her to carry out her duties.

The Principle of Capacity in Decision-Making

PRIANKA NAIR

ASSISTANT PROFESSOR OF CLINICAL LAW

BROOKLYN LAW SCHOOL

Legal Capacity

In the context of international law, legal capacity is generally understood as referring to the capacity of people to have rights, act on those rights and be recognized as having rights under the law.

- *Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women*: "States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals."
- *Article 12 of the Convention on the Rights of People with Disabilities:* States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law

Capacity

Capacity is term commonly used to refer to the cognitive ability of the person to make a decision and appreciate the consequences of making the decision or failing to make that decision. The law frequently links legal capacity with capacity, and removes legal capacity from those who are assessed as not possessing the capacity to make decisions.

For example, Article 81.02 (b) provides as follows:

(a) The determination of incapacity shall be based on clear and convincing evidence and shall consist of a determination that a person is likely to suffer harm because:

1. the person is unable to provide for personal needs and/or property management; and

2. the person cannot adequately understand and appreciate the nature and consequences of such inability.

Capacity: Fiction rather than Fact

Legal capacity and mental capacity are both constructs – a useful "legal fiction" that permits the state to "legitimately intrude" into the personal and property affairs of an individual: "Legal incapacity, so conceived, is important precisely because a [legal] fiction is determined by prevailing values, knowledge, and even the economic and political spirit of the time. . . . [The criteria or elements needed to establish legal incapacity are the products of society's prevailing beliefs concerning individual autonomy and social order, tempered by the restraint of legal precedent. Just as societal values and needs have evolved over time, so will the legal criteria for capacity and incapacity."

-Charles P. Sabatino & Erica Wood, The Conceptualization of Capacity of Older Persons in Western Law, in Beyond Elder Law: New Directions in Law and Aging 35, 36 (Israel Doron & Ann Snoden eds., 2012)

Ableism and Capacity

Ableism and Intersectionality

”[Intersectionality is] basically a lens, a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other. We tend to talk about race inequality as separate from inequality based on gender, class, sexuality or immigrant status. What’s often missing is how some people are subject to all of these, and the experience is not just the sum of its parts.”

- Kimberlé Crenshaw

Katy Steinmetz, *She Coined the Term ‘Intersectionality’ Over 30 Years Ago. Here’s What It Means to Her Today*, TIME (Feb 20, 2022), https://time.com/5786710/kimberle-crenshaw-intersectionality/

Parens Patriae and the Unequal Treatment of People with I/DD

"At English common law there was a "marked distinction" in the treatment accorded "idiots" (the mentally retarded) and "lunatics" (the mentally ill)…As Blackstone explained, a retarded person became a ward of the King, who had a duty to preserve the individual's estate and provide him with "necessaries," but the King could profit from the wardship. In contrast, the King was required to "provide for the custody and sustentation of [the mentally ill], and preserve their lands and the profits of them," but the King was prohibited from profiting thereby."

- *Heller v Doe by Doe*, 509 US 312, 326 (1993)

Buck v. Bell

"We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."

Buck v Bell, 274 US 200, 207 (1927)

Convention on the Rights of People with Disabilities

Article 12

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

International Covenant on Civil and Political Rights

Article 4

1 . In time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation… BUT

2. No derogation from articles …**16** …. may be made under this provision.

Article 16

Everyone shall have the right to recognition everywhere as a person before the law.

Meridian's other so-called genuine issues of material fact are simply statements of its belief that it was reasonable for it to take the risk that it could rely on the town's consultant to ensure that its (Meridian's) performance was in compliance with its legal obligations. However, in view of the nature of Earth Tech's contract with the town and Earth Tech's explicit, written memorandum issued to Meridian, it was neither reasonable nor justifiable for Meridian to rely on Earth Tech's performance of its contractual obligations to the town in ensuring that Meridian's own contractor complied with the requirements of the approved subdivision plan and the town's rules and regulations. See *Page v. Frazier,* 388 Mass. at 66, 445 N.E.2d 148.

3. *Conclusion.* Under the *Craig* principle of reasonable reliance, a professional employed by a town to inspect the construction of a subdivision does not owe a duty of care to a developer or its contractor with whom the professional has no contractual relationship unless it was foreseeable and reasonable for the developer or its contractor to rely on the services provided to the town by the professional, and the professional had actual knowledge that the developer or its contractor was relying on the professional's services. Because the record, when viewed in a light most favorable to Meridian, fails to show a genuine issue of material fact that would support the application of the *Craig* principle, the judge's allowance of summary judgment was not error.[9]

Judgment affirmed.

