

Childhood and Disability: Ethical Considerations

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In this thesis, I argue in favor of supported decision-making as a model for decisions made by people with intellectual and/or developmental disability, claiming that these individuals can and should control the decisions that impact their lives. I suggest that we can understand the support needs of individuals with ID/DD as a part of the decision-making process that undermines autonomy no more than the support afforded an abled individual. I also argue that the ongoing and pervasive infantilization of disabled adults disregards the breadth of decision-making capacity these individuals may have. I demonstrate the risks in infantilizing those with developmental and intellectual disability, while also noting the promise of reclaiming connections between disability and childhood. Finally, I argue that the state of Pennsylvania has an ethical obligation to fully fund Medicaid Waivers, which provide for Home and Community Based Services (HCBS), because HCBS is better realization of autonomy, dignity, and respect for disabled adulthood than institutional care.

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Preface

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1.0 Introduction

In medical school

They didn't teach us it was OK to kill people with disabilities

They just presented journal articles in Grand Rounds that combined "severe disability and death" under the category of "poor outcome." Peer reviewed, published journal articles.

Which defined severe disability as an IQ below 70

Or blindness

Or hearing impairment

Or seizures

Or cerebral palsy

There's a lot of living people in those categories combined with the dead ones

And no one in medical school seemed to notice

-Nightengale¹

Institutionalization of children with disabilities in remote facilities, an especially common practice prior to the 1970s, resulted primarily from the particular needs of disabled children being understood solely as medical problems. Disabled children are, of course, still children, but disability was not (and still generally is not) considered a part of normal childhood development. The lives of children are shaped by the expectations of their parents and others; recognition or diagnosis of disability, in turn, shapes those expectations. Thus, it was not even thought that

¹ Nightengale [username]. (2016, March 1). They didn't teach us it was OK to kill people with disabilities in medical school. *Livejournal*. <http://nightengalesknd.livejournal.com/104661.html>

disabled children could be educated alongside their peers, but instead they were shuffled into what were called ‘state schools,’ medical institutions where very little academic education actually occurred. By the mid 1900s, Pennsylvania alone had approximately 40 institutions for people with intellectual and developmental disability.

These institutions, which began to be founded in the early 1800s, were arguably better than the poor houses that came before. Yet, the conditions at institutions continued to be poor: staff-to-resident ratios were inadequate, resulting in lack of necessary care; little schooling occurred; and the institutions were, in fact, filthy. That these conditions remained shrouded in secrecy from their inception only contributed to the mistreatment of institutional residents. Parents were told by doctors that institutionalization was the best option for their children, with little to no discussion of alternatives. It was common for physicians and other professionals to tell families of children with disabilities that it was “best that you put him away and forget about him.”² After dropping their children off, parents would generally not allowed to see where their children were living.

1.1 Interjection One

You and I

I am a resident. You reside.

I am admitted. You move in.

I have behavior problems. You are rude.

² “A Brief History: As Remembered by Dennis Felty.” Last modified 2016. <https://www.keystonehumanservices.org/about-us/history/>.

When I ask you out to dinner, it is an outing. When you ask someone out, it is a date.

I don't know how many people have read the progress notes people write about me. I don't even know what's in there. You don't speak to your best friend for a month after she reads your journal.

I make mistakes during my check writing program. Someday I might get a bank account. You forget to record some withdrawals from your account. The bank calls and reminds you.

I wanted to talk with the nice looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers. You met your spouse in the produce department. He couldn't find the bean sprouts.

I celebrated my birthday yesterday with five other residents and two staff members. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounded wonderful.

My case manager sends a report every month to my guardian. It says everything I did wrong and some things I did right.

You are still mad at your sister for calling your mom after you got a speeding ticket. I am on a special diet because I am five pounds over my ideal body weight. Your doctor gave up telling you.

I am learning household skills. You hate housework.

I am learning leisure skills. Your shirt says you are a "couch potato".

After I do my budget program tonight, I might get to go to McDonald's if I have enough money. You were glad the new French restaurant took your charge card.

My case manager, psychologist, RN, occupational therapist, physical therapist, nutritionist, and house staff set goals for me for next year. You haven't decided what you want out of life.

Someday I will be discharged...maybe. You will move onward and upward.

Poem by Elaine Popovich, originally published in The Advocate, a publication of The Arc of Massachusetts³

1.2 Context

Today, thanks to the protections of the Rehabilitation Act, the Americans with Disability Act, and the Individuals with Disability Education Act, among other laws, we are confronted by disability all around us; our colleagues, our classmates have disabilities. Those of us in the next wave of disability activists can hardly remember a time before the ADA; it was passed the year I was born. The ancestors of our movement, those who fought for the Rehab Act and the ADA, lived and made real the *self-advocate*, paving the way for those of us who would follow.⁴ Yet, the independent living movement was primarily focused on physical disability; for those of us with intellectual or developmental disabilities, the self-advocacy movement would come much later.

For many decades, advocacy around intellectual and developmental disability would be centered on parents and families, rather than the person with a disability. Even today, in

³ Throughout this work, various interjections of poetry or other writings by folks with ID/DD will occur. These interjections are included to stand on their own merit, without explanation or analysis, so as to allow them to speak back and to bioethics in a way which is atypical.

⁴ “Americans with Disabilities Act of 1990, As Amended,” 2008, <https://www.ada.gov/pubs/adastatute08.htm>.

Pennsylvania, phrases like *family-centered planning* seem to pervade medical and political discussions of people with intellectual and developmental disability. I have chosen to focus on the subcategory of people with intellectual or developmental disability, rather than disability as a whole, because of the lack of attention to this particular population, as well as the opportunity to consider the ways in which intellectual and developmental disability [ID/DD] illuminates the social, at times arbitrary, constructions of disability, alongside concepts of childhood and childlike. In other bioethics and medical discourses family-centered decision making functions as an antidote to conceptualizing patients as isolated rational decision-makers. At times, however, the focus on family in these contexts functions not as a consideration of the influence of social context of the patient, but rather serves as a replacement almost entirely for the individual. Conceptualizing the family as a stand-in for the patient thus undermines a focus on the well being of the individual patient because it collapses the individual into their social context without substantial consideration of the patients' values, preferences, and decisional capacity. A more balanced approach is necessary, one which certainly elevates the decision-making status of individuals with intellectual/developmental disabilities (ID/DD), but which, at the same time, also reframes the supposedly competent atomistic rational decision-maker into a *relational* decision-maker.

Bioethics has long been concerned with defining rational moral agents and what it means to be a competent decision maker, but conversations about these issues are often grounded in privileged, medicalized conceptions of how minds and bodies ought to be. I challenge bioethicists to consider the role that differences in bodies and minds, termed *disabilities*, play in conceptions of self-identity and the self as a moral actor.⁵ Jackie Scully defined disability ethics as: “a form of

⁵ Disabilities may function to play a significant role in the development of a person's understanding of their selfhood because of the impact that disability has on life experience. This

ethical analysis that is consciously and conscientiously attentive to the experience of being or having a nonnormative embodiment...disability ethics looks at the effects of bodily impairment.”⁶ Adrienne Asch, Anita Silvers, Eric Parens, and Elizabeth Barnes, in addition to Scully, are among the few exceptions of bioethicists who have considered ethics through a disability-studies lens. The values frequently represented by disability studies researchers include principles that should be familiar to many bioethicists, like respect for autonomy, nonmaleficence, beneficence and justice.⁷ Yet, a disability studies perspective calls for bioethicists to reconsider what we mean by autonomy, nonmaleficence, beneficence, and justice. Often missing from bioethical understandings of these terms is a specific respect for disabled autonomy, experience, and culture and a view of disability as socially, historically, and culturally-constructed and as, possibly, not wholly harmful. Scully defines crucial questions which bioethics has failed to address, namely, “how we define disability...how we learn to characterize variations from bodily norms, and...which groups have the authority to make those identifications.”⁸

While Scully does well to look at bodily differences through what she calls her theory of *naturalized bioethics* or *reverse ethics*, disability ethics must also acknowledge the existence of mental and intellectual impairment. If we are to interrogate the experience of nonnormative embodiment, we must also pay attention to nonnormative ways of thinking; in so doing, our conceptions of what it means to be a competent decision-maker may shift.

difference in life experience then may function to influence a system of disability ethics that may differ vastly from more traditional systems of ethics.

⁶ Scully, J. L. (2008). “Moral bodies: Epistemologies of embodiment.” In H. Lindemann, M. Verkerk, & M. U. Walker (Eds.), *Naturalized bioethics: Toward responsible knowing and practice* (pp. 23-41). Cambridge: Cambridge University Press. Scully. (2008b)., p. 25.

⁷ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed., Oxford: Oxford University Press, 2013.

⁸ Scully. (2008b)., p. 25.

1.3 Argument

I call for bioethicists to examine additional complexities of the ‘competent’ decision-maker. Allen Buchanan and Dan Brock rightfully argue that competence is always decision-relative, or that, in other words, no individual is globally competent or incompetent, but rather may be competent to make some decisions, but not others.⁹ Likewise, they note that there are some decisions that require greater capacity than others. Building on the arguments made by Buchanan and Brock, as well as the work of disability bioethicists, I further argue that the particular stigmas that color the perspectives of bioethicists and medical professionals with regard to intellectually and developmentally disabled individuals may unfairly result in a judgment of complete incompetency when, in fact, the individual could be much more fully involved in the decision-making process. None of us are competent to make decisions alone; all of us are influenced by family, community, or other external influences and all of us need support during difficult decisions.

Nevertheless, while it is true that all of us need support during decision-making, the experiences of people who are labeled as ‘disabled’ are particular. Perception of a disabled individual’s competency is often impacted by stigma or discriminatory attitudes. This is especially true for non-physical disability and even more significant for intellectual disability. If, as I argue, everyone needs decision-making support that acknowledges the complexity of everything that impacts the decision, then bioethicists have to understand the ways in which intellectual and developmental disability influences decision-making. We might consider both internal influences

⁹ Allen E. Buchanan and Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making*, Cambridge: Cambridge University Press, 1990.

rooted in disability, like atypical emotions and disabled embodiment, as well as external influences, like the particular ways in which family, community, and culture function to *disable* decision-makers.

Therefore, like Scully, but particularly with regard to intellectual and developmental disability, I investigate the differences between medical and bioethical perceptions of the kinds of decision-making support disabled individuals need versus the support needs of abled individuals. Here, I point out again that every individual, regardless of disability, requires support during decision-making processes. Why is it, then, that bioethicists, particularly, regard the support needs of individuals with ID/DD as a decision-making deficit, rather than a normal part of human decision-making? The needs of individuals with ID/DD may be different in kind or in degree from those of individuals without ID/DD, but there is also broad diversity of support needs present in the general population at large. Thus, I believe we can understand the support needs of individuals with ID/DD as a part of the decision-making process that, when conducted under the constraints I explore later in this work, undermines autonomy no more than the support afforded an abled individual. Though some work exists, bioethics needs to more adequately consider and validate the experiences of people with non-physical disabilities, especially intellectual disability, and needs to more thoroughly investigate opportunities for supported decision-making for this population.

As a result of the scarcity of bioethics work in these areas, parent advocates, politicians, and medical professionals have been and continue to be compelled by a particular *child* narrative in which intellectually or developmentally disabled individuals are rendered visible as eternal children, a disabled childhood which is then medicalized; these individuals are positioned within what I call the ‘childlike’ role. The ongoing and pervasive infantilization of disabled adults reifies

a normative ethics that disregards the breadth of decision-making capacity these individuals may have.

While I argue that individuals with ID/DD experience an extended childlike role, I also note that race complicates this argument. In the media that I analyze, only white bodies are showcased, which does not accurately acknowledge that Black, Indigenous and People of Color (BIPOC) are disproportionately neglected in medical contexts, disproportionately targeted by the medical-industrial complex with regard to population control, ‘improvement,’ and research, and disproportionately imprisoned in institutions.¹⁰ We know that Black young people face a higher risk of being targets of police violence and are more often prosecuted as adults. The extension of the childlike role is complicated for BIPOC with ID/DD, given the ways in which Black people generally are marginalized and treated with paternalistic and/or bigoted attitudes in medical contexts. BIPOC with ID/DD may be positioned in an even more deeply entrenched childlike role, while simultaneously receiving fewer of the supposed ‘benefits’ of being treated like a child. White people placed in a childlike role could expect to be treated as less dangerous and given fewer responsibilities, while BIPOC in the same role might face bias positioning them as more dangerous, less innocent, and more responsible for their actions without the benefits of being treated as competent and knowledgeable. Given the limitations of the media with which I am working in this project, I cannot fully analyze the complex ways in which BIPOC with ID/DD are

¹⁰ David A. Ansell and Edwin K. McDonald. "Bias, Black Lives, and Academic Medicine." *The New England Journal of Medicine* 372, no. 12 (Mar 19, 2015): 1087-1088; S. Trawalter, Hoffman KM, Waytz A (2012) Racial Bias in Perceptions of Others’ Pain. *PLOS ONE* 7(11): e48546; Augustus A. White, III, and David Chanoff, *Seeing Patients: Unconscious Bias in Health Care*, Harvard University Press, 2011.

positioned in the childlike role, but I attempt to highlight the ways in which Whiteness presents itself as ubiquitous in discussions of disability.

Through the use of a case study of the Pennhurst institution from the state of Pennsylvania, I demonstrate the risks in associating developmental and intellectual disability inherently with childhood and with sickness, particularly the ways in which disabled individuals are made invisible as actors and decision-makers, both as adults and as children, as well as the way that linking of medicalized support to public school systems results in the “ageing out” phenomenon. These risks impact not only people with ID/DD, who are potentially disenfranchised from being part of decision-making, but also all who might find themselves occupying the ‘childlike’ role. These are risks also for bioethicists, who need to carefully consider who is made visible and who is made invisible in the decision-making process.¹¹

Yet, at the same time, I examine what promise the reclaiming of a comparison between disability and childhood might hold, while also problematizing the nearly all-consuming medicalization of disabled children. Medicalization naturalizes the reading of disability as a perpetual childhood insofar as medicalization makes disability seem a permanent and static (read: natural) childlike state. Like the process of growing out of childhood, disability is not static, but changes as a person and their environment grow and shift. Yet, because developmental and intellectual disabilities are diagnosed through, among other criteria, a failure to meet developmental milestones, medicalization connects ID/DD with childhood itself. This

¹¹ These same considerations should also apply in the context of the development of the structures, rules, laws, and policies which undergird moments of healthcare decision-making, as well as the larger structures which guide how individuals with ID/DD are treated in medical contexts and more broadly in society.

naturalization of the connection between disability and childhood further serves to reify the infantilization of disabled people in areas of life beyond medical contexts.

