

## On “And Vulnerable”: Catholic Social Thought and the Social Challenges of Cognitive Disability

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IN SEPTEMBER 1965, THE BISHOPS OF THE Second Vatican Council were deep into the drafting process of *Gaudium et Spes*. That document began with the now famous words: “The joys and the hopes, the griefs and the anxieties of the men of this age, especially those who are poor or in any way afflicted, these are the joys and hopes, the griefs and anxieties of the followers of Christ” (*Gaudium et Spes*, no. 1). That same month, Senator Robert F. Kennedy paid a surprise visit to the Willowbrook State School, a state-supported institution for children and young adults with intellectual and developmental disabilities (IDD) in Staten Island, NY.<sup>1</sup> Kennedy was astounded and disgusted by what he saw. At the time, Willowbrook was housing 6000 individuals in a space designed for 4000. The facilities were understaffed and in disrepair, disease was rampant, and education was non-existent. Kennedy described the situation as one that “borders on a snake pit...[where] the children live in filth...[and] many of our fellow citizens are suffering tremendously because of a lack of attention, lack of imagination, lack of adequate manpower.”<sup>2</sup>

I raise the chronological nearness of these two events in order to highlight just how important the words “in any way afflicted” are to

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<sup>1</sup> It is important, at the outset, to note a distinction between the terms “impairment” and “disability.” These terms have been used in various ways throughout the growing field of disability studies, but, for my purposes here, I will distinguish between the biological conditions which impair one’s cognitive abilities (i.e. cognitive impairment) and cultural meaning and identity ascribed to those with such a condition (i.e. intellectual and developmental disability). I address this distinction in greater detail later in this essay.

<sup>2</sup> “Senator Robert Kennedy Visiting Institutions in New York,” *Parallels in Time: A History of Developmental Disabilities*, [mn.gov/mnddc/parallels/five/5b/bobby-kennedy-snakepits.html](http://mn.gov/mnddc/parallels/five/5b/bobby-kennedy-snakepits.html). In the video, Kennedy’s use of the term “snake pit” is likely a reference to the 1949 movie “The Snake Pit,” a semi-autobiographical story about one women’s experience in a mental institution. The movie’s authentic telling of conditions in a mental institution is credited with inspiring a series of reforms in mental institutions in the 1950s; see “The Snake Pit,” *Turner Classic Movies*, [www.tcm.com/this-month/article/2768380/The-Snake-Pit.html](http://www.tcm.com/this-month/article/2768380/The-Snake-Pit.html).

the bold and beautiful claim that opens *Gaudium et Spes*. The suffering experienced by the residents of Willowbrook and other ‘schools’ like it ranks among the greatest atrocities committed in this country. While it would be a stretch to believe that the authors of *Gaudium et Spes* were thinking of Willowbrook when they claimed the griefs and anxieties of those “in any way afflicted” as a central concern of the Church, there should be little doubt that the suffering of those with IDD fits well under it, both in the institution system of the mid-twentieth century and at the hands of modern constructs today.

Thankfully, today, the inhuman conditions of institutions like Willowbrook have been exposed and the institutionalization model for persons with IDD has been largely dismantled. Moreover, with the establishment of the Americans with Disabilities Act (ADA) in 1990, protections have been set to ensure that such a situation will not be repeated. However, neither of these advancements have fully alleviated the particular griefs and anxieties experienced by persons with IDD in the modern world. The ADA certainly aspired to such a task when it set the lofty but worthwhile goals of “assur[ing] equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.<sup>3</sup> However, now more than twenty-five years on, much work remains to be done. While the challenges differ in degree, when compared to the institution era, intentional and unintentional segregation of those with disabilities remains a serious roadblock to “full participation” and a causal factor in the perpetuation of stigma. In turn, social stigma and inadequate advocacy severely limits the achievement of “equality of opportunity” as a norm. Likewise, community-based housing and employment programs—while well-envisioned for developing the conditions for “independent living” and “economic self-sufficiency”—suffer from inadequate funding, shortages of qualified care providers, and an overall lack of political will to respond to inadequacies in the system.

In light of the ongoing social challenges or issues facing individuals with IDD in our time, I want to highlight some underappreciated aspects of Catholic social teaching that we would do well to recall. The discussion proceeds in four parts. First, I identify several key contemporary social challenges that continue to face individuals with IDD. Second, I trace the root of those particular challenges to the social forces of industrialization, urbanization, and social Darwinism in the second half of the nineteenth century. Third, on the basis of that historical framework, I argue that the contemporary Catholic response to the various social challenges of disabled persons has much to gain from serious consideration of Catholic social

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<sup>3</sup> Americans with Disabilities Act of 1990, Public Law 101-336. 108th Congress, 2nd session (July 26, 1990), [www.ada.gov/pubs/adastatute08mark.htm](http://www.ada.gov/pubs/adastatute08mark.htm).

thought's beginnings in *Rerum Novarum*—the Church's response to the suffering of the working class, as they bore the burden of the nineteenth century social forces just mentioned. So conceived, developments in Catholic social teaching since *Rerum Novarum* offer clues as to how the tradition can be applied to the particular social challenges facing cognitively impaired persons. Finally, I conclude with a proposal on how this interpretation of the tradition might further be developed and promoted.

### THE CURRENT STATE OF COGNITIVE DISABILITY IN AMERICAN SOCIETY

I focus on four overlapping social challenges or issues facing individuals with IDD today: segregation and stigma; inadequate, unfulfilling, and unlivable wage-earning employment opportunities; lack of adequate housing and care; and poor education and training. These are by no means the only issues at stake, but they are some of the larger blocks to achieving the ADA goals of “equality of opportunity, full participation, independent living, and economic self-sufficiency.”