9. We decline to award the appellate attorney's fees requested by Earth Tech.

81 Mass.App.Ct. 136

GUARDIANSHIP OF Mary MOE.[1]

No. 12–P–18.

Appeals Court of Massachusetts, Norfolk.

Argued Jan. 10, 2012.

Decided Jan. 17, 2012.

Background: Department of Mental Health filed petition seeking to have mentally ill person's parents as guardians for purpose of consenting to the extraordinary procedures of abortion and sterilization. The Probate and Family Court Department, Norfolk Division, Christina L. Harms, J., appointed parents as guardians. Mentally ill person appealed.

Holdings: The Appeals Court, Grainger, J., held that:

(1) trial court violated due process by ordering sterilization sua sponte and without notice;

(2) sufficient evidence supported finding that person was incompetent; and

(3) trial court was required to hold evidentiary hearing to determine whether person would have an abortion if she were competent.

Reversed in part, vacated in part, and remanded.

1. Mental Health ⚿57

The personal decision whether to bear or beget a child is a right so fundamental that it must be extended to all persons, including those who are incompetent.

1. A pseudonym. See G.L. c. 112, § 12S.

2. Abortion and Birth Control ⚿117
Mental Health ⚿57

Because of the fundamental nature of the right to decide whether to bear or beget a child, in deciding whether a guardian may consent to an abortion or sterilization on behalf of the incapacitated person, a court applies the doctrine of substituted judgment.

3. Constitutional Law ⚿4340, 4450
Mental Health ⚿57

Trial court violated mentally ill person's due process rights, in granting petition for appointment of guardian for purpose of consenting to abortion, by sua sponte and without notice ordering that sterilization also be performed on mentally ill person. U.S.C.A. Const.Amend. 14.

4. Constitutional Law ⚿4340, 4450
Mental Health ⚿57

Because sterilization is the deprivation of the right to procreate, due process requires that an incompetent person be given adequate notice of the proceedings, an opportunity to be heard in the trial court on the issue of the ability to give informed consent, a determination on the issue of substituted judgment if no such ability is found, and the right to appeal. U.S.C.A. Const.Amend. 14.

5. Mental Health ⚿57

Personal rights implicated in petitions for sterilization of an incompetent person require a judge to exercise the utmost care; the judge must enter detailed written findings indicating those persuasive factors that determine the outcome.

6. Abortion and Birth Control ⚿117

Sufficient evidence supported trial court's finding that mentally ill person was incompetent to make decision as to whether to have an abortion, such as would support appointment of guardians to consent to abortion; although finding was not supported by person's mistaken beliefs that she had a daughter and that she had previously met the trial judge, person denied being pregnant, entitling trial court to infer that person was unable to confront the issue in a realistic manner.

7. Appeal and Error ⚿846(6)

When a trial court's findings do not justify its ultimate conclusion, an appellate court may examine the record to see if there are elements of uncontested evidence that would assist resolution of the question to be decided.

8. Mental Health ⚿14.1

A person may be adjudicated legally incompetent to make some decisions but competent to make other decisions.

9. Abortion and Birth Control ⚿123

Trial court, in proceedings on petition to appoint guardian for mentally ill person for purpose of consenting to abortion, was required to hold evidentiary hearing to determine, under doctrine of substituted judgment, whether person would decide to have an abortion if she were competent. M.G.L.A. c. 190B, § 5–306A.

10. Health ⚿912
Mental Health ⚿179

In utilizing the doctrine of substituted judgment, for purposes of making a decision on behalf of an incompetent person, a court does not decide what is necessarily the best decision but rather what decision would be made by the incompetent person if he or she were competent; if an individual would, if competent, make an unwise or foolish decision, the judge must respect that decision, assuming the judge were required to respect the same decision by a competent person. M.G.L.A. c. 190B, § 5–306A.

Jeffrey J. Isaacson for Department of Mental Health.

Douglas Charles Boyer for Mary Moe.

Present: GRAINGER, SIKORA, & HANLON, JJ.

GRAINGER, J.

Mary Moe appeals from an order by a judge of the Probate and Family Court Department appointing her parents as guardians for the purpose of consenting to the extraordinary procedures of abortion and sterilization. For the reasons stated herein, we reverse in part, vacate in part and remand the matter for further proceedings.