Finally, I conclude by arguing that the state of Pennsylvania, where over 2300 adults and over 1500 children continue to live in institutional or hospital-like settings,¹² has an ethical obligation to fully fund community-based, consumer-directed, integrated care for both disabled adults and children. I imagine care under this ethical obligation as more expansive than *healthcare*, as again, not all needs of disabled adults ought to be housed in a medicalized context. The criteria for this ethical obligation (community-based, consumer-directed, and integrated) are a reflection of the *Olmstead* decision,¹³ which argued that disabled individuals have a right to receive services under this framework. *Olmstead v. L.C.* is a ruling under the Americans with Disabilities Act that “requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs.”¹⁴ The Final Rule, which is guidance establishing specifically what qualifies as community, consumer-direction, and integrated settings, among other definitions, has been recently received by every state. Currently, the state of Pennsylvania is in the process of establishing and sending to the federal government the ways in which it will enforce and follow the Final Rule.

However, the Final Rule only applies to individuals receiving care in Home and Community Based Settings (HCBS), which means that they have qualified for a Medicaid waiver.

¹² Pennsylvania Department of Human Services, Office of Mental Health and Substance Abuse Services, “Pennsylvania State Hospital System Length-of-Stay, Demographics, & Diagnoses Report for December 31, 2014,” http://www.dhs.pa.gov/cs/groups/webcontent/documents/report/c_149849.pdf.; Author’s personal correspondence with Nancy Thaler, deputy secretary of the Office of Developmental Programs, November, 2016; 2014-2015 IDEA Data, author’s personal correspondence with Nancy Murray, President of The Arc of Greater Pittsburgh, December 1, 2016.

¹³ *Olmstead v. L.C.*, 527 U.S. 581 (1999)

¹⁴ United States Department of Justice Civil Rights Division, “*Olmstead: Community Integration for Everyone*,” Accessed November 29, 2016, <https://www.ada.gov/olmstead/>.

There are lengthy waiting lists for Medicaid waivers in every state, including Pennsylvania, for individuals with ID/DD. My argument is that, based on the considerations I outline in the chapters which follow, the state of Pennsylvania has an ethical obligation to fully fund these Medicaid waivers and eliminate waiting lists because HCBS is better realization of autonomy, dignity, and respect for disabled adulthood than institutional care.

1.4 Interjection 2

On March 6th, a 22-year-old autistic man named George Hodgins was murdered in Sunnyvale, California. His mother, Elizabeth, pulled out a gun, shot him point-blank, and then killed herself.

In the following days and weeks, journalists wrote about George Hodgins' murder. In their articles they called him "low functioning and high maintenance," and called Elizabeth Hodgins "a devoted and loving mother." They sought out quotes from other parents of autistic children, who normalized the crime by saying things like "every mother I know who has a child with special needs has a moment just like that."...

On March 8th, Robert Latimer went on television to talk about how loving and compassionate it was when he gassed his disabled daughter Tracy. He called for "euthanasia" – the murder of disabled children by their parents – to be legalized in Canada. A woman who appeared with him agreed. She has two disabled children who she would like to kill, but she can't because it is against the law. No opposing viewpoints were presented.

-An excerpt from Killing Words, by Zoe Gross¹⁵

1.5 Method

I have collected the contents of various archives related to institutionalization in Pennsylvania, including a 1968 exposé of the Pennhurst institution as well as historical newspaper clippings, telegrams and letters from parent advocates as housed at the Heinz History Center in the Bob Nelkin Collection of Allegheny County Chapter of the Pennsylvania Association for Retarded Children (ACC_PARC) Records 1953-2000. Through an examination of these resources, I trace the construction of adults with ID/DD as childlike, situating this practice within a larger movement toward disability justice in Pennsylvania, and as part of an argument for the ethical imperative of consumer-directed, integrated, community-based care for all, regardless of their type of disability. My study primarily uses textual thematic analysis. I engage theoretical perspectives from bioethics, childhood studies, and disability studies.

1.6 Interjection 3

I am volunteering at a sensory-friendly Santa event. The mall isn't open to the public yet, but Santa and his helpers are here bright and early. The event is intentionally held when the mall is quiet, so that the autistic children are exposed to as few sensory distractions as possible. I'm

¹⁵ <http://autisticadvocacy.org/2012/04/killing-words/>

working at the coloring table, trying to find unbroken crayons (or, let's be real, less broken crayons) for the kids. One of the youngest ones, glasses strapped tightly to his face, wears a suit and bowtie and is, frankly, adorable. He begins to run around the mall - the empty mall, no one to disturb but us – he's doing that screechy laugh giggle noise that children do, and his mom tries to stop him.

She comments to me, "it's the autism, I'm sorry."

I reply, "I think it's because he's two."

This is what I call,

autism-colored glasses,

where the child becomes the disability

the disability, the child.

This is not some kind of potentially productive identification,

no, this,

this is where everything about the child is not child

but is something to talk about in

40-hour-a-week therapy.¹⁶

1.7 A Brief History of Institutionalization

For Deaf and Blind children, mainstreamed education began during the 1810s. Education was given to these children with “the understanding that they could be integrated into society

¹⁶ Personal narrative by myself.

[mainstreamed] and did not need to be sent away to institutions.”¹⁷ Yet, the institutionalization of people with mental illness, ID/DD, and many physical disabilities continued. This was a time when disability was hardly acknowledged, when our family members, when people like me, were locked away from the rest of society.

In 1887, a Pittsburgh reporter went undercover at a New York asylum for people with mental illness, using the name Nellie Bly. Her expose revealed, “A human rat-trap...Easy to get in, but once there impossible to get out.” Reform in mental health care began around this time, though problems with treatment conditions and stigma continue into the present.

The early 1920s saw the creation of federally funded rehabilitation programs for physically disabled veterans, but little progress for others with disabilities. In the 1940s, parent advocates for children with intellectual disabilities began to organize under the heading of the Association for Retarded Children, later the Association for Retarded Citizens, now known as The Arc. For those with physical disabilities, the Independent Living Movement began in the 1960s and, unlike previous movements toward reform, was lead by people with disabilities, *self-advocates*.

The Independent Living Movement was responsible for protests surrounding the Rehabilitation Act of 1973 and the Americans with Disabilities Act. The Independent Living Resource Center tells the story:

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon’s veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon’s veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City, early leader for disability, fights, Judy Heumann, staged a sit-in on Madison Avenue with eighty

¹⁷ <http://www.wpdhac.org/historic-timeline/>

other activists. Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists.¹⁸

The Rehabilitation Act's Section 504 established a right to non-discrimination based on disability status, but discrimination was not clearly defined. As a result, the Department of Health, Education, and Welfare was tasked with developing implementation regulations.¹⁹ During the 1980s, the disability community was particularly involved in advocacy surrounding Section 504 cases at the Supreme Court.²⁰ Specifically with regard to employment, the Rehabilitation Act's Section 501 "prohibits federal employers from discriminating against qualified individuals with disabilities. It also obliges them to take affirmative action to hire and advance in employment qualified individuals with disabilities."²¹

Introduced with heavy involvement from the disability community, the Americans with Disabilities Act was passed after two years of lobbying, protesting, and canvassing by the disability community.²² The Los Angeles Times reported: "Crawling up the Capitol steps to dramatize the barriers confronting them, scores of disabled persons rallied Monday to protest delays in congressional action on a Senate-passed bill to expand their access to jobs, transportation and

¹⁸ "The Rehabilitation Act of 1973," Independent Living Resource Center, Accessed September 13, 2016, <http://www.ilrcnm.com/content/rehabilitation-act-1973/>.

¹⁹ Arlene Mayerson, "The History of the Americans with Disabilities Act," 1992, <http://dredf.org/news/publications/the-history-of-the-ada/>.

²⁰ Ibid.

²¹ "Rehabilitation Act of 1973," Disability.gov, Accessed September 13, 2016, <https://www.disability.gov/rehabilitation-act-1973/>.

²² Mayerson, "The History of the Americans with Disabilities Act."

public services.”²³ Heroes of the movement, whose names must be mentioned in any re-telling of our history, had these comments to make:

Justin Dart: “Two centuries is long enough for people with disabilities to wait before the constitutional promise of justice is kept.”

I. King Jordan: "If we have to come back, perhaps we'll simply stay until they pass (the bill)."

One of the most iconic images from the Capitol Hill Protest was of an 8-year-old girl with Cerebral Palsy, Jennifer Keelan, who left her wheelchair behind and insisted on crawling up the steps with the adult protestors.²⁴

Title 1 of the ADA extended the protection of Section 501 beyond federal employers to “employers with 15 or more employees, including State and local governments...employment agencies and to labor organizations.”²⁵ Because of these protections, a significant portion of the debate over the ADA was concerned about the economic well being of people with disabilities:

The ADA had the goal of ensuring full participation in society for people with disabilities by facilitating equal opportunity, independent living, and economic self-sufficiency. It was no accident that Congress spent a good deal of time during consideration of the law hearing testimony concerning the rate of poverty and unemployment for people with disabilities.²⁶

²³ William J. Eaton, “Disabled Persons Rally, Crawl Up Capitol Steps,” March 13, 1990, Los Angeles Times, http://articles.latimes.com/1990-03-13/news/mn-211_1_capitol-steps.

²⁴ “The Little Girl who Crawled Up the Capitol Steps 25 Years Later: Jennifer Keelan and the ADA,” July 24, 2015, CP Daily Living, <http://cpdailyliving.com/the-little-girl-who-crawled-up-the-capitol-steps-25-years-later-jennifer-keelan-and-the-ada/>.

²⁵ “Employment (Title I),” ADA.gov, Accessed September 13, 2016, https://www.ada.gov/ada_title_I.htm/.

²⁶ Ibid.

The 1999 Olmstead decision,²⁷ discussed above and more expansively later in this manuscript, further entrenched the notion that people with disabilities have a right to live in the community.²⁸

1.8 Précis of Chapters

In chapter 2, I introduce, in more detail, the theoretical concepts that serve to provide the underpinning to the remainder of this work. Specifically, I define my approach to *disability bioethics*, heavily informed by the work of Jackie Scully, Adrienne Asch, Elizabeth Barnes, and David Wasserman. I also describe what I mean by the *childlike role* and how it functions within a bioethics context. Finally, I review existing models of decision-making, emphasizing the need to both uplift the position of the individual with ID/DD and also emphasizing the importance of context and social support systems. To further demonstrate the usefulness of these concepts, I apply them within the context of the Neurodiversity Movement, a growing perspective championed by autistic self-advocates that challenges common medical and bioethical understandings of what it means to be on the autism spectrum. Because of this movement, which works to resist typical medical paradigms, autism is the ideal case study of a developmental disability to illustrate the complexity of my theoretical claims.

In chapter 3, I conduct a textual analysis of historical newspaper clippings, parent telegrams and letters from Pennsylvania, noting ways in which, throughout this history, adults with ID/DD

²⁷ *Olmstead v. L.C.*, 527 U.S. 581 (1999)

²⁸ *Ibid.*

have been constructed as children by medical professionals, media outlets, and parents. This section furthers my agenda of investigating the ways experiences of disabled individuals differ from those of able-minded individuals. The analysis of this archive also demonstrates both the risks and the promises in associating disability closely with childhood.

In chapter 4, I focus specifically on a case study of the 1968 exposé of Pennhurst, titled *Suffer the Little Children*, which serves as a specific example of infantilization of disabled adults, an example which complicates the ethics of using childhood as a metonym for disability within medical contexts. I conclude by advancing the claim that the State of Pennsylvania has a moral, ethical, and, I believe, soon-to-be legal obligation to fund community-based, integrated care.

1.9 Interjection 4

I have multiple disabilities. I am autistic. I have panic disorder. I have Ehlers Danlos Syndrome. I have fibromyalgia. I am depressed. People like to normalize disability by saying that we want what everyone else wants: the Good Life. And while that may be true, that we want the Good Life, our conception of what “Good Life” means may differ vastly from the opinions of our parents, caregivers, colleagues...and the rest of society. Yet, so often, others have told me what it is that I should want. What I want is a goddamn revolution.²⁹

²⁹ Personal narrative by myself.

2.0 Disability Bioethics: Embracing the Child?

For parents whose child has just been diagnosed with Autism Spectrum Disorder, the Internet is a dangerous place, filled with scary stories about self-harming, never-to-be-independent Autistic people, new research touting a cause-of-the-week for Autism, and many recommendations for potential treatments. Some of these potential treatments are totally innocuous, while others, like bleach enemas, are touted as having curative effects when they are incredibly dangerous.³⁰ In contrast, those in the Neurodiversity Movement view Autism as simply another way of being in the world, as a community and as a culture. Such divergent ways of speaking about the same diagnosis have obvious implications for conceptions of ethical decision-making; some parents would consider almost anything done in the service of curing their child to be ethical, while proponents of the neurodiversity movement criticize moves to wholly eliminate or cure Autism.

The implications of disability life experience for how we should define an ethical decision-making process have been, as I noted in the introduction, understudied. Adrienne Asch, Elizabeth Barnes, David Wasserman, and Jackie Scully are the major exceptions to this rule. I find Jackie Scully's perspective to be particularly salient because she specifically intends to create a broad theory of bioethics that includes disability, whereas the others mainly apply concepts that consider the value of disability life experience within more narrow ethical situations (i.e. Adrienne Asch and her articles about pre-natal genetic testing and abortion).

³⁰ "Son with autism." (2008, February 23). *Miracle Mineral Solution MMS Forum*. <http://www.curezone.org/forums/fm.asp?i=1118247>

Throughout most of her research, Scully applies her theory within the context of deaf culture, paying particular attention to choices made by deaf parents to increase odds of having a deaf child. She does so in order to argue that impairment has ethical implications and that disabled experiences are an important part theorizing disability.³¹ For Scully, moral knowledge is founded in specific communities, based in shared similar bodily experiences.³² She defines communities as composed of people who share common experiences and feel responsible for each other.³³ Scully found that the tendency of bioethics to draw boundary lines between what is ethically permissible and not permissible obfuscates valid differences in moral systems: she calls for an understanding of how morality emerges out of communities as a way to more fully understand decisions within particular ethical and moral systems.³⁴ Scully calls for us “to turn our attention from the significance of the boundary itself...to notice where it has been placed by a defined group of people,” which will allow us to understand the constraints that have caused the boundary to be placed there.³⁵

Scully calls this process *reverse ethics*, a way of doing ethics which “recognizes where a line has been drawn by individuals or communities, however tentatively, and works from there towards the constraints and orientations maintaining it.”³⁶ Defining disability identity as a particular sense of self, particularly regarding labeling, Scully described the difficulty of

³¹ Scully. (2008b).

³² Scully. (2008a).

³³ Scully. (2008a).

³⁴ Scully, J. L. (2001). Drawing a line: Situating moral boundaries in genetic medicine. *Bioethics*, 15(3), 189-204.