According to the Shriver Report, a survey conducted by the Harris Institute in 2015, only 56% of Americans personally know someone with a cognitive disability and a mere 13% say they have a friend with a cognitive disability. In contrast, a whopping 42% of Americans have had no personal contact with someone with a cognitive disability. Similarly, while 93% of Americans believe that adults with cognitive disabilities should be encouraged to work, and 80% said that they would be willing to hire someone with a cognitive disability, a paltry 5% have actually worked with someone with a cognitive disability.<sup>4</sup>

One of the primary reasons that only 5% of the national population reports having worked with someone with a cognitive disability is that only 6% of adults with a cognitive disability actually work in the community. According to a survey of family members of adults with cognitive disabilities, collected by the disability advocacy group, The Arc, 9% of those surveyed indicate that their family member was working in a “sheltered workshop or enclave setting” while a massive 85% of families report that their family members were unemployed. This despite the fact that “the majority of people with [cognitive] disabilities want to have a job in the community.”<sup>5</sup>

Making matters worse, even among those working, nearly half work for less than minimum wage. Subminimum wages, which can be

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<sup>4</sup> “Insight into Intellectual Disabilities in the 21st Century,” *Disabled World*, [www.disabled-world.com/disability/types/cognitive/21st-century.php](http://www.disabled-world.com/disability/types/cognitive/21st-century.php).

<sup>5</sup> “Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (FINDS).” *The Arc*, [www.thearc.org/document.doc?id=3672](http://www.thearc.org/document.doc?id=3672).

as low as \$0.25 per hour, are legal loopholes built into the Fair Labor Standards Act of 1938 with the intention of encouraging the hiring of people with disabilities.<sup>6</sup> Among those unemployed, or severely underemployed, approximately 4.9 million Americans with a cognitive disability—those with extremely low wages or unemployed, and lacking other resources—rely on Supplemental Security Income (SSI) for their basic survival. However, in 2014, the average annual income of a single individual receiving SSI payments was \$8,995, 23% below the federal poverty level. Twenty-one states do supplement federal SSI payments, but these are also meager, ranging from a high of \$362 in Alaska to a low of \$5 in Nebraska. Moreover, these supplements have declined by 7% since 1998.<sup>7</sup>

One consequence of these paltry rations is that those who do not live with family are effectively priced out of a decent living arrangement. The 2014 national average annual rent for a modest one-bedroom unit was \$9,360 or 104% of SSI income, and the national average rent for a studio was \$8088 or 90% of an average SSI payment.<sup>8</sup> The U.S. Department of Housing and Urban Development (HUD) Section 811 Supportive Housing program was established to help solve this cost by producing affordable, accessible housing units that are specifically designed for people with disabilities, but the program has historically been unable to keep up with identified demand.<sup>9</sup>

Housing is just one of many government-funded services with extremely long waiting lists, including personal assistance, therapy, employment supports, and transportation. One third of those interviewed for The Arc’s study reported that they are on a waiting list for government-funded services of some kind. “A conservative estimate is that there are more than 1 million people with [cognitive disabilities] waiting for services that may never come.”<sup>10</sup> At the same time, threats of a further shortage loom as nearly 900,000 individuals currently live with a caregiver (typically a family member) who is over

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<sup>6</sup> “Still in the Shadows”; Cheryl Corley, “Subminimum Wages For The Disabled: Godsend Or Exploitation?” *National Public Radio*, [www.npr.org/2014/04/23/305854409/subminimum-wages-for-the-disabled-godsend-or-exploitation](http://www.npr.org/2014/04/23/305854409/subminimum-wages-for-the-disabled-godsend-or-exploitation).

<sup>7</sup> Emily Cooper et al., “Priced Out in 2014: The Housing Crisis for People with Disabilities,” *Technical Assistance Collaborative*, [www.tacinc.org/knowledge-resources/priced-out-findings/](http://www.tacinc.org/knowledge-resources/priced-out-findings/).

<sup>8</sup> Cooper et al., “Priced Out in 2014.”

<sup>9</sup> The Frank Melville Supportive Housing Investment Act of 2010 was aimed at modernizing the Section 811 program to more efficiently meet demand as they have not before. Significant waiting lists remain, however.

<sup>10</sup> “Still in the Shadows.” See also “In California, Aid Withers For People With Developmental Disabilities,” *National Public Radio*, [www.npr.org/sections/health-shots/2015/12/04/458458916/in-california-aid-withers-for-people-with-developmental-disabilities](http://www.npr.org/sections/health-shots/2015/12/04/458458916/in-california-aid-withers-for-people-with-developmental-disabilities).

60 years old and thus will soon not be able to continue to care for the individual with a disability.<sup>11</sup>

Finally, there is an argument to be made that part of the reason the low employment rate for adults with cognitive disabilities is because they are not receiving proper education when they are young. In The Arc study, 52% of families reported that their family member left school without receiving a high school diploma—a necessary prerequisite for employment in many cases. At the same time, fewer than one third of students with cognitive disabilities are fully integrated into mainstream classes, while more than one third of students are completely segregated from the mainstream students.<sup>12</sup> Thus, our special educational system, beneficial as it is in many cases, is for most people the first encounter with the normativity of segregation that remains in our society and consequently serves to reinforce a norm of segregation throughout the lives of people with IDD. As it is normative in schools, it should be no wonder that 42% of American adults have had no personal contact with someone with a cognitive disability.

### **THE MODERN SOCIAL CONSTRUCTION OF COGNITIVE DISABILITY**

As with many social issues, alleviating the suffering of individuals with IDD will require more than the establishment of rights or a mere material response (i.e. proper funding of housing, education, and employment programs). Addressing the challenges just laid out will require a shift in the social understanding of disability. Thus, it is important to recall the distinction between disability and impairment:

Disability is not a physical or mental defect but a cultural and minority identity. To call disability an identity is to recognize that it is not a biological or natural property but an elastic social category both subject to social control and capable of effecting social change.<sup>13</sup>

This distinction is important because, while cognitive impairments are a natural part of the human experience and have been throughout history, the social boundaries that emerge in response to those impairments operate uniquely in each given society and are, in fact, a product of that society and its history. Historians of disability have frequently observed that our understanding—who is considered disabled, how disability is defined, what cultural meanings are

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<sup>11</sup> Cooper et al., “Priced Out in 2014.”

<sup>12</sup> “Still in the Shadows.”