[137] 1. *Background.* The facts are undisputed. Moe, thirty-two years old, is mentally ill, suffering from schizophrenia and/or schizoaffective disorder and bipolar mood disorder. Moe is pregnant, although the record is unclear how long she has been pregnant.[2] She has been pregnant twice before. On the first occasion she had an abortion, and on the second she gave birth to a boy who is in the custody of her parents. At some point in the time period between her abortion and the birth of her son, Moe suffered a psychotic break, and has been hospitalized numerous times for mental illness.

The Department of Mental Health (department) filed a petition seeking to have Moe's parents appointed as temporary guardians for purposes of consenting to an abortion. A probate judge appointed counsel for Moe and conducted a hearing at which Moe, her court-appointed attorney, and counsel for the department were present. At the hearing Moe was asked about an abortion and replied that she "wouldn't do that." Moe also asserted that she was not pregnant and that she had met the judge before, although according to the judge, she and Moe had never met. Moe also erroneously stated that she had previously given birth to a baby girl named Nancy.[3]

Based on "several and substantial delusional beliefs," the judge found Moe incompetent to make a decision about an abortion. The judge appointed a guardian ad litem (GAL) to investigate the issue of substituted judgment, G.L. 190B, § 5–306A, and to submit a written report.[4] Additionally, at the request of Moe's counsel, the judge authorized funds for an expert to investigate and submit a report on the necessity of the proposed abortion and to provide expert testimony. However, no subsequent hearing was held, and no testimony or report from the expert was received by the judge or the parties.

The GAL submitted a report noting the following: In October of 2011, Moe visited a hospital emergency room, where a test [138] found that she was two to three months pregnant.[5] A consultation was ordered to determine the effect on the fetus of the

2. The parties estimate that Moe may be up to five months pregnant.

3. As stated, Moe has never given birth to a girl; her only child is a boy.

4. The judge also appointed a second GAL to oppose the recommendation by the first GAL if the first GAL concluded that Moe would choose an abortion if she were competent. See *Matter of Jane A.,* 36 Mass.App.Ct. 236, 237 n. 1, 629 N.E.2d 1337 (1994). Because the first GAL concluded that Moe would not choose an abortion, the requirement of a second GAL report was not triggered.

5. Moe visited the emergency room on or about October 15, 2011. The department filed a guardianship petition reasonably promptly thereafter, on October 24, 2011. However, a hearing on the petition was not held until December 8, 2011, and the judicial finding of incompetence was issued on December 9, 2011. The order granting a guard-

medication used to treat Moe's mental illness. The consulting physician determined that the risk of stopping that medication while Moe was pregnant was higher than simply continuing the medication. See note 7, *infra*.

The GAL report and the record generally provide additional background. The defendant suffered a psychotic break when she was a college student. Thereafter, she believed people were staring at her and stating that she killed her baby. She becomes agitated and emotional when discussing the pregnancy that ended in an abortion. Consistent with denying that she is now pregnant, she refuses obstetrical care and testing.

Moe also states that she is "very Catholic," does not believe in abortion, and would never have an abortion. Her parents, however, have stated that she is not an "active" Catholic. Moe's parents believe that it is in the best interests of their daughter to terminate her pregnancy. After investigating these facts and Moe's desires, the GAL concluded on a substituted judgment analysis that Moe would decide against an abortion if she were competent.

Without conducting a hearing, the judge concluded to the contrary, notwithstanding Moe's expressed preferences and the recommendations [6] of the GAL. Specifically, the judge "[credited] the facts as reported by the GAL," but found them "inconclusive." The judge reasoned instead that if Moe were competent, she "would not choose to be delusional," and therefore would opt for an abortion in order to benefit from medication that otherwise 139could not be administered due to its effect on the fetus.[7] The judge ordered that Moe's parents be appointed as coguardians and that Moe could be "coaxed, bribed, or even enticed ... by ruse" into a hospital where she would be sedated and an abortion performed.

Additionally, sua sponte, and without notice, the judge directed that any medical facility that performed the abortion also sterilize Moe at the same time "to avoid this painful situation from recurring in the future."

Moe appealed to the single justice of this court. Because the appeal was from a final order, we transferred the case to a panel of the court.