³⁵ Scully. (2001)., p. 194.

³⁶ Scully. (2001)., p. 202.

constructing a collective political disability identity, because of a lack of clarity over common experiences or shared interests.³⁷

In this chapter, I describe and apply the theoretical concepts that serve to provide the underpinning to the remainder of this work: *disability bioethics*, the *childlike role*, and *supported decision-making*. To structure this chapter, I explore these concepts in relation to the notions of autonomy, beneficence, non-maleficence, and justice, core concepts within bioethics, as articulated by Tom Beauchamp and James Childress. To further demonstrate the usefulness of these concepts, throughout this chapter, I apply them within the context of the Neurodiversity Movement, a growing perspective championed by autistic self-advocates that challenges common medical and bioethical understandings of what it means to be on the autism spectrum. The Neurodiversity Movement, as Thomas Armstrong notes, has a long history in the Autistic rights movement:

Although the origin of the neurodiversity movement is often traced back to a speech entitled “Don’t Mourn for Us,” given by autism activist Jim Sinclair at the 1993 International Conference on Autism in Toronto, the word itself was first used by autism rights advocate Judy Singer and New York journalist Harvey Blume to articulate the needs of people with autism who did not want to be defined by a disability label but wished to be seen instead as neurologically different.³⁸

Today, many Autistic advocates will speak of themselves as disabled (often by an outside force, like lack of accessibility or stigma), but still embrace the Neurodiversity paradigm.

³⁷ Scully. (2008a).

³⁸ Thomas Armstrong, “The Myth of the Normal Brain: Embracing Neurodiversity,” *AMA Journal of Ethics*, April 2015: 17.4, 348-352.

It becomes much easier, I think, to talk about these theoretical concepts when one is considering a subset of a particular group. Thus, I propose to focus on Autistic proponents of the neurodiversity paradigm, who use their collective identity to call for change through the Neurodiversity Movement. Because of this movement, which works to resist typical medical paradigms through the creation of a shared autistic culture, autism is the ideal case study of a developmental disability to illustrate the complexity of my theoretical claims.

2.1 Interjection 5

Every time that someone says it was not a big deal to kill you because you couldn't speak, I need to step up and speak, because I have a voice, that you do not, because your life was prematurely ended.

Every time someone says that the parents lives are too hard, so its not unexpected for them to do these things, I need to step up and say that autism isn't about the parents, and murders are about those who's lives were taken. Because disabled people are people too...

Nobody deserves to be killed by a parent. Nobody deserves to be killed because they are disabled. Nobody.

I'm sorry it had to happen to you.

-Turtle is a Verb³⁹

³⁹ TuttleTurtle42. (2014, February 27). I am not a burden (Day of Mourning 2014). *Turtle is a Verb*. <http://turtleisaverb.blogspot.com/2014/02/i-am-not-burden-day-of-mourning-2014.html>

2.2 Neurodiversity Paradigm

Nick Walker is an Autistic professor who has spent significant time working with and defining the Neurodiversity Paradigm. He writes, “Neurodiversity is a biological fact. It’s **not** a perspective, an approach, a belief, a political position, or a paradigm. That’s the **neurodiversity paradigm**, not neurodiversity itself. Neurodiversity is **not** a political or social activist movement. That’s the **Neurodiversity Movement**, not neurodiversity itself.”⁴⁰ Walker articulates 3 core tenets of the neurodiversity paradigm:

- 1.) Neurodiversity is both normal and valuable.
- 2.) There is not one ‘normal’ kind of brain.
- 3.) “The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity.”⁴¹

The neurodiversity paradigm is the foundation for the Neurodiversity Movement, which is “a social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent.”⁴²

2.3 What Does It Mean To Be Childlike?

In many ways, intellectually or developmentally disabled adults are simultaneously positioned in both a ‘childlike’ and a ‘sick’ role. The key differences between the childlike role

⁴⁰ Nick Walker, “Neurodiversity: Some Basic Terms & Definitions,” Sept. 27, 2014. <http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/>

⁴¹ Ibid.

⁴² Ibid.

and the sick role⁴³ lie in which bodies are allowed to occupy these roles without losing status as competent or as developing toward competence and in the duration in which the roles last. Adults who typically occupy an able-bodied position are allowed to occupy the ‘sick’ role without an extended loss of the privileges and responsibilities of being able-bodied; in fact, their dependence on others while sick is viewed as appropriate and worthy of sympathy. There is an expectation that those in the sick role will progress to, or return to, an able adult state. Those who do not, who have illnesses from which they are not expected to recover, perhaps experience a similar childlike role as adults with ID/DD, rather than the same sick role occupied by adults expected to return to an abled adult state. An ongoing dependency on others, which I understand here as *childlike*, is stigmatized.⁴⁴ While the definition of ‘childlike’ may change and while someday there may be no category of person placed in the ‘childlike’ role, for the purposes of this research in this moment, I will contend that there are always certain categories of individuals pushed into the ‘childlike’ role that I have described.

Adults with ID/DD positioned in the ‘childlike’ role are not granted the privileges of ability, and their dependence on others is stigmatized and subject to concern. I might further assert that being intellectually or developmentally disabled is not the same as being sick, and that disability should not be wholly medicalized. The ‘sick’ role is typically temporary (and stigmatized when ongoing), and one might expect that the ‘childlike’ role would be similarly short in duration,

⁴³ Talcott Parsons (1951), *The Social System*. Glencoe, IL: The Free Press; Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, London: Penguin Random House, 1961.

⁴⁴ Of course, chronic illness challenges this ‘temporary’ conception of the sick role. I would argue, however, that people with chronic illness are stigmatized for their prolongation of the ‘sick’ role. This occurs perhaps similarly to the ways in which folks with ID/DD are boxed into an extended childhood. Nevertheless, as this is a paper about ID/DD and not about chronic illness, I shall leave the comparison to this footnote.

as children typically grow up. Yet, for folks with ID/DD, the ‘childlike’ role is prolonged and likely contributes to the treatment of people with ID/DD as less than competent.

Tyler Bickford describes the difficulty with associating childhood with particular behaviors by comparing the words *childlike* and *childish*: “‘childlike’ suggests neutral description or even valorization that are just as ideological, if less openly so, as ‘childish.’ If anything the value judgments implicit in ‘childish’ might be useful, insofar as they highlight the fact that children and childhood remain marginalized and disputed categories.”⁴⁵ Bickford makes the choice to use the word *kid* to reference lived experiences and the word *child* as “as a formal theoretical term with particular histories and currency in academic usage.”⁴⁶ Throughout this work, I will use language like *institutional residents* or *people with disabilities/disabled people*, and use the word ‘childlike’ to describe the ways in which Pennhurst residents have been marked as children. Yet, as Bickford suggests, that descriptor is not uncomplicated. In a 2010 Ted talk titled *What Adults Can Learn from Kids*, Adora Svitak suggests that behaviors associated with childhood are normal behaviors across the lifespan, arguing “the traits the word ‘childish’ addresses are seen so often in adults, that we should abolish this age-discriminatory word, when it comes to criticizing behavior associated with irresponsibility and irrational thinking.”

The ‘childlike’ role is also entrenched in the connection between childhood and innocence. Robin Bernstein writes, “By the nineteenth century, sentimental culture had woven childhood and innocence together wholly. Childhood was then understood not as innocent but as innocence itself; not as a symbol of innocence but its embodiment...This innocence was raced white.”⁴⁷ These

⁴⁵ Tyler Bickford, *Schooling New Media: Music, Language, and Technology in Children’s Culture* (Oxford University Press, 2017), qt. 21.

⁴⁶ *Ibid.*, 21.

⁴⁷ Robin Bernstein, *Racial Innocence: Performing American Childhood from Slavery to Civil Rights*, New York University Press, 2011, pg. 4.

connections between childhood, whiteness, and innocence might also underscore why children of color are more often diagnosed with behavior problems like Obsessive Compulsive Disorder and less often with developmental or intellectual disabilities.

I argue that the treatment of individuals with ID/DD as ‘childlike’ shapes bioethics conceptions of what a ‘good life’ looks like for people with ID/DD; further, the positioning of people with ID/DD in a ‘childlike’ role may shape their own conception of a ‘good life’ and their own constructions of life plans, and this may very well differ from the bioethical conceptions.

I also trouble the negative implications of *childlike*, wondering if the characterization offers opportunity for solidarity, rather than solely functioning as a diminutive. After all, as Tyler Bickford noted, even children don’t like the negative implications of *child*. Though disability studies has consistently rejected the comparison between childhood and disability, childhood studies questions why being compared to children is inherently negative. Childhood studies helps interrogate what it means to *treat someone like a child*, what it might be to construct an agentic childhood or even an agentic disabled childhood, and how a comparison between childhood and disability has the potential to be reclaimed for benefit.

Occupying this ‘childlike’ role provides the potential for solidarity between all groups who experience this kind of subjugation and stigmatization. The metaphor of the Child is one way through which to understand the stigma associated with reliance on others, and certainly other metaphors could also be appropriate.. Perhaps then, disabled people and kids are natural allies, in that descriptors like *moron*, *retard*, *childish* all critique the same behaviors by casting judgment on the actual people who are interpolated by those words. If we consider childhood to be a categorization through which particular populations are subjected, rather than being an age-bound identifier, then it becomes possible to imagine sites of cooperation between disabled people and

young people through which they might contest the effects of being hailed as children. Cooperation and solidarity function as very different modes of relation than dependence.

Here, I recognize also how people with ID/DD both fulfill and break the expectations of childhood, growing up in non-normative ways, and providing the possibility that developmental *delay* is not necessarily negative, merely a different way of playing with childhood.⁴⁸ In this content, I am thinking about the potential for play and playfulness to both be a pleasurable way for experiencing atypical development and as a site of resistance to the capitalist norms which constrain conceptions of the value of persons to their ability to be productive and engage in normative work. Derrida plays with play in relationship to the center, which is that which controls and organizes structures. Of the center, Derrida writes that it “constituted that very thing within a structure which governs the structure, while escaping structurality.”⁴⁹ The center both allows for play within the system, since it is its organizing force of the entire structure, but also forecloses the possibility of play, since play goes against the coherence of the structure. Much like the *center*, the development of any actual child resists the very definition of *development* itself, since development implies a forward, upward, or outward movement, and, as anyone who has met a child can attest, no child develops linearly and all children lose and gain skills in ways which do not perfectly match the ‘typical’ developmental progression. Yet, the existence of *development* as a concept allows for atypical development to resist, and therefore play with, development itself. A child’s development which verges so far from typicality seems to be foreclosed by the center of *development’s* structure, which thus lends itself to the claim that these children do not, in fact,

⁴⁸ Jacques Derrida, “Structure, Sign and Play in the Discourse of the Human Sciences,” in *The Languages of Criticism and the Sciences of Man: The Structuralist Controversy*, eds. Richard Macksey and Eugenio Donato, The Johns Hopkins University Press.

⁴⁹ *Ibid.*, p. 224.

develop at all, thus constraining play. In this way, development both enables and disabled playfulness, resulting in a seemingly elongated childhood.

I might even characterize developmental delay as a kind of resistance to normative development, a declaration that we need not firmly follow the prescriptions laid out for us. Here I do not mean a kind of intentional resistance, as children do not entirely choose how they develop, but rather a naturally occurring resistance wherein nature resists our human preoccupation with how things ought to be. There may be, as well, other groups who are pushed into this childlike role, who might find that pushing for a positive connotation surrounding reliance on others, and the other characteristics of ‘childlike’, to be useful, such as the elderly or the chronically ill. Tyler Bickford explores the relationship between disability and childhood, mentioning Alison Kafer’s work on temporality and disability in the context of talking about typical childhood development:

Discourses of childhood and disability explicitly overlap in many ways, not least in their shared construction in terms of ‘temporality’ (Kafer 2013). Disability is frequently articulated using the language of childhood development, so terms like ‘retardation’ identify a pause in a course of cognitive and psychological development that ‘normal’ children pass through.⁵⁰

While Bickford’s construction of disability and childhood through temporality is not inaccurate, I am not convinced that this is an argument that Kafer makes. In fact, Kafer seems to be making a very different argument. Kafer uses temporality not to argue that disability is a pause in normal development of children, but rather that disability is not considered a valued or valid way of developing and to imagine “what it means to project disability into the future.”⁵¹ Nevertheless,

⁵⁰ Ibid., 26.

⁵¹ Alison Kafer, *Feminist Queer Crip* (Bloomington, IN: Indiana University Press, 2013), 20.

both Bickford and Kafer draw attention to the ways in which *temporality* structures the experiences of children and disabled people.

Another possibility for reclaiming the childlike role is to understand it as an epistemological site from which ethical knowledge can be generated. There is social value in non-normative ways of thinking and feeling about the world. In the upcoming sections about neurodiversity, I offer insight on the value that non-normative ways of thinking and feeling contribute to the world through understanding both the fact that diversity of minds does *exist* and also arguing in favor of a movement toward accepting this diversity as valuable to society at large.

While *childlike* or *childish* may never be the adjectives of choice for disabled adults (or for children!), disability studies scholars might consider that these words are not merely infantilizing, but also offer the opportunity to consider new alliances, embrace the value of play and playfulness, challenge capitalist norms, and provide sites for the generation of new ethical knowledge. Bioethicists should also consider how the slipperiness of both disability and childhood challenges our conceptions of words like consent or autonomy; they should also further problematize the medicalization of disability and of childhood, both together and separately. Childhood studies scholars ought to attend to the intersection of disability and childhood, considering ways in which disability further undermines or reinforces the (in)stability of *child* and ways in which the medicalization of both disability and childhood through phrases like *mental age* or *developmentally appropriate* is arbitrarily constraining.

2.4 Supported Decision-Making

A few decision-making models for individuals with intellectual and developmental disabilities have been discussed in bioethics literature, which I shall endeavor to briefly overview here. It is, of course, imperative to note that not all individuals with intellectual and developmental disabilities will be ruled incompetent for every decision. Nevertheless, certain foundational texts in the field of bioethics seem to take as an axiom that, especially, those with ID and those with significant support needs are not competent to make decisions. For instance, in the Introduction to *Deciding for Others*, Buchanan and Brock write:

The scope of the problem of decision making for incompetent individuals is vast. If one focuses only on the elderly who are incompetent and, among the elderly incompetent, only on those who are incompetent due to Alzheimer's dementia, the number may be as high as two million in this country alone, and increasing. When all forms of dementia are included, the total is between three and six million. At the other end of life is the largest group of incompetents – those who are not competent to decide for themselves by virtue of their immaturity. In addition, there are those who are incompetent due to mental retardation, brain damage from trauma, stroke, and alcoholism, and those whose mental illness renders them incompetent to make at least some decisions, and in some cases all decisions.⁵²

'Mental retardation' is glossed over quickly in this list of probable incompetents, and unlike children, the elderly, and the mentally ill, does not receive a section within the book to further explore the complexities of such a heterogeneous group. Of course, a single book could never

⁵² Buchanan and Brock, p. 1.

cover every group in significant detail, so I do not fault them, but rather seek to expand what they began.