<sup>13</sup> Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 4, [hdl.handle.net/2027/mdp.39015082696892](http://hdl.handle.net/2027/mdp.39015082696892).

ascribed to a particular disability—is shaped largely by the social context of and the historical moment in which disability occurs.<sup>14</sup>

Moreover, not only are conceptions of disability historically located, but they are in fact the product of human effort. “Social problems like mental retardation are in fact social constructions...built from a variety of materials: the desire to help and the need to control, infatuation with science and technique and professional status, responses to social change and instability.”<sup>15</sup> With this in mind, I argue that our contemporary understanding of IDD has emerged in large part from the changes in the social status of those with cognitive impairments during the second half of the nineteenth century.<sup>16</sup> I contend that three factors—in particular, urbanization, industrialization, and the rise of social Darwinism—converged to lay the foundations of much of our contemporary understanding of IDD.

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<sup>14</sup> Katherine Castles, ““Nice Average Americans,”” in *Mental Retardation in America*, ed. Steven Noll and James W. Trent Jr., (New York: New York University Press, 2004), 352.

<sup>15</sup> James W. Trent, Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1994), 6.

<sup>16</sup> Space constraints limit my attempt to only a broad stroke summary in these pages. For a more detailed examination of the social construction of cognitive disability, see Trent, Jr., *Inventing the Feeble Mind*; Michael Wehmeyer, ed., *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, 1st ed. (Baltimore: Brookes Publishing, 2013); David Wright, *Downs: The History of a Disability* (Oxford: Oxford University Press, 2011), chap. 1; and C. F. Goodey, *A History of Intelligence and “Intellectual Disability”*: *The Shaping of Psychology in Early Modern Europe*, Kindle Edition (Burlington: Ashgate Publishing, 2013). Additionally, Henri-Jacques Stiker’s *A History of Disability*, trans. William Sayers (Ann Arbor: University of Michigan Press, 1999), focuses primarily on physical and sensory disability with occasional reference to cognitive disability but offers an important examination of the social construction of disability, widely construed, going back to antiquity. Similarly, Michel Foucault’s landmark text, *History of Madness*, ed. Jean Khalfa (New York: Routledge, 2006), while primarily an inquiry into mental illness and not cognitive disability, nevertheless offers important insight into the social construction of normalcy and abnormality with regard to human reason. See Shelley Lynn Tremain, ed., *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2010), 11: “An argument about disability that takes Foucault’s approach would be concerned to show that there is indeed a causal relation between impairment and disability, and it is precisely this: the category of impairment emerged and, in many respects, persists in order to legitimize the governmental practices that generated it in the first place.” Foucault occupies an important enough place in the field to be noted here, but a full Foucaultian critique leads away from the present topic. For more, therefore, Foucault’s ideas find application to disability in two important works edited by Shelley Tremain: the collection of essays *Foucault and the Government of Disability* as well as the June 2015 issue of the journal *Foucault Studies* offered on the 10<sup>th</sup> anniversary of the book (*Foucault Studies*, no 9).

## COGNITIVE DISABILITY IN THE PRE-INDUSTRIAL WORLD

In 1835, Thomas Cameron was a young postmaster in rural North Carolina; ten-year-old Lloyd Fuller was studying alongside his older brothers in their middle class New England home. Thomas and Lloyd would today be considered developmentally disabled; in the 1830s, that difference alone did not disqualify them from work, education, social invitations, or travel.<sup>17</sup>

Literature and historical accounts as far back as the sixteenth century give us images of the “village idiot” who was left to wander about in public, but, as historian David Wright notes, there is little historical evidence to sustain this stereotype as normative.<sup>18</sup> More typically, in the centuries leading up to the industrial revolution, individuals with cognitive impairments were integrated members of society and, more fundamentally, their families. The centrality of the family in this regard is evident in legal statutes going back at least to the thirteenth century English court document *Prerogativa Regis* (Kings Prerogative), which gave the King the right to seize the property of *fatui naturales* (natural fools) who were deemed unable to rule the estate themselves and place it in the care of a more capable family member, “who would commit themselves to administering the property (and maintaining the idiot and his family) in a responsible manner.”<sup>19</sup> When the “fool” passed away, his lands and title would be returned to his heirs. Similarly, at the other end of the economic spectrum, under the Poor Laws established under Elizabeth I, local parishes in England and Wales were deemed responsible for providing relief to the impoverished in their locality, including those with cognitive impairments. However, aid for those who could not care for themselves fell again to kin. Even when family was not available, aid took the form of “boarding out,” a form of early foster care (thus again following a familial model, artificial as it was).

That this familial care norm would continue well into the nineteenth century should not be surprising. During that time, the family was the fundamental social and economic unit of society. On the economic side, family farms and family businesses dominated the economy, and in America’s pre-industrial agrarian economy there was no lack of unskilled labor to be done. For the vast majority of society, education was largely provided at home. As such, families made a

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<sup>17</sup> Penny Richards, “Beside Her Sat Her Idiot Child: Families and Developmental Disability in Mid-Nineteenth-Century America,” in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James Trent (New York: New York University Press, 2004), 65.

<sup>18</sup> Wright, *Downs*, 24.

<sup>19</sup> Wright, *Downs*, 21.

place for all members of the clan, regardless of their abilities or disabilities. Social hierarchies in all classes remained very tied to familial lines. Hereditary rights remained a large part of the organization of society. Even as families served as the primary social unit, local communities also operated as an extension of the family as evidenced by the responsibility of the local parish in the Elizabethan Poor Laws and boarding out.

Early twentieth century sociologist Emil Durkheim identified these traditional, familial and community based networks as constructed on what he termed “mechanical solidarity.”<sup>20</sup> In mechanical solidarity, relationships are held together by commonality. Local communities in the pre-industrial West shared the same rituals, worshiped at the same churches, attended the same schools, and partook of the same festivals. They also shared the same immediate history: when a drought hit a localized agrarian community or when a harvest was plentiful, all in the community were affected. According to Durkheim, these shared experiences were what held society together.