[1, 2] 2. *Discussion.* "[T]he personal decision whether to bear or beget a child is a right so fundamental that it must be extended to all persons, including those who are incompetent." *Matter of Mary Moe*, 31 Mass.App.Ct. 473, 477, 579 N.E.2d 682 (1991), quoting from *Matter of Moe*, 385 Mass. 555, 563–564, 432 N.E.2d 712 (1982).[8] Because of the fundamental nature of this right, in deciding whether a guardian may consent to an abortion or

ianship for purposes of consenting to abortion and sterilization was not issued until January 6, 2012. Consequently a pregnancy that was diagnosed at approximately ten weeks was ordered terminated at approximately twenty-one weeks. See G.L. c. 112, §§ 12L, 12M.

6. We do not intend to imply that the role of the GAL is binding or greater than to make "recommendations to the court." G.L. c. 190B, § 5–106(*b*). See Minehan & Kantrowitz, Mental Health Law § 10.18 (2007) (GAL's role is to "assist the court in conducting an independent investigation").

7. In fact and as stated, the medical report does not support such a determination unequivocally. Rather, in the apparent context of Moe's pregnancy, the reporting psychiatrist stated that the "risk of medicating this patient is much lower than that of withdrawing medication."

8. For clarity we refer to the Supreme Judicial Court decision as *Matter of Moe* and to the Appeals Court decision as *Matter of Mary Moe*.

sterilization on behalf of the incapacitated person, we apply the doctrine of substituted judgment. See *Matter of Moe,* 385 Mass. at 565, 432 N.E.2d 712; *Superintendent of Belchertown State Sch. v. Saikewicz,* 373 Mass. 728, 751–752, 370 N.E.2d 417 (1977); G.L. c. 190B, § 5–306A.

[3–5] a. *Sterilization.* Because sterilization is the deprivation of the right to procreate, it is axiomatic that an incompetent person must be given adequate notice of the proceedings, an opportunity to be heard in the trial court on the issue of the ability to give informed consent, a determination on the issue of substituted judgment if no such ability is found, and the right to appeal. See *Matter of Moe,* 385 Mass. at 566, 432 N.E.2d 712. "[P]ersonal rights implicated in . . . petitions for sterilization require the judge to exercise the *utmost care* . . . . The judge must enter detailed written findings indicating those persuasive factors that determine |140the outcome" (Emphasis added.) *Id.* at 572, 432 N.E.2d 712. In ordering sterilization sua sponte and without notice, the probate judge failed to provide the basic due process that is constitutionally required under the Fourteenth Amendment to the United States Constitution. We reverse the order directing Moe's sterilization.

[6–8] b. *Abortion.* (i) *Incompetency.* "When the findings do not justify the ultimate conclusion, an appellate court may examine the record to see if there are elements of uncontested evidence that would assist resolution of the question to be decided." *Matter of Jane A.,* 36 Mass. App.Ct. 236, 240, 629 N.E.2d 1337 (1994), citing *Bruno v. Bruno,* 384 Mass. 31, 35–36, 422 N.E.2d 1369 (1981). The judge relied on several undisputed facts to determine that Moe was incompetent to decide whether to abort the fetus. Our examination of the record reveals only one finding that provides evidentiary support for the judge's determination. Specifically, the fact that Moe denied her pregnancy entitled the judge to infer an inability to confront the issue in a realistic manner. The other facts on which the judge relied—that Moe believed she had a daughter or that she had previously met the judge—do not support a determination of incompetency on the issue whether to terminate her current pregnancy. "A person may be adjudicated legally incompetent to make some decisions but competent to make other decisions." *Matter of Moe,* 385 Mass. at 567–568, 432 N.E.2d 712.[9] While the judge's finding that Moe does not have the capacity to decide whether to have an abortion is not necessarily one we might have made as a trier of fact, it has support in the record. *Matter of Mary Moe,* 31 Mass.App.Ct. at 480, 579 N.E.2d 682 (appellate court reviews decision on competency to consent to abortion to ascertain if trial judge's decision supported by record).

[9, 10] (ii) *Substituted judgment.* Assuming that Moe is incompetent to decide whether to terminate her pregnancy, the substituted judgment standard applies. G.L. c. 190B, § 5–306A. That standard requires a determination whether Moe would decide to bring the fetus to term if she were competent. See *Matter of Moe,* 385 Mass. at 565, 432 N.E.2d 712. "In utilizing the doctrine [of substituted judgment,] the court does not decide what is necessarily the best decision but rather what decision would be made by the |141incompetent person if he or she were competent. 'In short if an individual would, if competent, make an unwise or

9. The parties do not contest Moe's incompetence in connection with the need for guardianship generally.

foolish decision, the judge must respect that decision,' " assuming the judge were required to respect the same decision by a competent person. *Ibid.*, quoting from *Guardianship of Roe*, 383 Mass. 415, 449 n. 20, 421 N.E.2d 40 (1981).