For the three groups they do cover, Buchanan and Brock accept the necessity of a surrogate decision-maker and provide a list of ethical considerations for surrogates, including the advance directive principle, the substituted judgment principle, and the best interest principle. In bioethics literature, certain of the principles have been considered more relevant to the decision-making process for individuals with ID. Though there is some research discussing advanced directives and end-of-life care for individuals with ID,⁵³ the vast majority of the research on the topic appears to invoke either substituted judgment or best interest.

Yet, there is another decision-making structure that seeks to allow those who might otherwise be considered incompetent to still remain the decision-maker: supported decision-making. The Center for Public Representation (CPR) describes supported decision-making: “Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making. Supported decision-making is an alternative to guardianship. Guardians make decisions for the person with a disability. However, supported decision-making allows the person with the disability to make his or her own decisions instead of having someone else make them for him or her.”⁵⁴ CPR further explains that all of us, regardless of ability, engage in supported decision-making, because we all seek advice from other people or sources of information. CPR provides a resource library with

⁵³ See: Abbie Kirkendall, Kristen Linton, and Saritha Farris, “Intellectual Disabilities and Decision-Making at the End of Life: A Literature Review,” *Journal of Applied Research in Intellectual Disabilities*, 30.6 (2016): 982-994.

⁵⁴ <http://supporteddecisions.org/about-sdm/>

sample supported decision-making agreements. Essentially, the way that it works is that the individual identifies areas in their life where they need decision-making support and identifies a group of people, called supporters, who will provide information to help them make that decision. Adopting a supported decision-making model in a medical context means that, instead of substituted judgment or best interest as the standard, the patient would work with their supporters to come to a decision themselves. Obviously, there are still situations where substituted judgment might be necessary, such as when someone is in a coma. However, the supported decision-making model asks us to use substituted judgment only as a last resort and argues that nearly everyone is a competent decision-maker, if they have the proper support.

The ACLU notes the civil rights violations associated with stripping someone of decision-making power: “This condemns an adult with a disability to a perpetual childhood – first parents make all decisions, and then, when the parents are no longer able to serve, a complete stranger may be appointed to make every choice for the individual.”⁵⁵ The ACLU further describes the role of the supporters: “The supporters help the person with a disability understand, make, and communicate her own choices.”⁵⁶ Here, I argue that using a supported decision-making model helps prevent people with ID/DD from being placed in a perpetual childlike role, providing them with the autonomy to make their own choices and respecting their dignity as adult humans. In the sections that follow, I will describe the ways in which supported decision-making as a model upholds the core tenets of autonomy, beneficence, non-maleficence, and justice, while also applying those concepts to the Neurodiversity Movement.

⁵⁵ <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making>

⁵⁶ Ibid.

2.5 Autonomy

Likely because autonomy is one of the core concepts within bioethics, the meaning and implementation of the concept within healthcare has been debated. While lack of definitional consensus makes articulating the relationship between autonomy, disability, childhood, and relational decision-making difficult, the challenge presents an opportunity to further understand how clinical and ethical conceptions of autonomy impede or support decision-making by people with ID/DD.

Lisa Dive and Ainsley J. Newson argue that there are at least three different conceptions of autonomy at play in bioethics literature: most common is what they call the *default conception*, but they also note the presence of both procedural and substantive, perfectionist definitions. They draw the default conception of autonomy from Beauchamp and Childress' work. Returning to Beauchamp and Childress, then, I note the intrinsic connection between intellectual disability and autonomy in their definition. They write: "A person of diminished autonomy...is in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans. For example, cognitively challenged individuals and prisoners often have diminished autonomy. Mental incapacitation limits the autonomy of a severely retarded person, whereas coercive institutionalization constrains the autonomy of prisoners."⁵⁷ Outdated language aside, Beauchamp and Childress argue that mental incapacitation can limit autonomy; I argue, instead, that mental incapacitation does not, in fact, limit autonomy. Rather, people who are considered 'mentally incapacitated' are often prevented from acting autonomously not by their own mental

⁵⁷ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics, 6th Edition*, New York: Oxford University Press, 2009, p. 99-100

capabilities but by the lack of supportive structures within society writ large to enable them to act autonomously. Supported decision-making, as outlined above, would provide one such strategy to increase the autonomous capabilities of individuals with intellectual disabilities, one group often considered ‘mentally incapacitated.’

The second definition of autonomy that Dive and Newson note is *procedural autonomy*, through which autonomy is seen not as a characteristic of decisions, but rather as a characteristic of persons. Here, the individual must partake in a procedure involving a critical examination of their goals and underlying desires is required in order to be capable of acting autonomously. Dive and Newson note the importance of relationships to a procedural understanding of autonomy because all individuals make decisions in relation to their social and interpersonal context. Supported decision-making would be consistent with this approach to autonomy because supported decision-making highlights procedures and relationships through which to support individuals as they make decisions. Through a procedural understanding of autonomy, an individual with DD/ID engaged in a supported decision-making process could still be understood as acting autonomously.

Dive and Newson advocate most strongly for the final approach which they overview: substantive perfectionist autonomy. This approach considers not only the procedures through which decisions are made, but also the content of the decisions. By perfectionist, Dive and Newson mean that this conception of autonomy requires an individual be capable of identifying goals and participating in actions to reach those goals; perfectionist also means that this concept of autonomy applies not only to large decisions, but also to everyday decisions like what outfit we wear. By substantive, Dive and Newson mean that the content of the decisions matters because people do have real preferences relevant to the substance of the decision; in order for a decision to be made

autonomously, the relationship between the decision and the controlling factors of the decision is important. Not all kinds of control, the authors note, undermine autonomy. Rather, if the Self (one's values and goals) is truly expressed through the decision, then the decision is autonomous; if the Self is not expressed, then this is a failure to act autonomously. In many ways, this definition of autonomy helps highlight the potential risk of supported decision-making: that those providing support might overshadow the ability of the decision-maker to properly express the Self through the decision. Those providing the support must exercise caution to not influence in ways which undermine autonomy, but rather should take great care to help the decision-maker explore their own values and goals and to understand how those values and goals relate to the substance of the decision.

2.5.1 Autonomy and the Neurodiversity Movement

The neurodiversity movement is an attempt by Autistic self-advocates to reclaim their rights to self-definition and autonomy. For people with disabilities, autonomy has historically been viewed as unimportant and under-emphasized, despite its relevance as an ethical standard in bioethics. Scully argues that ethicists need to consider who is granted the freedom to decide what is ethically permissible and not permissible. For Autistic individuals, the ethical boundaries have historically been drawn by psychiatric, medical, and therapeutic professionals or by parent-run advocacy organizations. *Nothing about us without us* has been the rallying cry of the Independent Living Movement, an activist community of disabled people that is the philosophical forerunner of the neurodiversity movement. Even the Americans with Disabilities Act was predicated by an acknowledgement of how the autonomy of disabled Americans has been violated:

Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness...based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.⁵⁸

Eric Rosenthal and Arlene Kantar emphasize that one of the worst violations of autonomy is forced institutional segregation, noting that the practice continues today.⁵⁹ Shula Wilson argues, “institutionalization, which means handing over control and giving up autonomy, perpetuates and increases the need for help.”⁶⁰

The neurodiversity movement celebrates Autism “as a part of the spectrum of human neurological conditions”⁶¹ and generally argues against institutionalization and segregation because these limit personal choice.⁶² As one proponent wrote of the movement, “When we say we believe in the neurodiversity paradigm, we’re not saying our lives are all butterflies and sunshine – we’re saying that our minds are normal and natural for us, and we shouldn’t be subjected to attempts to cure or fix us. If we choose for ourselves to seek treatment or a cure for

⁵⁸ Parallels in Time: A History of Developmental Disabilities, “The Americans with Disabilities Act,” <http://mn.gov/mnddc/parallels/six/6c/9.html>.

⁵⁹ Eric Rosenthal and Arlene Kanter, “The Right to Community Integration for People with Disabilities Under United States and International Law,” *Disability Rights Education and Defense Fund*, <https://dredf.org/news/publications/disability-rights-law-and-policy/the-right-to-community-integration-for-people-with-disabilities-under-united-states-and-international-law/#sdfootnote1sym>

⁶⁰ Shula Wilson, *Disability, Counselling and Psychotherapy: Challenges and Opportunities*, Palgrave Macmillan 2002 qt 11.

⁶¹ Jack, J. (2012). Gender copia: Feminist rhetorical perspectives on an Autistic concept of sex/gender. *Women's Studies In Communication*, 35(1), p.1.

⁶² Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1).

the parts of our disabilities that are distressing or difficult, that's fine.”⁶³ Autistic proponents of neurodiversity make claims about agency and autonomy with regard to seeking treatments or cures, but don't necessarily comment specifically on the ethics of the cure or treatment itself. Clearly, then, a neurodiversity perspective has implications for ethics, particularly with regard to who gets to judge what is ethical or appropriate treatment. Specific concerns mentioned in frequent conversations I have had with other autistic individuals include being left out of conversations about Applied Behavior Analysis (ABA) therapy and Electric Shock Therapy. Autistic individuals deserve a seat at the table when decisions are made about them and the opportunity to consent (if possible) or assent to treatment.

2.6 Interjection 6

In medical school

They didn't teach us it was OK to kill people with disabilities

They just told the pregnant person to get the blood test so that "if the baby has Down syndrome, you can terminate the pregnancy"

(Where's the choice in that?)

-Nightengale⁶⁴

⁶³ Leibowitz, C. (2016, March 4). Here's what neurodiversity is – and what it means for feminism. *Everyday Feminism*. <http://everydayfeminism.com/2016/03/neurodiversity-101/>

⁶⁴ Nightengale. (2016, March 1).

2.7 Non-Maleficence and Beneficence

Non-maleficence and beneficence seem like two sides of the same coin, but Beauchamp and Childress are careful to draw a distinction. They write: “Obligations not to harm others are distinct from obligations to help others.”⁶⁵ They further define: “Each of the three principles of beneficence requires taking action by *helping* – preventing harm, removing harm, and promoting good – whereas non-maleficence requires only *intentionally refraining* from actions that cause harm.”⁶⁶ Each of these four ethical obligations are useful for participants in supported decision-making contexts, as they provide sharp boundaries for how those providing support must act. Certainly, supporters must engage in non-maleficence, which is to say that they should not directly engage in actions that harm the decision-maker. For example, this would include, but is not limited to, physical violence or intimidation, harassment, or intentionally traumatizing the decision-maker. Supporters should also not inappropriately focus on the resulting content of the decisions (non-maleficence) and should support the values and preferences of the individual (promoting a good) even if these values and preferences do not align with the personal views held by the supporter. If an abled person can chose to eat ice cream or get drunk, even though both those things are ‘bad’ for them, then a person with ID/DD ought to be able to make a supported ‘bad’ decision as well. Further, this allowance for ‘bad’ supported decisions extends beyond the mundane into significant life decisions. Abled individuals make choices all the time to stay in ‘bad’ relationships or make ‘bad’ financial decisions; while it is important for supporters to make sure that the decision-maker fully understands all the consequences of a choice, the obligation to beneficence does not extend

⁶⁵ Beauchamp and Childress, p. 150.

⁶⁶ *Ibid.*, p. 151.

to overriding their choice once it has been made. A supporter should not override the decision-maker's conceptions of what is 'good' and what is 'harm,' nor the decision-maker's values with regard to what sorts of 'harm' are tolerable...or, even enjoyable! After all, despite what it does to my waistline, I am currently enjoying a delicious bowl of rainbow sherbet on a lovely sunny day on my front porch. Would I accomplish more on this manuscript if I was eating a protein bar and locked away inside from distractions? Likely so. But I have chosen to enjoy writing, sunshine, AND ice cream – and no one should stop me.

Beneficence is also an important obligation because of the duty to actively prevent or remove harm. In the decision-making process, preventing or removing harm could involve slowly presenting information in plain English, without the use of jargon, and using the communication mechanism that the individual prefers (Alternative and Augmentative Communication, the use of images, Sign Language, etc.). While power differentials are likely unavoidable due to broader social structures, supporters should actively avoid reinforcing these structures while centering the individual decision-maker in all interactions.

2.7.1 Non-Maleficence, Beneficence, and the Neurodiversity Movement

Proponents of the neurodiversity model necessarily think of Autism as an identity category, “a natural part of themselves.”⁶⁷ Autistic individuals are often pressured to conceal Autistic traits by conventional medical therapies like ABA. Bascom wrote, “Passing as non-Autistic, passing as neurotypical, means that you never get to actually *be* human. Be a person. You just get really good

⁶⁷ Kapp, et al. (2013)., p. 66.

at faking it.”⁶⁸ The Neurodiversity Movement rejects this pressure to pass, viewing such therapies as a harm rather than as a benefit.

Furthermore, most of the language we have to describe disabled experiences positions disability negatively.⁶⁹ This is certainly true with regard to the language of Autism as well: Autism Spectrum Disorder, Autism Epidemic, Autism as a *missing puzzle piece*, and *Autistic* as a slur (sometimes used in place of *retarded*), for example. The Neurodiversity Movement provides a foundation for attempts to reclaim language and reposition it positively. This has led to conflict over language use within and between communities particularly with regard to person-first or identity-first language (person with Autism vs. Autistic person), demonstrating that the ethics of language are very much specific to a particular community. Mary Tobin, an early childhood specialist at Virginia Commonwealth University, wrote, “Person-first language is a philosophy of putting individuals before their disability.”⁷⁰ However, the neurodiversity model advocates for the reappropriation of slurs associated with Autistic identity, especially the word *Autistic*. Jim Sinclair, founder of Autism Network International, described person-first language by stating, “Saying ‘person with Autism’ suggests that Autism is something bad- so bad that it isn’t even consistent with being a person. Nobody objects to using adjectives to refer to characteristics of a person that are considered positive or neutral.”⁷¹ Physicians, healthcare providers, and bioethicists should ask individuals on the spectrum about their preferred self-descriptive language.

⁶⁸ Bascom, J. (2011). Anatomy of an Autistic. *Just Stimming*, para. 1. Retrieved from <https://juststimming.wordpress.com/2011/04/05/anatomy-of-an-Autistic/>

⁶⁹ Scully, J. L. (2003). Drawing lines, crossing lines: Ethics and the challenge of disabled embodiment. *Feminist Theology*, 11(3), 265-280.