#### **CARE FOR DISABILITY IN AN URBANIZED WORLD**

The nineteenth century was a period of exponential growth, massive change, and important tests for America. The nation expanded its borders, its population, its economy and its power. It was a century of turmoil and new beginnings. Near the eve of the century, America mourned the death of its first president and by mid-century survived its bloodiest and only civil war. And yet, over the course of the century, technology advanced like never before:

By the end of the 1880s, workers in urban settings rode elevators up to their offices in the amazing 10-story skyscrapers that were popping up seemingly everywhere. Once at their desks, they turned on the lights in their electrically lit offices, made calls on one of Bell’s amazing telephones, and typed letters on their new Remington typewriters.<sup>21</sup>

The advance of technology had a tremendous effect on society at large. New farm machinery meant that less manual labor was needed on the farms. At the same time, the rise of technology created an insatiable appetite for factory work. These two factors catalyzed a mass migration from rural areas to urban cities in America.

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<sup>20</sup> Emile Durkheim, *The Division of Labor in Society* (New York: Simon and Schuster, 2014), 57ff.

<sup>21</sup> Phillip M. Ferguson, “The Development of Systems of Supports: Intellectual Disabilities in Middle Modern Times (1800 CE to 1899 CE),” in *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, ed. Michael Wehmeyer (Baltimore: Brookes Publishing, 2013), 81.

The urbanization of America had a weakening effect on family bonds. With less work needed on the farms, many young adults left their family for work in the city. Distanced from traditional familial structures, urbanized workers sought new social structures in their new environment. The factory, rather than family, became the economic hub of society, while class replaced family as the fundamental unit of culture. Moreover, in the cities, factory work and especially the assembly line were made efficient by a specialization of labor.

The urban living environment encouraged specialization in other areas as well. No longer did each family own its own cow and churn its own butter. Rather, these former domestic tasks became centralized and sold as commodities. These shifting conditions created a functional difference in the forces that previously held society together. Under mechanical solidarity, similarity drew neighbors into community, but, in the new urbanized, centralized, and individualized world, society was held together by an individualized need of the other, or what Durkheim termed “organic solidarity.” When each individual has a highly specialized task in society, both the survival of the individual and the functioning of society as a whole rely on the specialization of countless others.<sup>22</sup>

Amidst these vast changes in society, it was likely inevitable that our societal response to cognitive impairment would also change.

Although people with intellectual disability seldom drove the engines of change, they were carried along with dramatic shifts in both definition and response to what was perceived to be a growing population of unproductive and dependent people, draining energy from the marketplace and distracting families from their proper role as sources of labor and respite for a hard-working population.<sup>23</sup>

While individuals with cognitive impairments found a natural place in the family and local community under the bonds of mechanical solidarity, in the urbanized, industrialized, and individualized economy, where an individual was measured by what they could bring to the table, what they could offer to the collective machine, those who were “unproductive” and “dependent” had no natural place.

### **WORK AND DISABILITY IN AN INDUSTRIALIZED WORLD**

In the midst of the great industrialization and urbanization of the nineteenth century, two economic downturns (1837-1843 and 1857-1861) prompted a need for an economic safety net in the new urbanized landscape. As noted above, in traditional economies, entire

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<sup>22</sup> Durkheim, *The Division of Labor in Society*, 88ff.

<sup>23</sup> Ferguson, “The Development of Systems of Supports,” 81.

communities would bear their fates together, sharing the burdens of economic hardships around the community. In the new industrialized economy, social structures built around individualism meant that some would remain afloat while others sank. For those in the latter category, a wide array of “institutional solutions for all types of devalued, or simply nonproductive, groups of people” arose.<sup>24</sup>

The first of these “institutional solutions” was the explosion of government-run almshouses in the late eighteenth and early nineteenth centuries.<sup>25</sup> These almshouses were intended to serve as a temporary respite for unemployed individuals as they got back on their feet. While these almshouses did serve a social good, they were also viewed with disdain—a last resort solution that marked the lowest point for a prideful worker. During this same time, work was also becoming more technical as the operation of machinery replaced many simple manual tasks, while mass urbanization prompted tremendous competition amongst workers for available jobs. Thus, even when a task was relatively low skill, competition favored those who could do low skill tasks faster and more efficiently. Soon a class of individuals emerged that had a very difficult time of ever securing and holding a job in this new economy and so remained dependent on the almshouses. In this environment, a distinction arose between the temporary poor and those with disabilities or mental illness. Those with disabilities had come to be understood as the “legitimate” poor, free from public disdain: “*True* or *justifiable* poverty entailed disability.”<sup>26</sup> When the economy recovered in the 1860s, public almshouses fell out of favor, but the view that those with disabilities should “legitimately” be supported by the state remained, demanding a new solution for the organized care of “idiots.”

### EDUCATION AND DISABILITY IN A MODERN WORLD

It was around this same time, psychology began to emerge as a distinct academic discipline and the specialized study of “idiocy” (as opposed to “insanity”) grew as its own sub-discipline. In 1840, a French doctor named Edward Séguin had begun a school in Paris dedicated to the education of individuals with cognitive disabilities. Public education for mainstream children was only just becoming a public priority, so the idea of specialized education for those with disabilities was especially novel. Séguin’s model was rooted in an

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<sup>24</sup> Phillip M. Ferguson, “The Legacy of the Almshouse,” *Mental Retardation in America: A Historical Reader*, eds. Steven Noll and James Trent (New York: New York University Press, 2004), 48.

<sup>25</sup> Between 1824 and 1850, Massachusetts went from 83 almshouses to 204. In the same years, New York went from 30 local almshouses in the metropolitan areas of the state to a county almshouse system in which 56 of 60 counties had centralized almshouses by 1857. See Ferguson, “The Legacy of the Almshouse,” 48.