In this context the law requires an evidentiary hearing or, failing that, a finding that "extraordinary circumstances [exist] requiring the absence of the incapacitated person." G.L. c. 190B, § 5–306A(*d*), inserted by St.2008, c. 521, § 9. The judge's findings may, however, be based exclusively on "affidavits and other documentary evidence" if the judge makes an additional finding, based on representation of counsel, that there are no contested issues of fact. *Ibid.* The order here, issued without a hearing and without any findings to support the failure to conduct a hearing, did not comply with the conditions for its issuance established by law.

We note as well that Moe's "actual preference 'is an important part of the substituted judgment determination.' " *Matter of Mary Moe*, 31 Mass.App.Ct. at 477–478, 579 N.E.2d 682, quoting from *Matter of Moe*, 385 Mass. at 570, 432 N.E.2d 712. As stated, Moe has consistently expressed her opposition to abortion, and the GAL report concludes that she would continue to do so if she were competent.

3. *Conclusion.* We reverse that portion of the order requiring sterilization of Moe. No party requested this measure, none of the attendant procedural requirements has been met, and the judge appears to have simply produced the requirement out of thin air.

We vacate that portion of the order requiring Moe to undergo an abortion. We remand the case for a proper evidentiary inquiry and decision on the issue of substituted judgment. The record indicates that a determination should ensue with all possible speed before a different judge, and that such a determination will benefit from an immediate examination establishing the viability and status of the pregnancy.

We vacate that portion of the order insofar as it makes the appointment of the parents as guardians conditional on the need for them to approve an abortion (which issue is now subject to the preceding paragraph), and the order shall be modified to [142] allow their appointment for general purposes relating to Moe's routine medical care, health and welfare, including, as appropriate, the duration, condition, and viability of her pregnancy.

So ordered.

Standards of Capacity

MIRA B. WEISS,
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STANDARDS OF CAPACITY

- Matter of state law, no standard definition and there is no "bright line" test .
- The terms "capacity/competence" are used interchangeably.
- Individuals may have the capacity to perform one function and not another and individuals lacking the capacity to manage their affairs may still have the ability to participate in making decisions. *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 Fordham Urb. L.J. 495 (2016) https://ir.lawnet.fordham.edu/ulj/vol43/iss3/2
- There are more than 500 different standards for legal capacity in NY covering a myriad of laws.

COMPETENCE AND CAPACITY

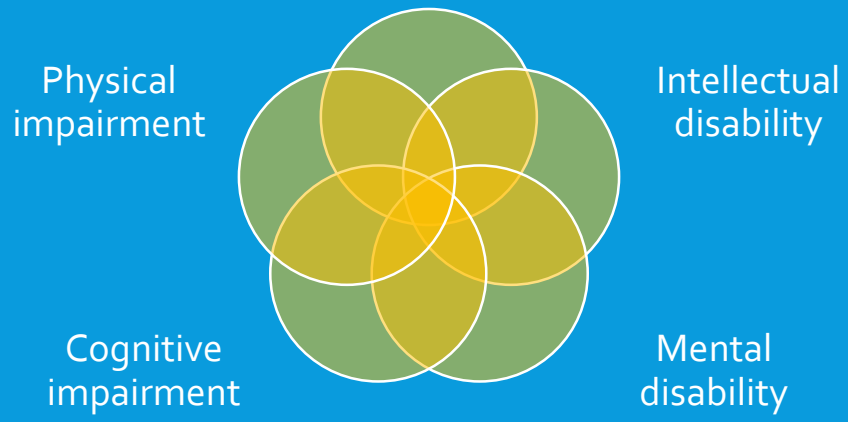
- **Testamentary Capacity** looks at (1) whether the testator understood the nature and consequences of executing a will; (2) whether she knew the nature and extent of the property she was disposing of; and (3) whether she knew those who would be considered the natural objects of her bounty and her relations with them. *In re Estate of Kumstar*, 487 N.E.2d 271, 272 (N.Y. 1985).
- **Contractual Capacity** requires the (1) functional ability to engage in a transaction; (2) actual knowledge of the matter being transacted. The general rule for determining the "capacity" necessary to enter into a valid contract is set forth in the Restatement (Second) of Contracts which reads: (2) A natural person who manifests assent to a transaction has full legal capacity to incur contractual duties thereby unless he is (c) mentally ill or defective.
- Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act UGCOPAA_Final_2020apr3.pdf) https://www.uniformlaws.org/search?executeSearch=true&SearchTerm=guardianship&l=1