⁷⁰ Tobin, M. (2011). Put me first: The importance of person-first language. *Virginia Commonwealth University's Department of Education's Training and Technical Assistance Center*. Retrieved from <http://www.ttacnews.vcu.edu/2011/05/put-me-firstthe-importance-of-person-first-language/>

⁷¹ Sinclair, J. (1999). Why I dislike “person first” language. *Syracuse University*. Retrieved from

Additionally, developmentally disabled people have to endure horrible comments about their conditions by scientists and doctors. Richard Dawkins tweeted, regarding prenatal genetic testing of individuals with Down Syndrome: “Abort it and try again. It would be immoral to bring it into the world if you have the choice.”⁷² When a follow-up question about Autistic individuals was posted to him, Dawkins responded: “People on that spectrum have a great deal to contribute, maybe even an enhanced ability in some respects. DS not enhanced.”⁷³ While there does not yet exist a prenatal genetic test for Autism, Dawkins’ distinction between Down Syndrome and Autism with regard to contributions, presumably to society, seems to reflect a hypercognitivist⁷⁴ bias. Dawkins’ admonition also seems decidedly anti-choice. As Asch argued, prenatal testing should be reflective, as an assumption that a woman should or would terminate a pregnancy if the test showed a child would be disabled takes away choice.⁷⁵ A naturalized, reverse bioethics provides the foundation for developing disability ethics that reflect the perspectives and ethics of disabled communities, rather than scientists like Dawkins.

Asch noted that children born or predicted to be born disabled face challenges to continued existence from the time of conception, with some bioethicists arguing that it would be ethically preferable to abort or let these children die.⁷⁶ Scully broadly explored the implications of genetic testing with regard to disability, arguing that we shouldn’t decide to select against disability

http://web.syr.edu/~jisincla/person_first.htm

⁷² Fiano, C. (2014, August 20). Richard Dawkins: It is immoral to not abort babies with Down Syndrome. *Live Action News*. <http://liveactionnews.org/richard-dawkins-it-is-immoral-to-not-abort-babies-with-down-syndrome/>

⁷³ Fiano. (2014).

⁷⁴ Stephen Post created this term.

⁷⁵ Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health*, 89(11), 1649-1657.

⁷⁶ Asch, A. (2001). Disability, bioethics, and human rights. In G. L. Albrecht, K. Seelman, & M. Bury (Eds.) *Handbook of disability studies* (pp. 297-327). Thousand Oaks, CA: Sage Publications.

without imagining what a world without social and attitudinal limitations would be like.⁷⁷ Wasserman and Asch echo this concern: “We are concerned with the overreliance on genetically based characteristics to predict how well the lives of a child and a child’s parents will go.”⁷⁸ Within the Neurodiversity Movement, a shared moral prohibition against selective abortions has developed. Pitney wrote, “selective abortion angers disability rights activists, with some using terms such as ‘eugenics’ and ‘genocide’.”⁷⁹ Amy Sequenzia, an Autistic self-advocate, expressed concerns about selective abortions, stating, “the likely outcome [of any research on Autism genetics] is to prevent births of autistic people -- as in selective abortion. Autism is not a disease, a brain cannot be prevented, and the research money could be better used to find better ways for all neurodivergent people to participate in all things.”⁸⁰ While a prohibition against selection abortion is also seemingly anti-choice, understanding the societal context in which these autistic individuals have grown up seems to make their claims more sympathetic, while not necessarily justifying them.

2.8 Justice

Justice is one of the most difficult terms to define in this work, as the ways in which justice is interpreted vary widely. Beauchamp and Childress overview many different theories of justice

⁷⁷ Scully. 2003.

⁷⁸ Wasserman, D. & Asch, A. (2012). Selecting for disability: Acceptable lives, acceptable reasons. *The American Journal of Bioethics*, 12(8), p. 30.

⁷⁹ Pitney, J. J. (2015). *The politics of autism: Navigating the contested spectrum*. Lanham, MI: Rowmann & Littlefield, p. 120.

⁸⁰ As cited in Perry, D. (2016, January 10). Autism: Can other candidates match Hillary Clinton’s plan? *CNN*. Retrieved from <http://www.cnn.com/2016/01/10/opinions/perry-autism-hillary-clinton-plan/>

in their seminal work: utilitarian, libertarian, communitarian, and egalitarian. Perhaps what would be most useful here would be to describe the theory of justice that most directly informs my work here: Disability Justice. *Disability Justice* was coined by disabled queer women of color to push back against the disability rights framework and imagine a more just future. Disability rights, per Patty Berne, one of the organizers of the movement, is underscored by capitalist frameworks and doesn't acknowledge oppression beyond that which is rooted in disability.⁸¹ In contrast, as Mia Mingus writes: "Disability justice activists are engaged in building an understanding of disability that is more complex, whole and interconnected than what we have previously found. We are disabled people who are people of color; women, genderqueer and transgender; poor and working class; youth; immigrants; lesbian, gay, bisexual and queer; and more."⁸²

To bring disability justice into the context of medical establishments, I rely on the work of Jasbir K. Puar and Leah Lakshmi Piepzna-Samarasinha. Through the lens of disability justice, Puar outlines a critique of the medical industrial complex, writing, "The goal of these activist efforts does not remain at the restitution of the disabled subject – soliciting tolerance, acceptance and empowerment – but rather directs attention to the debilitating conditions of the medical-industrial complex itself."⁸³ Thus, the larger critique from a disability justice politics is of the entire privatized medical system, based in capitalism, which incapacitates people through many vectors: medical debt, lack of accessibility, stigma, improperly diagnosing women's pain as hysteria, etc. etc. In this work, I particularly focus on the ways in which the medical-industrial complex positions certain categories of people as childlike. While there are many categories I could consider, such

⁸¹ <http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne>

⁸² <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>

⁸³ Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability*, Durham: Duke University Press, 2017, p. 16.

as women (especially BIWOC), the chronically ill, or the elderly, I have specifically narrowed my focus to the young and those with ID/DD in order to make a more detailed comparison and analysis.

Piepzna-Samarasinha's work describes "the ways in which sick and disabled people attempt to get the care and support we need, on our own terms, with autonomy and dignity."⁸⁴ They detail the failures of the medical-industrial complex, a system that only validates some disabilities and does not adequately provide care for all. They write, "in the face of systems that want us dead, sick and disabled people have been finding ways to care for ourselves and each other for a long time."⁸⁵ They further critique the ways in which white disabled people have co-opted the phrase 'disability justice,' a co-option I attempt to resist as a white disabled person by extensively citing the BIPOC who founded the movement. I also acknowledge the ways in which the media that I analyze reinforces the whiteness of the disability rights movement by showcasing only white bodies. While this is not uncommon for the era, I want to point out that this white-centered media ignores the ways in which Black and Brown bodies are disproportionately targeted by the medical-industrial complex and disproportionately imprisoned in institutions, even if this fact is not acknowledged by the media of the era. Furthermore, any essay about disability, childhood, and justice must acknowledge the ways in which childhood is a raced category, wherein The Child is raced White.

⁸⁴ Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice*, Vancouver: Arsenal Pulp Press, 2018, p. 33.

⁸⁵ *Ibid.*, p. 41.

2.8.1 Justice and the Neurodiversity Movement

Wasserman et al. describe the tensions that disability brings to discussions of justice:

Disability is of particular interest for justice because of the way in which it juxtaposes two basic and powerful senses of injustice: first, the treatment of some people as moral, social, or political inferiors on the basis of irrelevant characteristics; second, the creation, perpetuation, or simple failure to correct disparities between individuals in income, wealth, health, and other aspects of well-being on the basis of morally irrelevant factors.⁸⁶

They call for us to examine ways in which we can ensure people with disabilities have access to “social participation and individual flourishing,” calling this essential to disability justice.⁸⁷

Similarly, proponents of the neurodiversity movement call for public and institutional policies that allow for equitable participation, both in society at large and in one’s own healthcare. Speaking from personal experience, I know that being autistic in this society is not easy, and it is made more difficult by healthcare providers who do not listen, who do not treat me respectfully, and whose tone changes to pure condescension as soon as they read “Autism Spectrum Disorder” on my chart.

And what does ‘disability justice’ look like within the context of the Neurodiversity Movement? Like the mainstream disability rights movement, the Autistic rights movement has also been extremely white-centered. Just yesterday morning, I was seeing a new hashtag popping up on my Twitter feed: #AutismTooWhite. A play on the existing #DisabilityTooWhite, the discourse happening around the hashtag noted the ways in which Autism tends to be raced White

⁸⁶ David Wasserman, Adrienne Asch, Jeffrey Blustein, and Daniel Putnam, “Disability and Justice,” In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta, 2015, <https://plato.stanford.edu/entries/disability-justice/>.

⁸⁷ Wasserman et al.

– BIPOC are extremely under-diagnosed relative to white boys especially and white children in general. If the Neurodiversity Movement is to be committed to disability justice, then its proponents must follow the lead of those most impacted and also engage more in cross-movement organizing.

2.9 Interjection 7

In medical school

They didn't teach us it was OK to kill people with disabilities

And they would be shocked if someone said they had

They just implied in 100 little ways we might be better off dead

And that others might be better off if we were dead

In medical school

They didn't teach us it was OK to kill people with disabilities

They just emphasized the difference between us and them

That is us and we

I mean, us and me

In medical school

They didn't teach us it was OK to kill people with disabilities

Out loud

They didn't have to.

2.10 Conclusion

Jackie Scully's work, which calls for further research into the embodied ethics of disability, provides the foundation for my own call for additional research: Bioethics needs to consider also how medical and bioethical expectations for decision-making position some kinds of decision-making support as naturalized and normal, but other types as reflecting upon the competence and autonomy of an individual. The experiences of individuals with non-physical disabilities provides bioethics with an understanding of how to more fully respect the autonomy of disabled people, to better allow them to be full participants in a more just healthcare decision-making process, and to consider beneficence and non-maleficence through the lens of the patient's goals, not the providers'.

In this chapter, I have provided a reflection on the ways in which supported decision-making could be one vehicle for respecting the autonomy of a patient with ID/DD, allowing for better, more just outcomes in which the patient and their support network are more personally invested. I have also used the example of the Neurodiversity Movement to demonstrate the ways in which communities founded in shared values around developmental and intellectual disability can develop their own shared ethical perspectives and norms of behavior. In the chapter that follows, I begin my analysis of the case study of the Pennhurst Institution through the lens of the concepts I have introduced in this chapter.

⁸⁸ Nightengale. (2016, March 1).

3.0 Parent Advocacy and the Construction of Disabled Childhood

In 1903, construction of the Eastern State Institution for the Feeble Minded and Epileptic, later known as Pennhurst State School, began. The campus was expanded throughout the 1920s and 30s, but was quickly filled to capacity again. Institutional conditions at Pennhurst were never ideal, but the facility quickly became overcrowded, without funding keeping pace. The history of the Pennhurst State School underscores the necessity of support decision-making. In this chapter, I review the sordid history of Pennhurst, using it as a case study to further illustrate the concepts I introduced in the previous chapter. Pennhurst's history is the most preserved and documented, though I will also reference other institutions briefly throughout this chapter.

Despite attempts to keep family members in the dark, people eventually became aware of the living situations at these institutions and began to advocate for change: “parents, journalists, and advocates joined together to reveal the issues surrounding the rights of people with disabilities in state-run and state-funded institutions, and strove to correct the issues brought about by the overcrowding, understaffing, and seclusion.”⁸⁹ These campaigns and the subsequent lawsuits resulted in the closure of many institutions in Pennsylvania and sparked a nationwide battle against institutional care. This battle birthed a generation of parent advocates who would fight to close the institutions and move funding to integrated, community care.

Many of these parent advocates came together under the heading of Pennsylvania Association for Retarded Children, later Pennsylvania Association for Retarded Citizens, (PARC) to advocate for social change: PARC was founded in 1949, as a chapter of the national

⁸⁹ “From wrongs to rights,” n.d, <http://uwac.omeka.net/about>.

ARC. Initially, the national ARC's primary focus was on research; the government affairs office in D.C. did not open until the 1960s.⁹⁰ In Pennsylvania, other important historical context included an act mandating that individuals with intellectual disability be provided education in public schools which was passed in 1956 and, in 1966, the passage of the Pennsylvania Mental Health/Mental Retardation Act, providing some funding for community-based supports.

It wasn't until the 1970s that the majority of ARC's activism would occur.⁹¹ In Pennsylvania, this activism was sparked following a 1968 exposé of Pennhurst, "Suffer the Little Children," hosted by Bill Baldini, which ran for a week on NBC10, out of Philadelphia. The influence of this exposé in pushing parents to advocate will be highlighted throughout this chapter.

Some research on the history of Pennhurst, on the legal implications of the related lawsuit, and on the ethics of institutionalization generally exists, but I seek to fill a gap in the literature by examining the link between societal attitudes about disability and advances in medical ethics. The theoretical foundation laid in the previous chapter, which provides an understanding of disabled autonomy that considers the rhetorical and ethical role of childhood as well as emphasizes the need for supported decision-making, undergirds my analysis here. In this chapter, I argue that changes in public perception of people with disabilities influenced a shift in medical ethics regarding the best settings for care of individuals with disabilities, suggesting that bioethics do not operate in a philosophical sphere separate from the rest of society. Specifically, I, first, examine the ways in which parent advocacy constructed their adult disabled offspring as childlike, while also meaningfully improving their living conditions. Second, I note the ways in which both the government and medical establishments resisted parent challenges to institutional conditions.

⁹⁰ "Six Decades of Advocacy," accessed November 28, 2016, <http://www.thearc.org/who-we-are/history/advocacy>.

⁹¹ Ibid.

3.1 Parent Advocacy and Disabled Childhood

The documentary *I Go Home* describes the common procedure for visitors at Pennhurst: children would be showered, dressed in clean clothing, and medicated until they were calm, then brought into a clean, separate visiting room. Parents, then, rarely knew about the horrendous conditions at the institutions. And conditions were, indeed, horrendous, as Emily Beitiks reports:

Investigations in the late 1960s found that over 3,500 residents were living in Pennhurst with only 600 workers to assist them, and that many staff were mistreating and sometimes physically harming the residents. There were cases in which residents were raped, sometimes while others watched and did not attempt to stop it. Residents who acted out were cruelly punished—one man was beaten repeatedly with a toilet bowl brush, leaving welts all over his body. Others were neglected, some left naked in beds or caged in cribs all day long.⁹²

Journalists noted: “Pennhurst clients receive inadequate medical care and are often exposed to life-threatening conditions,”⁹³ and “A team of two outside doctors...found serious inadequacies in treatment, poor record-keeping, and heavy emphasis on drugging.”⁹⁴ Local media had run numerous exposés of failing institutions, but Bill Baldini’s *Suffer the Little Children* was the “first time that conditions in the [Pennhurst] facility have been shown to the general public.”⁹⁵ In the parent advocacy that followed the exposé’s reveal of these conditions, parents constructed

⁹² Emily S. Beitiks, “The Ghosts of Institutionalization at Pennhurst’s Haunted Asylum,” *The Hastings Center Report* 42.1 (2012): 22-24. doi: 10.1002/hast.10

⁹³ Clifton O. Lee, 1980, ““Pennhurst care hit in report,”” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/877>.