<sup>26</sup> Ferguson, “The Legacy of the Almshouse,” 51; original emphasis.

assumption that education could only be effective if the students were segregated from family and community. The belief was that, with the proper education, individuals with cognitive disabilities could be “freed from inactivity and no longer a burden to their families” and would return to their families and communities upon completion of the program.<sup>27</sup>

Within a decade, schools using Seguin’s model emerged in the United States. The Massachusetts Asylum for Idiotic and Feeble-minded Youth (est. 1847) and the New York Asylum for Idiots (est. 1851) were two of the first. When Séguin, himself, emigrated to America in 1850, his stature in the world medical community added legitimacy to the cause, and, by 1870, the state school had replaced the almshouse as a “solution” for disability in America.<sup>28</sup>

Initially, this education movement met some successes in training and graduating “productive idiots.” However, for every successful case, there were other residents whose “limitations were great and whose eventual release was doubtful.”<sup>29</sup> For those that did “graduate,” expectations of a smooth transition into the community never materialized. The turbulent economic landscape meant that many could not find work in their home communities. With no place to go in the community, many graduates were forced back to the asylums. By the 1880s, the focus of the state schools began shifting from education and graduation to care and custody.

### SEGREGATION AND DISABILITY IN AN EVOLVING WORLD

In the 1860s, John Langdon Down (for whom Down syndrome is named) was the medical superintendent at the Earlswood Asylum for Idiots in England. Down had made a name for himself as a proponent of separating idiot asylums from lunatic asylums. (Cognitive disability and mental illness had previously been treated as similar conditions.) The Earlswood Asylum was the first asylum dedicated specifically to individuals with cognitive impairments in England.

Down was also a strong proponent of specialized education and separate treatment for individuals with cognitive impairments. Down, however, came up a generation after Seguin, Howe, and Wilbur and thus was influenced to a much greater degree by Darwinism and the biological experiments and hereditary studies of Gregor Mendel, O.S.A. Down began to speculate whether cognitive disability represented a regression of species to an earlier form. Drawing on popular notions that non-Caucasian races represented less developed species, Down claimed that each of these conditions represented a

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<sup>27</sup> Trent, Jr., *Inventing the Feeble Mind*, 26; Ferguson, “The Development of Systems of Supports,” 87.

<sup>28</sup> Trent, Jr., *Inventing the Feeble Mind*, 17–18.

<sup>29</sup> Trent, Jr., *Inventing the Feeble Mind*, 28.

regression to an earlier form of humanity and began to classify different types of idiots according to the races they most resembled. The most well-known of these was the "Mongolian idiot" (the condition now called Down syndrome), but other classifications included "Malay," "Ethiopian," "Aztec," and "Caucasian."<sup>30</sup> Down claimed that this "great Mongolian family" represented "the reversion of Caucasian children to an earlier 'less developed' race."<sup>31</sup> While the racially discriminatory undertones of this analysis cannot be ignored, Down's ethnic classification was never fully adopted by medical science, and, in the 1930s, Lionel Penrose conducted blood type studies that debunked Down's devolutionary theory. Socially, however, the lasting effects of Down's work and the notion that those with disabilities were somehow less human were immeasurable.

Down was not the only person who saw implications for disability in Darwinism. In the 1870s, the eugenics movement emerged in Europe and America. This movement proposed that, if Darwin's theory of evolution is correct, then it places upon society a moral burden to actively advance our species in future generations.<sup>32</sup> The simplest way to accomplish this was by eliminating from our reproducing population traits that could be viewed as negative and unproductive.<sup>33</sup> In the United States, this meant segregation (and later sterilization) of those with "undesirable traits," such as cognitive disabilities. During this time, the view of those with disabilities as "legitimate poor" gave way to a view of disability as a menace to society. In 1870, the U.S. census, which had counted "idiots" as a separate category since 1840, began placing this category in the same column as criminals and convicts. And in 1882, Congress passed the "Undesirables Act," which excluded convicts, paupers, the insane, and idiots from immigrating to the United States.<sup>34</sup> In 1878, Josephine Shaw Lowell opened the Custodial Asylum for Feeble Minded

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<sup>30</sup> Down noted that Mongolian idiocy was the most prevalent at Earlswood. This observation has proven indicative of the greater population as Down syndrome remains the most common condition of cognitive disability.

<sup>31</sup> David Wright, "Mongols in our Midst," in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James Trent (New York: New York University Press, 2004), 102. Historians today are quick to note that while these classifications seem offensive today, they were actually considered liberal in Victorian England. While the common theory of the time was that other races represented completely different species of lesser value, Down's theories understood that all humans evolved from the same species. See Wright, "Mongols in our Midst," 103-104.

<sup>32</sup> It should be noted that the 19<sup>th</sup> century not only marked the rise of evolutionary theory in biology, but also utilitarian theory in philosophy. Eugenics represented the merger of the absolutist forms of both of these theories.

<sup>33</sup> Of course, the industrial revolution had simultaneously helped to solidify the commonly-held view that "success" was defined in terms of productivity, and productivity was a function of intelligence.

<sup>34</sup> Trent, Jr., *Inventing the Feeble Mind*, 86.

Women in Newark, N.Y., marking the first American institution established specifically for the custodial care (as opposed to the education) for individuals with IDD.

Shall the State of New York suffer a moral leprosy to spread and taint her future generations, because she lacks the courage to set apart those who have inherited the deadly poison and who will hand it down to their children, even to third and fourth generations?<sup>35</sup>

The Custodial Asylum represented a new model of care in which segregation was permanent and the end in and of itself. In the state schools, education was the goal, and the “boarding” nature of the school was a means to that end. Moreover, while the original state schools were set up close to state capitals, as custodial care became the primary focus, institutions were designed as farm colonies in remote rural environments. During this time, families were discouraged from visiting individuals in the asylums and instead encouraged to forget that the family member even existed. Finally, in contrast to the state schools, there was little hope in the institutions that anyone would be able to “graduate” and return to mainstream society. Under this model, custodial care was permanent, non-educational, and as far removed from mainstream society as possible.

In summary, in the span of three generations in the second half of the nineteenth century, the typical life of an American with a cognitive disability went from being an integrated part of the education, work, and social life of one’s family and local community to a menial and segregated existence of custodial care, removed from family and community as a menace to mainstream social life. Today, while the most glaringly undignified aspects of this era have been dismantled, several social constructs regarding disability remain. First and foremost, even as society moves, in theory, toward greater integration of those with cognitive impairments into mainstream society, the legacy of cognitive disability understood as a menace, mystery, and drain on society still looms large in our current context and creates a reality in which nearly half of American adults have never had any serious contact with an individual with a cognitive impairment.<sup>36</sup> Second, the shift away from a traditional family structure and toward

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<sup>35</sup> Josephine Shaw Lowell, “One Means for Preventing Pauperism,” in *Proceedings of the National Conference of Charities and Correction* (1879): 189-200, as quoted in Nicole Rafter, “The Criminalization of Mental Retardation,” in *Mental Retardation in America*, ed. Steven Noll and James W. Trent Jr. (New York: New York University Press, 2004), 239.