JURY SELECTION (JUD. LAW 510)

- In order to qualify as a juror a person must: (1) be a citizen of the United States, and a resident of the country; (2) be not less than 18 years or age; (3) Not have been convicted of a felony; and (4) be able to understand and communicate in the English language. N.Y. JUD. LAW § 510 (McKinney 2019).
- The Commissioner of Jurors "determine[s] the qualification of a prospective juror, and is specifically permitted to examine a prospective juror in person "as to his or her ***competence***." N.Y. JUD. LAW (a)(b) (McKinney 2019). But competence is not defined.
- "At a minimum, a juror must be able to understand all of the evidence presented, evaluate that evidence in a rational manner, communicate effectively with the other jurors during deliberations, and comprehend the applicable legal principles, as instructed by the court." *People v. Guzman*, 555 N.E.2d 259. 261 (N.Y. 1990). *See also People v. Montada,* 671 N.Y.S.2d 62, 63 (N.Y. App. Div. 1998)

DETERMINING CAPACITY NY GUARDIANSHIP

ELEMENTS



Functional approach
MHL Art. 81

Diagnosis Driven
SCPA Art. 17A

Supported Decision
MHL Art. 82

GUARDIANSHIP MENTAL HYGIENE LAW (MHL ART. 81)

- Functional Article 81 applies to alleged incapacitated persons ("AIP")
  - Lacking the capacity to manage "person" and/or "property"
  - Cannot adequately understand and appreciate the nature and consequences of such an inability and is likely to suffer harm as a result. N.Y. MENTAL HYG. LAW § § 81.01, 81.02, and 81.03
- Least restrictive form of intervention
  - Powers limited to an individual's functional limitations
  - Takes into account AIP's wishes, preferences and desires
  - Affords independence and self-determination to the extent the individual is capable. N.Y. MENTAL HYG. LAW § 81.01
  - Requires clear and convincing evidence (higher than "best interest" standard which apply to SCPA Art. 17A guardianships.

STANDARDS OF CAPACITY NY GUARDIANSHIP LAW

"Throughout most of our legal history, judges and litigants have utilized unitary concepts like 'competent' or 'incompetent,' 'sane' or 'insane.' … It is only relatively recently, however, that the law has explicitly embraced the more nuanced view of modern psychology and psychiatry which recognizes that an individual may be perfectly 'competent' in one area, and 'incompetent' in another. Our legislature adopted this functional approach to determining capacity when it enacted Article 81 of the Mental Hygiene Law in the early 1990's."

Hon. Kristen Booth Glenn

In re Will of Khazaneh, 15 Misc. 3d 515 (Surr. Ct. New York County 2006)

SURROGATE'S COURT PROCEDURES ACT (SCPA 17-A)

- Provides guardianship over a person incapable of managing their affairs by reason of an intellectual disability or developmental disability." N.Y. SURR. CT. PROC. ACT § 1750(1).
- Plenary guardianship - Does not allow for the exercise of discretion to limit or tailor the scope of guardianship.
- Hearing not required /Assumes indefinite and in most cases, complete disability.
- Decision-making for the individual is based on the "best interest" of the disabled individual which is lower than clear and convincing evidence. *In re Muller*, 887 N.Y.S. 2d 768 (Surr. Ct. Duchess County 2009)

CIVIL RIGHTS VIOLATIONS

- Equal Protection and Due Process of People with I/DD Violates constitutional rights of "equal protection" and "due process" and Section 504 of the Rehabilitation Act of 1973 (see, Disability Rights New York v. 916 F.3d 129 (2d Cir. 2019)
- Article 12 of the United Nations Convention on the Rights of Persons with Disabilities declared that everyone, regardless of mental disability or cognitive impairment, is entitled to make decisions and have those decisions recognized under the law and that governments may not deprive individuals of their "legal capacity," or right to make decisions and have those decisions recognized. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/611, U.N. Doc. A/RES/61/611, art. 12 (Dec. 6, 2006)

SUPPORTED DECISION MAKING (MHL ART. 82)