⁹⁴ ““Two doctors say Pennhurst uses drugging as program substitute,”” 1980, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/878>.

⁹⁵ “Pennhurst Timeline,” n.d., <http://www.preservepennhurst.com/default.aspx?pg=93>.

institutional residents as children in two ways: first, through the specific words and language they used to describe institutional residents, many of whom were significantly above the age of majority; and second, through the implications of a right-to-education lawsuit.

3.1.1 Rhetorical Construction of the Disabled ‘Child’

I begin by noting two of the most obvious ways in the discourse in which institutional residents are constructed as childlike, excluding the ‘Suffer the Little Children’ exposé which is covered in great detail in chapter four. These include a shift in PARC’s discourse from talking about children to talking about citizens and a debate over the distinction between playpens and cages.

3.1.1.1 The R*** Child Becomes a Citizen**

Now referred to only as ‘The Arc,’ the national organization under which PARC was structured has gone through many name changes in its history. Most relevant for my analysis here is the change from the ‘National Association for Retarded Children’ to the ‘National Association for Retarded Citizens’ in 1974.⁹⁶ The Arc notes: “This more fully showed the association’s emphasis on serving persons of all ages, regarding issues pertinent to all stages of living.”⁹⁷ Given that the average age of a Pennhurst resident was 39, it’s likely that the age range of individuals that The Arc served never changed.⁹⁸ However, the increased emphasis on recognizing that disabled adults are adults was a significant shift.

⁹⁶ <https://www.thearc.org/who-we-are/media-center/FAQs?chid=1>

⁹⁷ ARC, Pennsylvania, “Historical Overview,” page 8, retrieved from http://thearca.org/file_download/43ed8851-baa8-4cbd-8399-a089896dc377.

⁹⁸ “Pennhurst Longitudinal Study,” p. 53.

But, why ‘citizens’? The obvious reason is to keep the acronym the same. ‘Retarded Comrades’ is *clearly* too communist, ‘Retarded Characters’ too Shakespearean...and with that I’ve reached the end of the list of nouns that start with C that can generally describe a human. It’s *possible* I spent a little too much time on this thought experiment. Though they may exist somewhere, I have been unable to locate meeting minutes from the National ARC that describe any thought process or debate over this name change. While my brief research into nouns that start with C shows that ‘citizens’ was likely the best choice, it is not without implications.

Indeed, children are often citizens, and the relationship between childhood and citizenship is even more intriguing in a country, like the U.S., where citizenship is assigned to children born in this country regardless of parental citizenship status instead of an alternative like citizenship by blood (a system which requires one or both parents to be citizens). Yet, children in the U.S. do not typically have the full rights or responsibilities of adult citizens, though certain categories of children are often treated as more adult than other categories. Here, I am thinking of the frequency with which brown and black boys are more often sentenced as adults.

And where do people with disabilities fall in this citizenship classification scheme? Like children, adults with ID/DD are considered citizens, but sometimes without the full rights or responsibilities of a non-disabled adult citizen. Despite common misperception, people with intellectual and developmental disabilities have the right to vote, a common implication of citizenship. People with ID/DD who work pay taxes, but can be paid sub-minimum wage. People with ID/DD can get married...sometimes...unless someone decides they are incompetent to make that decision⁹⁹ or if doing so could cause them to lose the benefits they rely on to survive. People

⁹⁹ Is it even possible to be incompetent to love someone romantically and with great commitment? A question for another time, perhaps

with ID/DD can have children, but sometimes those children are taken away from them solely because of the parents' disability. People with ID/DD can be organ donors, but they are sometimes denied a transplant solely because of their disability. People with ID/DD can have many of their rights taken away from them under guardianship, especially if their guardian isn't invested in involving them in decision-making. The question of whether people with ID/DD are fully vested in citizenship is clearly a complicated one. Prisoners, like individuals with ID/DD, are often denied civil rights. Further research might consider the similarities between prisons and institutions in infantilizing those held within, especially considering how high a percentage of our prison population in the U.S. has a disability. Official figures from the Department of Justice place the percentage at around 40%, but the reality is likely higher due to barriers to diagnosis behind bars.¹⁰⁰

Thus, the rhetorical choice to rename from 'children' to 'citizens' is both an important move in validating the adulthood of people with ID/DD, but also fraught with the possibility of erasing the complicated tensions in which adults with ID/DD exist within the citizenship system in the United States and abroad (see, for instance, the recent controversy over Autism and the Driver and Vehicle Licensing Agency in the UK).¹⁰¹ Changing an advocacy organization's name does not change the ways in which our medical, social, and ethical discourses continually invalidate the perspectives and personhood of disabled adults, especially those with ID/DD. Perhaps changing a name even helps to obscure the ways in which these systems continue, even in the present day, to contribute to the infantilization of disabled adults. My research seeks to pull back that curtain.

¹⁰⁰ <https://www.americanprogress.org/issues/criminal-justice/reports/2016/07/18/141447/disabled-behind-bars/>

¹⁰¹ <https://www.theguardian.com/society/2019/mar/03/autistic-people-angry-at-having-to-disclose-diagnosis-to-dvla-even-if-driving-not-affected>

3.1.1.2 Cages or Playpens?

This is the way in which adults with ID/DD are constructed as children that I find most abhorrent: instruments of torture or punishment named as items used to care for children. In this section, I reference a historical example from PARC's advocacy and then present a contemporary example of these practices continuing.

In 1973, Dr. James McClelland, superintendent, was fired from the Polk Center in Venango County because of his use of cages to contain patients. As abhorrent as this practice sounds, parents complained that the conditions at Polk worsened after he was fired: one reporter noted, "Parents are complaining about more bruises, scratches and even teeth marks found on their loved ones now than before."¹⁰² The ways in which the cages were described furthers the comparison between adults with ID/DD and children: while only some of the people contained in cages were adults, the vast majority were at least teenagers. Yet, some who worked at Polk described the cages as being playpens, like those comfortable structures meant to safely contain very small babies and toddlers as they play. A Polk food service worker described these cages as, "a safe play pen...the child has freedom of hands, legs, and the room to move about."¹⁰³ A Polk night attendant similarly noted, "We are dealing with medically and mentally disturbed people and methods of restraints must be used for the self protection of both residents and employees...why the fuss over large playpens."¹⁰⁴

¹⁰² Ken Strom, 1973, "'Polk Conditions Called Worse Since Firing,'" *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/862>.

¹⁰³ Jos. Schiffer, 1973, "'Outside Visitors,'" *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/728>.

¹⁰⁴ Sandra McQuiston, 1973, "'Polk Situation,'" *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/727>.

So, were the cages more like playpens? According to a news article, “The cages were described as wooden-slat type structures about 5 feet by 5 feet by 5 feet.”¹⁰⁵ While it is true that some playpens in the 1970s were constructed out of wood slats (a quick Google image search of ‘1970s playpen’ reveals a few examples), they were more commonly made out of plastic, fabric, squishy mats, and mesh – and none of them had a ‘roof’ like a cage – which would presumably be necessary to keep teenagers and adults contained within. Secretary of Public Welfare Wohlgemuth also found that Polk staff were using cattle prods on the residents, meaning a comparison of the structures to cages (like those that would contain animals) rather than to playpens is likely more accurate.¹⁰⁶ I cannot find any images of the cages at Polk, though I imagine some do exist, since Secretary Wohlgemuth brought a cage and put it on display in the Capitol Rotunda. The Mental Patient Civil Liberties Project, directed by David Ferleger, issued a press release condemning the use of seclusion and restraints in state hospitals, arguing that they are unnecessary.¹⁰⁷ And certainly, whether we call them cages or playpens, adults with ID/DD cannot experience autonomy while contained within.

And yet, as we flash forward to today, we find many of the same practices still at play at the Judge Rotenberg Educational Center. The Judge Rotenberg Center provides both residential and day school programming to individuals ages 5 and up ‘with conduct, behavior, emotional, and/or psychiatric problems, as well as those with intellectual disabilities or on the autism

¹⁰⁵ “Head of School Fired for Caging Retarded,” 1973, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/711>.

¹⁰⁶ <https://www.keystonehumanservices.org/about-us/history/history-2.php>

¹⁰⁷ Mental Patient Civil Liberties Project, 1973, “Press Release from the Mental Patient Civil Liberties Project- Local Mental Health Lawyer Supports Wohlgemuth Firing of Polk Institution Superintendent But Attacks Use of Seclusion and Restraints in Local Hospitals,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/717>.

spectrum.”¹⁰⁸ It is located in Canton, Massachusetts and was founded in 1971. National Public Radio (NPR) describes that backpacks, which are commonly worn by children who attend school, serve a different purposes at the Rotenberg Center, where 48 adults wear backpacks “equipped with a battery and wires that are attached to [their] bod[ies] to deliver a two-second shock if [they] misbehave.”¹⁰⁹ The Guardian reports that the Rotenberg Center also uses restraints and isolation rooms, which while not cages, still, according to Disability Rights International, violate the rights of students under the UN convention against torture.¹¹⁰

Though the individuals who wear the backpacks are legally adults, some have called this practice ‘state sanctioned child abuse,’¹¹¹ which might inspire some to feel emotionally moved, but delegitimizes the adulthood of these individuals. The Guardian continues, “The FDA said the application of shocks could induce “significant psychological and physical risks ... including depression, anxiety, worsening of self-injury behaviors and symptoms of post-traumatic stress disorder, pain, burns and tissue damage”. The Food and Drug Administration (FDA) proposed a ban of any electric shock device ‘used for self-injurious or aggressive behavior because they present an unreasonable and substantial risk to public health.’¹¹² Nevertheless, despite proposing the ban in 2016, the FDA has not yet taken action, though NPR reports that the FDA intends to issue a ban sometime before the end of 2019.¹¹³ When their every move is analyzed via video surveillance and potentially punished with painful shocks, the human rights of these adults are

¹⁰⁸ <https://www.judgerc.org/>

¹⁰⁹ <https://www.npr.org/2019/01/23/687636057/massachusetts-school-defends-use-of-electric-shock-treatments>

¹¹⁰ <https://www.theguardian.com/us-news/2018/nov/16/judge-rotenberg-center-massachusetts-electric-shocks>

¹¹¹ Ibid.

¹¹² Ibid.

¹¹³ <https://www.npr.org/2019/01/23/687636057/massachusetts-school-defends-use-of-electric-shock-treatments>

violated every day in ways that go far beyond constraining autonomy more than 50 years after concerns were expressed about cages and cattle prods at Polk. Using infantilizing language about people with ID/DD obscures the ways in which they are treated less like children and more like non-human animals, who arguably also should not be treated this way.

3.1.2 The Right-To-Education Lawsuit

In the early 1970s, PARC members sat down with attorney Tom Gilhool, a renowned civil rights lawyer, to discuss possible legal action against Pennhurst.¹¹⁴ Gilhool, who had a brother institutionalized at Pennhurst, recommended a lawsuit against the state of Pennsylvania claiming the right to education for all children, based on the decision in *Brown v. Board of Education*, because the institution was technically a state school for the mentally retarded.¹¹⁵ *PARC v. Pennsylvania* (1972), according to Gilhool, was “the first right-to-education suit in the country [for people with disabilities]...[and] was quickly settled before the U.S. District Court for the Eastern District of Pa., resulting a consent decree in which the state agreed to provide a free public education for children with mental retardation.”¹¹⁶ The choice to sue based on a right to education made sense; after all, 20 years earlier, *Brown v. Board of Education* had established a precedent for arguing against segregated school settings. Most importantly, the PARC case emphasized that children must be given a free, equal education in “the least restrictive environment possible.”¹¹⁷

¹¹⁴ Dr. Norman Mulgrave, 1972, “Relationship with State Organization relative to possible legal action against the commonwealth of Pennsylvania and this agency,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/438>.

¹¹⁵ Thomas Gilhool, “Turning Points in Pennsylvania’s Disability Rights History: Pennhurst and Deinstitutionalization,” panel conducted at the University of Pittsburgh, November 14, 2016.

¹¹⁶ “Six Decades of Advocacy,” accessed November 28, 2016, <http://www.thearc.org/who-we-are/history/advocacy>.

¹¹⁷ *Ibid.*

This lawsuit would lay the groundwork for the federal Education for All Handicapped Children Act (1975), now Individuals with Disabilities Education Act (1990).

Important to note, however, is that the vast majority of institutional residents were not, in fact, children and would be age-ineligible for this free education in the least restrictive setting. While the construction of institutional residents as children made them sympathetic, it did not reflect the reality of the typical middle-aged individual. Moreover, while the right to education for all individuals with ID/DD is of critical importance, there are several problems with the approach taken and with the tying of disability to childhood. With many supports and services being administered by the school system, for example, there is highly detrimental service interruption when they age out of the school system. This is an obvious symptom of the fundamental problem of tying disability too closely to childhood, rather than creating a better system of supports and services that are intended to change throughout the lifespan.

To continue the story from the 1970s, because of continued problems with standards of care at state institutions, Gilhool, representing PARC and Pennhurst residents, brought another suit: *Halderman v. Pennhurst State School and Hospital* (1978). In this lawsuit, the plaintiffs argued “that the institutionalization of the residents violated their constitutional rights under the First, Eighth, Ninth and Fourteenth Amendments, as well as under federal civil rights laws and the Pennsylvania Mental Health and Mental Retardation Act of 1966.”¹¹⁸ Judge Broderick ruled in favor of the plaintiffs and articulated three constitutional rights held by the residents of Pennhurst: “right to habilitation...right to be free from harm...right to non-discriminatory habilitation.”¹¹⁹ As a result of violations of these basic rights, Judge Broderick in 1978 ordered that Pennhurst be

¹¹⁸ “Halderman v. Pennhurst State School & Hospital,” 2016, *Disability Justice*, <http://disabilityjustice.org/halderman-v-pennhurst-state-school-hospital/>.

¹¹⁹ Ibid.

closed and that residents be placed in community living arrangements. This lawsuit embodies the shift from thinking about institutional residents as children to thinking of them as citizens, which is also highlighted in the shift from the C in PARC standing for children to it standing for citizens.