<sup>36</sup> Couple this history with a nearly a century of institutionalization in which the typical American neighborhood, school, and church did not include cognitive disability, and a certain mystery and trepidation about how to relate to those with cognitive impairments compounds the issue all the more.

government provided care, education, housing, and employment for those with disabilities remains at least partially normative today. Even those who continue to live with their families into adulthood still often participate in public special education and other training, draw SSI and other government funds, and partake of other public services for those with disabilities, making the current role of the family as much advocacy as caregiving. Third, the post-industrial capitalist economy that is built on organic solidarity and values individuals based on their skill, ability, and contribution remains our standard today as it was at the height of the industrial revolution. Such a society can only locate individuals with cognitive disabilities at the economic bottom and dependent on either a social safety net or the charity of others (an economic state that is underscored by a historical legacy in which disability was synonymous with a condition of legitimate poverty.)

### **CATHOLIC SOCIAL THOUGHT: A RESPONSE TO SOCIAL UPHEAVAL**

It is no coincidence that modern Catholic social thought emerged around the same time that institutionalization was becoming the new standard of care for individuals with IDD, for when he wrote *Rerum Novarum*, Pope Leo XIII was aiming to address many of the same social forces that gave rise to such treatment of individuals with IDD. In his opening soliloquy that set the stage for the entirety of the tradition, Leo wrote,

The elements of the conflict now raging are unmistakable, in the vast expansion of industrial pursuits and the marvelous discoveries of science; in the changed relations between masters and workmen; in the enormous fortunes of some few individuals, and the utter poverty of the masses; the increased self-reliance and closer mutual combination of the working classes; as also, finally, in the prevailing moral degeneracy. The momentous gravity of the state of things now obtaining fills every mind with painful apprehension; wise men are discussing it; practical men are proposing schemes; popular meetings, legislatures, and rulers of nations are all busied with it - actually there is no question which has taken deeper hold on the public mind.

Therefore, venerable brethren, as on former occasions when it seemed opportune to refute false teaching..., We thought it expedient now to speak on the condition of the working classes. (*Rerum Novarum*, no. 1)

Leo XIII leaves no doubt that the ultimate object of his work is the plight of working people of that age. While Leo XIII's words are not directly addressed to individuals with IDD, in identifying the social shifts of the urbanized, industrialized, modern world as the cause of the plight of the working classes, *Rerum Novarum* and the Catholic

social tradition it spurred offer a theologically grounded critique of modernism that is useful for the task at hand.

### **LAYING THE GROUNDWORK: THE THEOLOGICAL IMPORTANCE OF HUMAN DIGNITY**

The cornerstone of Catholic social teaching is the fundamental dignity of the human person. “God has imprinted his own image and likeness on man (see Gen 1:26), conferring upon him an incomparable dignity.... In effect, beyond the rights which man acquires by his own work, there exist rights which do not correspond to any work he performs, but which flow from his essential dignity as a person” (*Centesimus Annus*, no 11). This dignity is unique to humans—as the only part of creation made in the image of God—but universal to all humans, regardless of age, race, gender, creed, or (dis)ability. A simplistic application of this theme would argue that those with disabilities are made in the image of God and thus share in the unique dignity of humanity. Equally human, the Church and her members have a duty to protect the dignity of those with disabilities against the forces in this world that would seek to take that dignity away. As the US Catholic Bishops note, human dignity defines the fundamental and basic orientation each must take towards another: “Human personhood must be respected with a reverence that is religious. When we deal with each other, we should do so with the sense of awe that arises in the presence of something holy and sacred. For that is what human beings are: we are created in the image of God.”<sup>37</sup>

From John Langdon Down’s devolutionary theory of disability to capitalism’s emphasis on material production as the means of valuation for individuals, significant forces in the modern world have contributed to the view that individuals with disabilities are of less value than those who are not disabled. In response, Catholic social teaching appeals to the dignity of humanity as the theological justification for the establishment of basic rights (*Gaudium et Spes*, no. 26ff), such as those laid out in the ADA. This is all good, so far as it goes, but, as I have noted, the establishment of rights alone is insufficient for addressing the depth and the breadth of the social constructions that are embedded into our very understanding of disability. Fortunately, while Catholic social thought provides a framework for rights, it does not end with the bare assertion of rights.

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<sup>37</sup> National Conference of Catholic Bishops, *Economic Justice for All: Pastoral Letter on Catholic Social Teaching and the U.S. Economy*, 10<sup>th</sup> Anniversary edition, [www.usccb.org/upload/economic\\_justice\\_for\\_all.pdf](http://www.usccb.org/upload/economic_justice_for_all.pdf), no. 28.

### RELIEVING THE TENSION BETWEEN FREEDOM AND COMMUNITY IN THE MODERN WORLD

For Catholic social teaching, human dignity, rooted in the *Imago Dei*, also provides the theological grounding for both human freedom and human community.

For Sacred Scripture teaches that man was created “to the image of God,” is capable of knowing and loving his Creator, and was appointed by Him as master of all earthly creatures that he might subdue them and use them to God’s glory. “What is man that you should care for him? You have made him little less than the angels, and crowned him with glory and honor. You have given him rule over the works of your hands, putting all things under his feet” (Ps. 8:5-7). But God did not create man as a solitary, for from the beginning “male and female he created them” (Gen. 1:27). Their companionship produces the primary form of interpersonal communion. For by his innermost nature man is a social being, and unless he relates himself to others he can neither live nor develop his potential. (*Gaudium et Spes*, no. 12)

Human freedom, present in each individual from the moment of creation, is our freedom to make choices and act independently from the Divine will of God. However, even as humans are free to abuse this freedom, we are called to perfect our freedom by directing our choices toward God (*Catechism*, no. 1731). Community emerges from freedom as one of the primary commands of the Divine will:

God, Who has fatherly concern for everyone, has willed that all men should constitute one family and treat one another in a spirit of brotherhood. For having been created in the image of God, Who “from one man has created the whole human race and made them live all over the face of the earth” (Acts 17:26), all men are called to one and the same goal, namely God Himself.