- 82.03. Presumption of capacity.
- (a) For the purposes of this article, every adult shall be presumed to have the capacity to enter into a supported decision-making agreement, unless that adult has a legal guardian, appointed by a court of competent jurisdiction, whose granted authority is in conflict with the proposed supported decision-making agreement. This presumption may be rebutted only by clear and convincing evidence.
- (b) Capacity shall include capacity with decision-making support and/or accommodations.
- (c) A diagnosis of a developmental or other disability or condition shall not constitute evidence of incapacity.
- (d) The manner in which an adult communicates with others shall not constitute evidence of incapacity.
- (e) Neither the execution of a supported decision-making agreement by an individual, nor the interest in or wish to execute a supported decision-making agreement by an individual, nor the failure of an individual to execute a supported decision-making agreement may be used or considered as evidence that the individual lacks capacity, or to deny the decision-maker benefits to which they are otherwise entitled, including adult protective services.
- (f) A decision-maker may make and execute a supported decision-making agreement, if the decision-maker understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily. Guardianship to be last resort (considering all other decision-making alternatives) and tailored to the needs of each person (not plenary).
- (N.Y. MENTAL HYG. LAW § 82.03 (Consol., Lexis Advance through 2022 released Chapters 1-789))

WHO DECIDES?

- "I'm Petitioning … for the Return of My Life ", https://www.nytimes.com/2018/12/07/nyregion/court-appointed-guardianship-like-prison.html

- Program Compelling Outpatient Treatment for Mental Illness Is Working, Study Says https://www.nytimes.com/2013/07/30/us/program-compelling-outpatient-treatment-for-mental-illness-is-working-study-says.htm

RESOURCES

- Rebekah Diller ,*Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 Fordham Urb. L.J. 495 (2016) https://ir.lawnet.fordham.edu/ulj/vol43/iss3/2
- Kristin Booth Glen, *Not Just Guardianship: Uncovering the Invisible Taxonomy Of Laws, Regulations and Decisions That Limit Or Deny The Right Of Legal Capacity For Persons With Intellectual And Developmental Disabilities. And Developmental Disabilities*, 13 Alb. Gov't L. Rev. 25, 25, n.2 (2019-2020)
- Convention on the Rights of Persons with Disabilities, G.A. Res. 61/611, U.N. Doc. A/RES/61/611, art. 12 (Dec. 6, 2006)
- www.nycourts.gov/ip/gfs/ScpaArticle17-A.pdf

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Supported Decision-Making and Human Rights

Albany Government Law Center Webinar

January 12, 2023

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Surrogate, NY County (Ret.)

Director, Supported Decision-Making New York

Supported Decision-Making (SDM) and Human Rights: The Starting Point

- Guardianship removes all of a person's legal and civil rights
- Guardianship is based on some finding of lack of "capacity", usually conflated with "mental" capacity, whether diagnosis driven or "functional assessment"
- Particular guardianship laws are overlaid by constitutional and statutory imperatives of "least restrictive alternative" (Supreme Court, NY Court of Appeals, Second Department case law; Art. 82); and "most inclusive setting" (Olmstead)

Limitations of this lens

- The focus is on what a person can't do
- The assessment looks at the person "on their own" although this is not the way anyone makes decisions
- An underlying premise is that "normal", neurotypical people make "rational" decisions but neurodiverse people do not/cannot
- This premise has now been rebutted by mountains of research/evidence from, e.g. neuroscience and behavioral economics (e.g.3 recent Nobel Prize winners)
- It often leads to unnecessary guardianship and loss of fundamental rights

Human Rights: A better (or at least useful) Lens

The starting point is that everyone has the right to make their own decisions and have them legally recognized

This is not a rebuttable presumption

The existence–and recognition– of rights carries with it a corresponding obligation by government to provide the supports necessary to enable their citizens to exercise that right

So the question to be asked is not, “What can’t this person do” but

“What would it take to enable them to do it?”

How the HR lens applies here

- We already name and utilize supports where people with I/DD or cognitive decline are not able to make decisions about: Rep payee, SNTs; ABLE accounts, etc., and the law recognizes them as “less restrictive alternatives” to guardianship
- Applying the “least restrictive alternative” standard, to life decisions (where to live, work, with whom to associate, whether to arry, etc.) ask, “What supports would this person need to be able to make their own decisions instead of having someone else make those decisions for them?
- Which brings us to…..

Supported Decision-Making

- What is it?
- Where does it come from?
- What is happening in NY about SDM?
- How is SDM relevant to, and a resource for, practice?

What Is Supported Decision-making?

- Supported decision-making (SDM) is “a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”
  - Robert Dinerstein

Where does SDM come from?