Not all parents were in favor of deinstitutionalization, however. The Pennhurst Longitudinal Study, a five-year review of the impact of deinstitutionalization on Pennhurst residents, their families, and the community, acknowledged the existence of a “schism among parents of retarded citizens regarding the future of institutional care.”¹²⁰ A *Daily Local* article on the Pennhurst case noted, “People who oppose Pennhurst’s closing often claim community living is insecure and dangerous to residents.”¹²¹ Jim Conroy, a medical sociologist and lead researcher on the conditions at Pennhurst, noted his lack of surprise that parents still believed that institutions were the best place for their children.¹²² Because, for so long, medical professionals had told parents institutionalization was the best solution for their children, it was understandable that parents wouldn’t believe an alternative, contradictory claim. Yet, the majority of parent advocates, according to PARC, were in favor of closing the institution and, per legal mandate, deinstitutionalization continued. Conroy noted that, even parents who had doubted the success of deinstitutionalization for their children, when interviewed 6 months, 18 months, and 5 years later, were happy that their children had come home.¹²³

¹²⁰ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, “The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis,” <https://aspe.hhs.gov/sites/default/files/pdf/74381/5yrpenn.pdf>, p. 41

¹²¹ Bill Mooney, 1980, “Pennhurst Problems,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/880>.

¹²² *I Go Home*

¹²³ *I Go Home*

Though the successful closing of Pennhurst wouldn't have happened without the efforts of lawyers, it is clear that passionate parent advocates led the way to change. In fact, allegations were levied at PARC that parent advocates had excessive control over the Department of Welfare: "the Pennsylvania Association for Retarded Children had enough influence on the Department of Public Welfare to formulate specific decisions regarding the operation of state-operated institutions for the mentally retarded...Father Kirk said that he felt it was irresponsible for government to give into such pressure" (*sic.*).¹²⁴ Irresponsible or not, the reality is that without the advocacy of parents, changes in standard of care for those with intellectual disability would not have occurred so quickly.

3.2 Resistance from Medical Professionals and Government Agencies

Broderick's ruling in *Halderman* was revolutionary, according to the Pennhurst Longitudinal Study: "Unlike other federal judges who had primarily focused their attention on the improvement of institutional settings, Broderick ruled that Pennhurst State School and Hospital was incapable of providing constitutionally appropriate care and habilitation. This finding led him to conclude that the residents of Pennhurst, those on the waiting list to the institution, and any other mentally retarded person in the community 'at risk' of institutionalization at Pennhurst should be provided services in less restrictive settings in the community."¹²⁵ Yet, despite the rulings in *PARC*

¹²⁴ Carolee Michener, 1973, "'Cite PARC's influence in molding state policy,'" *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/864>.

¹²⁵ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, "The Pennhurst

and *Halderman*, opposition from both the state and from medical professionals delayed the implementation of deinstitutionalization by making specific arguments, which are examined below.

The state significantly resisted both the idea that conditions were not optimal and the implementation of court mandates. “State Secretary of Welfare Helen B. O’Bannon said today that a medical crisis does not exist at the Pennhurst Center... ‘clients there are not medically at risk,’ she said.”¹²⁶ O’Bannon further resisted the idea of placing patients in community living arrangements, stating “We should in no way be forced to dump these people into unaccepting, hostile environments, where they can’t get services and where they will be shoved in the back rooms and attics that replace the back wards of these institutions of yesteryear.”¹²⁷ The concern that people would be unable to receive services was unfounded, as the Pennhurst Longitudinal Survey found better outcomes were achieved for everyone who left Pennhurst.

The state also appealed the *Halderman* decision, which was then upheld in the U.S. Third Circuit Court of Appeals, but then further appealed to the U.S. Supreme Court.¹²⁸ The *Pittsburgh Press* noted, “The crux of Pennsylvania’s appeal is that, although state and federal laws indicate a preference for group homes, neither the legislature nor Congress meant to require the immediate closing of all institutions such as Pennhurst.”¹²⁹ The U.S. Supreme Court overturned the decision

Longitudinal Study: A Report of Five Years of Research and Analysis,”

<https://aspe.hhs.gov/sites/default/files/pdf/74381/5yrpenn.pdf>, p. 1

¹²⁶ Rich Kirkner, 1980, “O’Bannon Defends Pennhurst,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/879>.

¹²⁷ A.W. Geiselman Jr., 1981, “Pa. aide stirs ire of judge,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/882>.

¹²⁸ Phillip Dixon, 1980, “State asks high court to reverse Pennhurst rulings,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/453>.

¹²⁹ “Pennhurst Climax,” 1980, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/804>.

in the Third Circuit Court, finding “that federal law does not give mentally retarded persons a right to treatment outside large state hospitals in smaller, community-based settings.”¹³⁰ Members of PARC reacted with disappointment: “We saw abuses. That’s why we brought the suit.”¹³¹ By 1981, however, there had been a shift in the opinions of state officials, who, despite the high court’s ruling, “committed to a policy of treating mentally retarded persons outside state hospitals.”¹³² In 1983, after significant advocacy by PARC, the Supreme Court reheard arguments on the Pennhurst case, a rare move.¹³³ Ultimately, Broderick’s argument “on the constitutional rights of the residents of Pennhurst were never overturned.”¹³⁴ A settlement agreement with the state arranged for the rest of Pennhurst’s residents to be situated in community living arrangements.

Yet, many medical professionals continued to support the kinds of treatment seen in state hospitals. For instance, according to an article in the *Patriot*, “the use of wooden pens to confine acutely retarded patients who become aggressive is a common, accepted treatment, says the staff psychiatrist at Haverford State Hospital.”¹³⁵ The Pennhurst Longitudinal Study noted: “In Pennsylvania there was widespread skepticism about the capacity of community systems to provide adequate care for people with severe or profound impairments.”¹³⁶ Many doctors were concerned about the speed of deinstitutionalization: “the data, they argue, do not warrant a

¹³⁰ Doug Harbrecht, 1981, ““State Backs Retarded Care Policy Despite Ruling,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/454>.

¹³¹ Ibid.

¹³² Ibid.

¹³³ Combined News Services, 1983, ““Supreme Court rehears Pennhurst Hospital case,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/456>.

¹³⁴ “Halderman v. Pennhurst State School & Hospital,” 2016. *Disability Justice*, <http://disabilityjustice.org/halderman-v-pennhurst-state-school-hospital/>.

¹³⁵ ““Use of Wooden Pens "Accepted" Treatment,” 1973, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/561>.

¹³⁶ U.S. Department of health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, “The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis,” p. 210.

wholesale abandonment of institutions for the retarded.”¹³⁷ Yet, I can find no data suggesting institutions were providing quality care for residents and substantial data indicating the reverse, as noted throughout this project.

While the horrible conditions at many of these institutions were due to lack of resources, rather than poor standards of care, the medical profession did play a role in slowing reform, because of the opposition of some medical professionals. According to the Syracuse University Center for Human Policy, “Today, arguments for institutional care are made largely on...clinical [grounds].”¹³⁸ Doctors like Dr. C. Duane Youngberg, who tested a rewards system for behavioral modification and opposed the use of punishment techniques, were rare, but even Dr. Youngberg noted, “I’d rather see very aggressive patients in pens than killing other people.”¹³⁹ Some medical professionals even encouraged the use of useless punishments, such as “pushing dry scrub”; “an official of the welfare department said the brushes weigh about 40 pounds and were used for no other reason than as punishment for residents at Polk...some were at it from morning to night, except during meal time.”¹⁴⁰

Once forced by legal mandate to change, medical professionals began to recognize the benefits of community-based care that they personally reaped. “Some county personnel noted that caring for returning residents of Pennhurst had helped to increase provider confidence. Some mentioned a sense of pride that they had brought all of their local citizens home from Pennhurst

¹³⁷ “The Community Imperative: A Refutation of All Arguments In Support Of Institutionalizing Anybody Because of Mental Retardation,” 1979, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/236>.

¹³⁸ “The Community Imperative.”

¹³⁹ ““Doctor Tests "Reward" Plan,” 1973, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/146>.

¹⁴⁰ ““Pushing Dry Scrub,” 1973, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/141>.

and that these individuals were doing surprisingly well in the community,” stated the Pennhurst Longitudinal Study¹⁴¹ While the deinstitutionalization of mentally ill patients lent a powerful precedent for deinstitutionalization, it was primarily “the development of powerful new medications that could ameliorate the effects of many forms of mental illness” which prompted physician support.¹⁴² Certainly, prescription of medication also had the potential to be abused. The situation was obviously different for people with intellectual disability, as there were not broad advancements in applicable medication, which resulted in slower physician support for the change than for deinstitutionalization of people with mental illness. Ultimately, the Pennhurst longitudinal study found that it is overall more cost effective to have people in smaller community living arrangements.

3.3 Conclusion

Throughout this chapter, I have considered the ways in which parent advocates conceptualized institutional residents through the lens of infantilization and recounted some of the negative impacts infantilization can have on the ways in which medical professionals, family and community members, and ethicists treat disabled adults. Nevertheless, I want to highlight one positive result of infantilization as well. Because institutional residents were positioned in a relational role – childlike – parents and other community members were reminded of their social

¹⁴¹ U.S. Department of health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, “The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis,” p. 176.

¹⁴² U.S. Department of health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, “The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis,” p. 50.

relationship to the individual residents of the institutions. These relational connections serve to underscore the importance of advocacy and spur those positioned in the parent role to act.

4.0 Conclusion

The movement to deinstitutionalize provided a conception of people with ID/DD that created conceptual space for a disabled adulthood. This movement provided space for individuals to make autonomous decisions about how they want to live their lives, emphasized the harm of infantilizing and patronizing people with ID/DD, demonstrated the great benefits of an integrated society. In this conclusion, I revisit the concepts I have developed throughout this work in the context of the movement toward post-institutionalization, demonstrating the practical utility of supported decision-making.

4.1 Autonomous Decision-Making

Segregated care in institutions frequently violated the autonomy of people with disabilities. Eric Rosenthal and Arlene Kanter note that disabled individuals are institutionalized, this is often done against their will.¹⁴³ Wilson argues, “institutionalization, which means handing over control and giving up autonomy, perpetuates and increases the need for help.”¹⁴⁴ Thus, institutionalization

¹⁴³ Eric Rosenthal and Arlene Kanter, “The Right to Community Integration for People with Disabilities Under United States and International Law,” *Disability Rights Education and Defense Fund*, <https://dredf.org/news/publications/disability-rights-law-and-policy/the-right-to-community-integration-for-people-with-disabilities-under-united-states-and-international-law/#sdfootnote1sym>

¹⁴⁴ Shula Wilson, *Disability, Counselling and Psychotherapy: Challenges and Opportunities*, Palgrave Macmillan 2002 qt 11.

and autonomous decision-making are linked in that the control typically present in institutional settings precludes autonomous decision-making.

Integrated care is more respectful of disabled autonomy than segregated care. Tim Clement and Christine Bigby note, “A degree of autonomy is a consequence of the way community-based services are structured.”¹⁴⁵ Randall G. Krieg argues that the “least restrictive doctrine,” which is what provides the basis for deinstitutionalization and movement to group homes, “is based on the assumption that this is what is best for the patient, not what is best for the community.”¹⁴⁶ Medicaid waivers, which pay for community care settings, provide a vehicle through which people with disabilities can choose where they will live and who provide care for them. Beauchamp and Childress provide three conditions for autonomous decision-making: intentionality, understanding, and substantial non-control.¹⁴⁷ Applying for a Medicaid waiver requires an intentional choice to apply for a waiver, and the application process requires an understanding – from the individual or a proxy – of what changes will happen. Non-control is difficult to measure in this case, but I would argue that, given the length of the waiting lists, coercion or pressure is less likely, as it would have to be sustained for many years. Furthermore, in my own personal experience sitting on the Information Sharing and Advisory Committee for the Office of Developmental Programs for the State of Pennsylvania [The office responsible for managing and overseeing the relevant waiver programs), I have found that caregivers and family members are less likely to want a waiver than the individual themselves. Considering how difficult it is to apply for and retain a Medicaid waiver,

¹⁴⁵ Tim Clement and Christine Bigby, *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation* (London: Jessica Kingsley Publishers, 2010).

¹⁴⁶ Randall G. Krieg, “An Interdisciplinary Look at the Deinstitutionalization of the Mentally Ill,” *The Social Science Journal* 38(2001): 367-380, qt. 369.

¹⁴⁷ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed., Oxford: Oxford University Press, 2013.

waiver recipients must not only demonstrate all three of those conditions for autonomy, but also a considerable amount of determination and perseverance. Samuel Simon and Matthew Hodges found that disabled individuals experienced a significant increase in personal control and choice after leaving institutional settings.¹⁴⁸ Autonomy, personal control, and choice are key indicators of a society that has begun to treat adults with ID/DD as adults rather than as childlike.

Yet, even under deinstitutionalization, many adults with ID/DD find themselves placed under guardianship, where decisions are made on their behalf, potentially without their own meaningful participation. Pennsylvania has a bill of rights for individuals under guardianship, which requires that they be meaningfully involved in decision-making. Nevertheless, in my own experience advocating through the Pittsburgh Center for Autistic Advocacy, I often find that these rights are, in practice, essentially ignored. Guardianship should be a last resort, reserved, I would argue, for individuals absolutely incapable of communicating their preferences or indicating their values (in a coma, for instance). Implementing a system of supported decision-making, instead, places the individual with ID/DD in control of their own decision-making process and allows them to choose the people they want to support them in that process.

In fact, the Final Rule, which is in the process of being implemented in Pennsylvania in 2019, requires that people receiving Home and Community Based Services (HCBS) be in charge of their own decision-making process, at least in the context of HCBS. I'm conducting trainings for individuals with ID/DD this summer about the Final Rule and fully endorse that funding has been provided for trainings led by people with ID/DD, for people with ID/DD. Supported decision-

¹⁴⁸ Samuel E. Simon and Matthew R. Hodges, "Money Follows the Person: Change in Participant Experience During the First Year of Community Living," *Reports from the Field* 6 (2011). <http://www.cds.hawaii.edu/goinghome/wp-content/uploads/2014/11/2011MFPReport.pdf>

making, however, goes further than the context of HCBS, encompassing all areas of life, including relationships, marriage, sex, and home purchasing.

Supported decision-making is the model that we employ at the Pittsburgh Center for Autistic Advocacy. Individuals who regularly meet with us control their own decision-making process, while PCAA staff function as supporters, providing information, accommodations, and knowledge of structures and systems. In practice, supported decision-making generally looks as follows at PCAA:¹⁴⁹

Patricia is a 43-year-old woman who is Autistic and has an intellectual disability. She currently lives in a group home in the Greater Pittsburgh area, where she has lived for 5 years following the closure of the state institution where she previously resided. Patricia is under guardianship and has a professional guardian appointed by the State of Pennsylvania who is a limited guardian of the person and a plenary guardian of Patricia's estate. This means that Patricia's guardian has control over her choices only in the scope of the dictates of a court order, but has control over Patricia's estate under the scope of PA chapter 5500. In this case, according to the court order, Patricia's guardian has the power to designate where Patricia lives and to consent to medical treatment, but not over Patricia's day-to-day activities and decisions (with the exception of those decisions which involve financial considerations).