For this reason, love for God and neighbor is the first and greatest commandment. Sacred Scripture, however, teaches us that the love of God cannot be separated from love of neighbor: “If there is any other commandment, it is summed up in this saying: Thou shalt love thy neighbor as thyself .... Love therefore is the fulfillment of the Law” (Rom. 13:9-10; see 1 John 4:20). To men growing daily more dependent on one another, and to a world becoming more unified every day, this truth proves to be of paramount importance. (*Gaudium et Spes*, no. 24)

Thus, while freedom is fundamental to our humanity, the proper use of that freedom is to serve God and serve each other.

The concepts of freedom and community are important as the devastating forces that emerged in the wake of the industrial

revolution were, in many ways, a perversion and overindulgence of human freedom and the undermining of human community. The status quo in 1891 was a condition in which freedom went unchecked by Church, state, or other communal organization:

[S]ome opportune remedy must be found quickly for the misery and wretchedness pressing so unjustly on the majority of the working class: for the ancient workmen's guilds were abolished in the last century, and no other protective organization took their place. Public institutions and the laws set aside the ancient religion. Hence, by degrees it has come to pass that working men have been surrendered, isolated and helpless, to the hardheartedness of employers and the greed of unchecked competition. (*Rerum Novarum*, no. 9)

Leo's solution was to recognize the moral burden borne by the owner to each worker in accordance with natural law and the dignity of each human person: "The following duties bind the wealthy owner and the employer: not to look upon their work people as their bondsmen, but to respect in every man his dignity as a person ennobled by Christian character" (*Rerum Novarum*, no 20). That is, the owner ought to use his freedom in the service of God and community.

At the same time, Leo cautioned about inverting the paradigm, and placing the community as the sole value to the exclusion of the exercise of individual human freedom, as the communists proposed. Leo defended private property and sought limits on the power of the communal government:

The contention, then, that the civil government should at its option intrude into and exercise intimate control over the family and the household is a great and pernicious error. True, if a family finds itself in exceeding distress, utterly deprived of the counsel of friends, and without any prospect of extricating itself, it is right that extreme necessity be met by public aid, since each family is a part of the commonwealth. In like manner, if within the precincts of the household there occur grave disturbance of mutual rights, public authority should intervene to force each party to yield to the other its proper due; for this is not to deprive citizens of their rights, but justly and properly to safeguard and strengthen them. (*Rerum Novarum*, no. 16)

Here again, however, he does not reject the notion of communal authority and the need for public aid on the part of the commonwealth. Rather, he takes what modern society has placed at odds—individual freedom and the common good—and instead draws them together in service of the same ends: service of God and neighbor.

There is a lesson in this for cognitive disability. Of the various social structures put in place to respond to cognitive disability, those

systems that allow too much individual freedom and favor the capitalist market will inevitably leave individuals with IDD in a position of scarcity and suffering. We saw this in the early industrial age, prior to the state schools. On the other hand, efforts to restrict freedom and create tightly controlled environments, such as in the institutional era, find philosophical parallels in the centralizing functions of communism. History has shown that overreaching by central authorities in the name of the common good leads to poor results for those with disabilities.

It is in this impasse that society finds itself today. In recent decades, American society has stepped away from the atrocity of the institution system with the creation of successful community-based programs that seek explicitly to allow the greatest degree of freedom possible. At the same time, certain legacy factors keep society from being able to achieve such a state. On the one hand, society is still built on individualism and organic solidarity, so if the system allows too much individualized freedom—as is the case, for example, with employment today—then individuals with IDD will inevitably be left out. On the other hand, the legacy of centralized control means that funding and authority for any of these programs still runs through the centralized state, and, since individuals with IDD rank fairly low when it comes to governmental priorities, funding shortages and waitlists are common.

In *Rerum Novarum*, Leo argued that “no practical solution for this [impoverishment] will ever be found apart from the intervention of religion and the Church” (no. 16). This is as true for disability as it was (and is) for poverty, for solving either of these issues requires a teleological anthropology that orients our freedom toward the love of God and neighbor. Secular documents of rights, while necessary to avoid a regression into atrocity, merely set a floor for societal treatment of those with disabilities. The recognition of the *Imago Dei* serves as a reminder that, by the grace of God, all are free and equal in dignity. Recognition of the *Imago Dei* in others, reminds us that in that freedom and in dignity, God calls us to community.

### A ‘THIRD WAY’ OF SOLIDARITY

Being called to community requires the Church, both the institution and its membership, to be intentional about the basis of communal life. Earlier in this essay, I noted that, in his examination of the shift from traditional to modern economies, sociologist Emil Durkheim identified two types of solidarity. Durkheim’s “organic” solidarity was rooted in interdependence. I interact with you because I need something from you. This is the way of the modern world, built on a robust individualism, market capitalism, the division of labor, and exchange of goods. It is also one of the most fundamental stumbling blocks to the advancement of people or individuals or persons with

disabilities, since they often have less (materially) to offer than the nondisabled in the exchange and, consequently, are often excluded from active participation in society.

Durkheim's "mechanical" solidarity, on the other hand, arose not out of need for what the other can offer but out of commonality with the other. I interact with you because I share something in common with you. For Durkheim, mechanical solidarity typified the traditional way of life in small towns, where experiences, good and bad, were shared by all. Today, society cannot return to its pre-industrial norms, nor should it. The local bonds of mechanical solidarity, while perhaps a better state of affairs for people with disabilities, also gave rise to tremendous violence. Such bonds, rooted in cultural and material similarity, are at the very root of war, slavery, ethnic cleansing, racism, and genocide.