- Our common experience of how everyone makes decisions
- The human right of every person to make her/his own decisions regardless of disability

Components of Decision-Making/Kinds of Support

- Gathering necessary information
- Understanding that information
- Identifying possibilities and alternatives
- Understanding consequences
- Weighing alternatives (“Deciding”)
- Communicating the decision to others
- Helping to implement the decision

Thinking about the variables in the broad definition of SDM

- Relationships, arrangements practices
- Degrees of formality and intensity
- Persons with disabilities that result is diminished capacity:intellectual and developmental; psychosocial; cognitive decline and dementia; traumatic brain injury (TBI)
- Kinds of decisions

SDM facilitation model as one practice, with one degree of formality, for one group of PWDD

- Fairly robustly developed for persons with intellectual and developmental disabilities based on pilots around the world inspired/incentivized by the UN Convention on the Rights of Persons with Disabilities (CRPD)
- In NY, beginning in 2016, SDMNY developed and piloted a 3-phase facilitation process that has enrolled more than 150 “Decision-Makers” and trained more than 200 volunteer facilitators
- Trained facilitators, under the supervision of mentors, work with the person with I/DD (the “Decision-Maker” or DM) (Phase 1); the DM and their chosen supporters (Phase 2); to negotiate and finalize a Supported Decision-Making Agreement (SDMA) (Phase 3)

SDMNY Facilitation: What it *Is*

- It *is*: utilizing trained facilitators to assist the parties in creating a process for the way in which the DM will *make decisions* (including delineating the areas in which the DM wants/needs support, the kinds of support desired, and the trusted persons in their lives who will give that support) going forward, hopefully for many years, after the facilitation is completed.
- It *is*: describing and formalizing that process in a Supported Decision-Making Agreement (SDMA), which may, if pending SDMA legislation passes, prevent discrimination against the person because of concerns about their legal capacity

Limitations on What We've Done and Learned So Far

- SDM may not work for people with the most severe impairments
- Many people have no natural support networks or viable supporters
- The facilitation model that works for people with I/DD is not directly transferable to other groups
- Pilot projects around the world have mainly focused on PWIDDs, with much less attention to people with psychosocial disabilities and virtually none on older persons with cognitive decline, dementia, etc.

Importance for Older Persons with Cognitive Decline and/or Dementia

- However worthwhile and valuable what comes in the future may be…it will not include greater freedom or autonomy. When freedom is curtailed in early dementia, it is final chances that are being foregone, not first chances with plenty of second chances to come. These are the last times something will be attempted or done, and perhaps it is a recognition of this, however dimmed by disease, that makes the desire to do something so curiously linger, even intensify, after the physical or mental capacity to do it safely has begun to slip away.

Bruce Jennings, *Freedom Fading: On Dementia, Best Interests and Public Safety,*35 Ga. L. Rev. 593, 609 (2001)

CRPD Article 12

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to ***the support they may require*** in exercising their legal capacity.

Legal Capacity Defined

- “legal capacity includes the ‘capacity to act’ intended as the **capacity** [capability?] **and power to engage in a particular undertaking or transaction** to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships”

  Background Paper on Legal Capacity—Office of the High Commissioner for Human Rights

CRPD Art. 12(4)

4.States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the ***rights, will and preferences of the person,*** are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests. (emphasis added)

Project Guardianship already actively advances human rights and principles enumerated in the CRPD

- Article 19 guarantees a right to live in the community in a place of one's choosing
- CRPD General Principles:

  (3) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices…

  Project Guardianship describes itself as "a program centered on human dignity"

Why is SDM important for Project Guardianship

- It aligns with PG's Mission Statement

"Project Guardianship was founded to create a solution to the injustices in the guardianship system. We designed and demonstrated a working model of providing guardianship that maximizes autonomy and engages the client in decision-making."

But also, an extraordinary opportunity

- It's not enough (or fiscally feasible) to make guardianship much better
  - As PG recognizes in its Strategic Plan, "Project Guardianship's goal is to reduce the overall need for guardianship and, *when all else fails*, to ensure that those who require guardianship are supported by high-performing guardians who have the resources to provide person-centered care that promotes autonomy and guarantees the least restrictive setting possible."(emphasis added)
- So how, with the unique resource you present, could you contribute to developing and pilot the supports necessary to make SDM work as an effective, viable "less restrictive alternative" to guardianship?

Some useful resources

- The SDMNY website
- The UN Convention on the Rights of people with Disabilities
- Decision-Make Jessica speaks about SDM and SDMNY facilitation
- Rebekah Diller's article on SDM and older persons