Catholic social teaching calls individuals to solidarity but not in either of the senses that Durkheim uses the term. Catholic solidarity, by contrast, is a prescriptive command derived from our shared creation and existence.

Interdependence must be transformed into *solidarity*, based upon the principle that the goods of creation are meant for all. That which human industry produces through the processing of raw materials, with the contribution of work, must serve equally for the good of all. (*Sollicitudo Rei Socialis*, no. 39)

Or, as interpreted by the US Bishops:

We have to move from our devotion to independence, through an understanding of interdependence, to a commitment to human solidarity. That challenge must find its realization in the kind of community we build among us. Love implies concern for all - especially the poor - and a continued search for those social and economic structures that permit everyone to share in a community that is a part of a redeemed creation. (*Economic Justice for All*, no. 365)

By calling individuals each to embrace a solidarity that is rooted in a shared humanity rather than material interdependence (organic solidarity), Catholic social teaching includes people with disabilities as a fundamental part of society, rather than a dependent burden on society.

### **SUBSIDIARITY, THE PRIMACY OF THE FAMILY, AND LOCAL ASSOCIATIONS**

For the Church, the primary model of solidarity is the nuclear family. The family is "the most intimate sphere in which people

cooperate...., [It is] the ‘first cell of society.’”<sup>38</sup> As such, it is notable that families do not operate out of any type of functional interdependence. At birth, a child is fully dependent on her or his parents, and, the power of a smile or a giggle aside, an infant offers nothing of material value in exchange for his or her care. Rather, families are the most intimate and fundamental example of the bonds inherent in our nature as social beings.

I have already noted the important advocacy role that family members play on behalf of individuals with disabilities today. Despite the efforts of the Church, the industrialized world continues to reward individuals on the basis of material merit and, thus, reject those who seem to have little of material value to offer. By exalting the bonds of family, however, Catholic social teaching acknowledges the family as the fundamental social unit to which individuals belong regardless of material merits. As such, it also gives warrant to the family’s role as advocate for individuals with IDD.

The Church does not expect families to carry the load themselves, however. The bonds of the family, strong as they are, also offer the model of solidarity for the rest of the world to emulate.

The roots of the contradiction between the solemn affirmation of human rights and their tragic denial in practice lies in a notion of freedom which exalts the isolated individual in an absolute way, and gives no place to solidarity, to openness to others and service of them ... [E]very [person] is his “brother’s keeper,” because God entrusts us to one another. (*Evangelium Vitae*, no. 19)

While the call to solidarity is universal, the Church also recognizes the importance of it being fulfilled locally.

Government should not replace or destroy smaller communities and individual initiative. Rather it should help them contribute more effectively to social well-being and supplement their activity when the demands of justice exceed their capacities. This does not mean, however, that the government that governs least, governs best. Rather it defines good government intervention as that which truly “helps” other social groups contribute to the common good by directing, urging, restraining, and regulating economic activity as “the occasion requires and necessity demands.” (*Economic Justice for All*, no. 124)

This principle of “subsidiarity” offers valuable caution against the centralized and institutionalized responses to social problems that have, time and time again, failed to adequately respect the human dignity of individuals with disabilities.

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<sup>38</sup> Thomas Massaro, *Living Justice: Catholic Social Teaching in Action* (Lanham: Rowan & Littlefield Publisher, 2000), 124–125.

### IN DEFENSE OF “AND VULNERABLE”

If the principle of human dignity provides the cornerstone of Catholic social thought, then the principle of a Preferential Option for the Poor and Vulnerable is its capstone, that which completes the arch and holds it all together. For the past few decades the Preferential Option for the Poor has served as a summative claim, bringing together the whole of Catholic social thought into the singular idea. This principle places special burdens on those who are blessed with great fortune—be it material riches or physical or cognitive abilities—and special rights on those who do not.

Whoever has received from the divine bounty a large share of temporal blessings, whether they be external and material, or *gifts of the mind*, has received them for the purpose of using them for the perfecting of his own nature, and, at the same time, that he may employ them, as the steward of God's providence, for the benefit of others. “He that hath a talent,” said St. Gregory the Great, “let him see that he hide it not; he that hath abundance, let him quicken himself to mercy and generosity; he that hath art and skill, let him do his best to share the use and the utility hereof with his neighbor.” (*Rerum Novarum*, no. 23)<sup>39</sup>

In this way, the preferential option inverts the typical paradigm in which those with fortune and power may wield those resources to gain more fortune and power, while those who lack these riches remain powerless and often, thereby, victimized. Without the principle of the preferential option, a follower of Catholic social thought might well be satisfied with equal treatment of the powerful and the powerless. A preferential option for the poor and vulnerable calls those who possess power and privilege to aim beyond equal treatment and, instead, seek a special place for those who are poor, lowly, and vulnerable.

Often, however, the “and vulnerable” clause of the principle is omitted, thus reducing Catholic social concerns only to the materially poor. This is a mistake. A preferential option *for those with disabilities* suggests that it is not enough to simply tear down the institutions and asylums and return individuals with disabilities to mainstream society. Rather, the Church must give special attention to the needs of people with disabilities in a modern world that otherwise leaves no place for them. Special education, specialized group homes, and dedicated work programs that help to promote the livelihood of those with disabilities are necessary, but, as a society, we must also be mindful that an overemphasis on “special” programs encourages segregation rather than integration.

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<sup>39</sup> Leo XIII cites Gregory the Great, *Hom. in Evang.*, 9, n. 7 (PL 76, 1109B). Emphasis added.

As a capstone, the Preferential Option for the Poor and Vulnerable not only stands on its own, but it also draws our attention to all of the other principles of Catholic social thought. As such, while the promotion of the dignity and freedom of the human person are noteworthy goals, a preferential option for people with disabilities, ensures that efforts are aimed at the promotion of human dignity and the protection of the freedom *of individuals with disabilities specifically*. Similarly, while the advancement of community is vital for sustaining human life, consideration to the principles of subsidiarity and solidarity and special attention to the role of the family will ensure that we are doing our best to serve the vulnerable in community first. It is only when all of these points are taken in sum that we can truly be making a preferential option for people with disabilities. **M**