Patricia found PCAA after searching on the Internet for organizations run by self-advocates and made an appointment with our social worker using the online appointment tool on our website. She carefully examined the instructions on our website for using public transit to come to our office and wanted to come by herself, but her group home informed her that a staff member had to drive her to her appointment and accompany her inside.

When Patricia and her staff member arrived at our office, our social worker informed both of them that meetings between PCAA staff and clients are private and that Patricia could request for the staff member to leave. Patricia asked the staff member to leave. The staff member expressed discomfort at leaving Patricia alone with PCAA staff, so upon Patricia's request, I located a chair, which I set outside our office window so that the staff member could observe, but not hear, what was occurring. I also stepped outside of our office and went to sit in the third floor lobby of our office because Patricia's appointment was not with me.

Patricia communicated to our social worker that this was the first time someone had listened to her instead of to her staff member. Over the course of the first appointment, our

¹⁴⁹ The example that follow is fictitious, uses pseudonyms, and does not perfectly resemble the experiences of any one individual ever seen at PCAA.

social worker listened to Patricia detail the goals she had for her life and supported Patricia as she identified the barriers that currently prevented her from reaching those goals. Our social worker documented all of Patricia's goals and barriers in a peer assessment document (PAD) and began to show Patricia all of the options that we know about for overcoming the barriers Patricia identified. Patricia liked some of these options and not others, so our social worker documented these preferences in the PAD as well.

Our social worker helped Patricia understand, using plain language, what rights Patricia had to control her own life, even under the constraints of guardianship. Under the terms of her guardianship, Patricia has significant rights under PA chapter 6100, which our social worker explained using plain English and answered as many questions as Patricia wanted to ask.

One of the questions that Patricia had was about whether she had the right to come to her next appointment at PCAA by herself using public transit. Our social worker explained that, under chapter 6100, she had the right to "make choices and accept risks," to control her "own schedule and activities," and "to choose where, when, and how to receive needed services." Because of this, our social worker said, Patricia did have the right to use public transit to come to her next appointment. Our social worker helped explain how public transit works, showed her maps of the public transit route from her home to our office, and helped explain the risks of using public transit, like getting lost or mistreated by strangers. Patricia continued to ask questions, and our social worker provided information and explanation until Patricia indicated that she understood. Our social worker made sure that the information was written down in a way that Patricia was able to understand. Patricia decided that, next time, she did want to use public transit, but that she still wanted her staff person to accompany her. Our social worker wrote this down on the PAD as well.

Next, our social worker asked Patricia how she would like to receive the notes from today's appointment. Patricia said she would like both a hard copy and an emailed version, so our social worker provided the notes in both formats. Patricia wanted to be able to share the information about guardianship with her friends at the group home and to be able to stand up for her rights to staff and her guardian. Our social worker wrote down the date of our next self-advocacy training, where Patricia could learn more of these skills, in case she wanted to put it on her calendar.

As this case demonstrates, at PCAA, important aspects of supported decision-making include:

- Privacy: This means giving the individual control over who is present during the appointment and who has access to information about them.

- **Communication:** This includes using words and/or pictures that the person understands and providing copies of appointment notes in the format(s) that the person finds most useful.
- **Respecting a person's priorities and preferences:** For us, this means making sure that we not only respect a person's priorities and preferences during the appointment, but help provide tools and skills that the person can use to encourage others to respect their preferences and priorities after the appointment time.
- **Rights and responsibilities:** At PCAA, we always want to ensure that people know what their rights and responsibilities are, and we want to help support the self-advocacy of others.
- **Autonomy and choice:** Autonomy and choice are the foundation of supported decision making.

Supported decision-making can look different in other contexts and should involve an ongoing relationship between the individual and the supporters so that the supporters can truly learn how best to support the individual. Nevertheless, the core concepts of respecting privacy, utilizing clear communication, honoring priorities and preferences, acknowledging rights and responsibilities, and supporting autonomy and choice are key.

4.2 Benefits of Integrated Care

Integrated, consumer-directed care provides a significant benefit to disabled consumers over institutional care. However, some have been concerned about the ability of community-based

care to adequately care for disabled patients. The Pennhurst Longitudinal Study acknowledged the existence of a “schism among parents of retarded citizens regarding the future of institutional care.”¹⁵⁰ A Daily Local article on the Pennhurst case noted, “People who oppose Pennhurst’ closing often claim community living is insecure and dangerous to residents.”¹⁵¹ Yet, the studies of Pennhurst residents post-institutionalization found that both former residents and their family members were happier and living in better conditions.¹⁵²

What constitutes benefit, of course, is highly subjective, but, based on all available evidence, integrated care clearly provides for the well-being of disabled consumers more effectively than segregated care settings. In fact, this was also another argument made by Judge Broderick, who argued that institutionalization violated the “right to non-discriminatory habilitation.”¹⁵³ Through examining 71 other studies, Eric Emerson and Chris Hatton found that group homes provided increased resident satisfaction, increased choice, increased time spent in the community and in doing activities, and better support from staff.¹⁵⁴ K. Charlie Lakin and Roger Stancliff more recently (2007) found similar results.¹⁵⁵ Furthermore, the national study referenced above found that residents had a substantially increased quality of care, from 71% in the institutional setting to 90% in the community.¹⁵⁶

¹⁵⁰ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy, March 1995, “The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis,” <https://aspe.hhs.gov/sites/default/files/pdf/74381/5yrpenn.pdf>, p. 41

¹⁵¹ Bill Mooney, 1980, “Pennhurst Problems,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/880>.

¹⁵² Jim Conroy, *I Go Home* documentary.

¹⁵³ “Halderman v. Pennhurst State School & Hospital,” 2016, *Disability Justice*, <http://disabilityjustice.org/halderman-v-pennhurst-state-school-hospital/>.

¹⁵⁴ Eric Emerson and Chris Hatton, *Moving Out: The Impact of Relocation from Hospital to Community on the Quality of Life of People with Learning Disabilities* (London: HMSO, 1994).

¹⁵⁵ K. Charlie Lakin and Roger J. Stancliff, “Residential Supports for Persons with Intellectual and Developmental Disabilities,” *Developmental Disabilities Research Reviews* 13.2 (2007): 151-159.

¹⁵⁶ Simon and Hodges.

Judge Broderick also argued that being held in the institution violated the “right to be free from harm.”¹⁵⁷ Today, institutions in Pennsylvania continue to perpetrate harm against individuals with disabilities. While conditions are better than they were in the 1970s, criticism is still relevant. The *Pittsburgh Post-Gazette* reported of Torrance State Hospital, “The sprawling state hospital, in the rolling hills of Derry, has been plagued by high physician turnover and criticized by state auditors, civil rights activists and federal regulators.”¹⁵⁸ Following the death of Brandi Logsdon, who died at Torrance in June of 2016, her family sued the hospital, arguing that misdiagnosis and subsequent improper treatment were responsible for the young woman’s death.¹⁵⁹ Her death followed the death of Shelley M. Florian, 27, in 2014 at Torrance due to prescription of drugs with fatal interactions.¹⁶⁰ The *Post-Gazette* reported on the treatment of patients at Torrance: “Four current Torrance patients who spoke with the *Post-Gazette* in recent weeks said they were doing little there beyond sitting in plastic chairs, watching TV for 14 hours per day, sometimes punctuated by an hour per day of programming — either group therapy, recreation or courtyard time.”¹⁶¹

¹⁵⁷ “Halderman v. Pennhurst State School & Hospital,” 2016, *Disability Justice*, <http://disabilityjustice.org/halderman-v-pennhurst-state-school-hospital/>.

¹⁵⁸ Rich Lord, “Young Woman’s Journey Ends Tragically in Mental Hospital,” September 4, 2015, <http://www.post-gazette.com/news/health/2016/09/04/Young-woman-s-journey-ends-tragically-in-mental-hospital/stories/201609040069>.

¹⁵⁹ *Ibid.*

¹⁶⁰ Rich Lord, “Drug Combination Blamed in Death of 27-Year-Old,” September 4, 2016, <http://www.post-gazette.com/news/health/2016/09/04/Drug-combination-blamed-in-death-of-27-year-old-Torrance-State-Hospital/stories/201609040071>.

¹⁶¹ Joe Smydo and Rich Lord, “No Safe Harbor: Part IV: Region’s Last State Hospital Mental Health Ailing,” April 10, 2016, <http://www.post-gazette.com/news/health/2016/04/10/No-Safe-Harbor-Part-IV-Pittsburgh-region-last-state-mental-hospital-Torrance-State-Hospital-ailing/stories/201604060142>.

Clement and Bigby note, “The failure of old, large institutions to realize the important features of human well-being has been explored extensively.”¹⁶² Catherine Thornberry and Karin Olson argue that abuse is part of the very culture of institutionalization.¹⁶³ Yet, some argue that group homes are just as likely to facilitate harm as institutions, as countless news sources have reported on abuse at group homes in many states.¹⁶⁴ This anecdotal evidence is countered by the existing data, however. The only national study comparing rates of abuse during institutionalization and after transition to community living found that, in fact, rates of abuse substantially decreased post-transition.¹⁶⁵

Integrated care ultimately reflects a respect for disabled adulthood because it facilitates access to participation in society for disabled adults, which many (though not all)¹⁶⁶ categories of non-disabled adults are guaranteed. People do not choose to be born disabled and do not generally choose to become disabled; yet they are generally treated inequitably by society. A report written by the Syracuse University Center on Human Policy noted, “Policies of forceably (*sic.*)

¹⁶² Tim Clement and Christine Bigby, *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation* (London: Jessica Kingsley Publishers, 2010), qt. 25.

¹⁶³ Catherine Thornberry and Karin Olson, “The Abuse of Individuals with Developmental Disabilities,” *Developmental Disabilities Bulletin* 33.1 (2005): 1-19.

¹⁶⁴ See: Michael Levenson, “Scathing Report Details Failings at Group Homes,” *Boston Globe* (July 14, 2016), <https://www.bostonglobe.com/metro/2016/07/13/scathing-report-details-failings-group-homes/gXx87GpHkixBJTuROkJL1L/story.html>, Susan K. Livio, “Stories of Abuse at N.J. Group Homes Spark Lawmakers to Demand Action,” http://www.nj.com/politics/index.ssf/2016/09/stories_of_abuse_and_neglect_at_group_homes_sparks.html, Joaquin Sapien, “Connecticut Oversight Agencies Failed to Investigate Years of Abuse and Neglect in Group Homes for Disabled,” *ProPublica* (May 29, 2016), <http://www.allgov.com/news/top-stories/connecticut-oversight-agencies-failed-to-investigate-years-of-abuse-and-neglect-in-group-homes-for-disabled-160529?news=858894>, Michael J. Berens and Patricia Callahan, “Suffering in Secret: Illinois Hides Abuse and Neglect of Adults with Disabilities,” *Chicago Tribune*, <http://www.chicagotribune.com/news/watchdog/grouphomes/ct-group-home-investigations-cila-met-20161117-htmlstory.html>

¹⁶⁵ Samuel E. Simon and Matthew R. Hodges.

¹⁶⁶ For example, prisoners, poor people, non-college-educated individuals, people of color, LGBTQ, among other groups of adults, are not guaranteed the same levels of access as wealthy, college-educated, white, straight, cis people.

segregating groups of labeled people...frequently reflect the possibility that the subject people have been devalued. In our culture...institutions have provided the mechanism for large scale devaluation of certain identified groups.”¹⁶⁷ Group homes provide more equitable access to the good of community living and the goods that accompany being in the community. They are thus not only more beneficial for residents, but also more just than institutional housing. Nevertheless, a group home is not the ultimate move toward well being promotion in adultlike treatment or desinstitutionalization, as the case I examined in the section above clearly demonstrates. Instead it is a step toward what I envision as an even less restrictive future in which individuals with disabilities will be cared for in their own homes with, or without, housemates of their own choosing.

4.3 Conclusion

In January of 2017, the Pennsylvania Department of Human Services announced the beginning of an 18-24 month process of closing two more institutions: Norristown State Hospital and Hamburg State Center.¹⁶⁸ This process includes individualized strategies for moving discharged residents to places where they can receive community-based-care. With the closure of these two institutions, deinstitutionalization supports the adulthood of people with ID/DD by giving more space for disabled autonomy. Deinstitutionalization further reinforced the notion that

¹⁶⁷ The Community Imperative: A Refutation of All Arguments In Support Of Institutionalizing Anybody Because of Mental Retardation,” 1979, *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/236>.

¹⁶⁸ David Wenner, “Pa. will close two state institutions for people with intellectual disabilities, mental illness,” *Penn Live* (Jan. 11, 2017), http://www.pennlive.com/news/2017/01/norristown_hamburg_close.html.

attitudes toward people with disabilities based in non-maleficence and beneficence can become inappropriately paternalistic, far too easily, when applied to people with ID/DD. Deinstitutionalization was also grounded in and advanced understanding that all people should have freedom to choose where they live, who they live with, and where and how they spend their time. While I can't seem to trace the origin of the 'burrito test,' I believe it holds true: that if a person can't get up at 3 AM and microwave a frozen burrito, then they probably live in an institution. Moving beyond the childlike role for people with ID/DD requires the state, parents, lawyers, guardians, and others in positions of power to be invested in giving up power, sharing or giving up responsibility, and investing in the freedom of those in their care. Control is not an inherent part of caregiving. Caregivers should be invested in the civil rights of those for whom they care and should recognize that, quite often, the 'cared for' care back. Freedom from the childlike role requires a mutual investment in recognizing and valuing that supported decision-making is a valid and useful approach.

Patterns of institutionalization have continued to shift to reflect values of community inclusion, but change is not happening quickly enough. In 2014, the latest data available, the number of adults with mental illness institutionalized in state hospitals in Pennsylvania was 1503, with 830 people having been there for more than 2 years.¹⁶⁹ In 2016, the number of adults with intellectual or developmental disabilities institutionalized in state centers was 886,¹⁷⁰ bringing the combined total between the mental illness and ID/DD systems to over 2300 people still in institutions. An additional 1154 children live in residential facilities, while 476 live in hospitals or

¹⁶⁹ Pennsylvania Department of Human Services, Office of Mental Health and Substance Abuse Services, "Pennsylvania State Hospital System Length-of-Stay, Demographics, & Diagnoses Report for December 31, 2014," http://www.dhs.pa.gov/cs/groups/webcontent/documents/report/c_149849.pdf.

¹⁷⁰ Author's personal correspondence with Nancy Thaler, deputy secretary of the Office of Developmental Programs, November, 2016.

are homebound.¹⁷¹ These over 3400 people with disabilities DESERVE to have a place in our communities, a home, not an institution.

Furthermore, 13,000 people who have waived their right to institutional care in order to be placed on a waiting list for community based care are as much of a concern as those who are institutionalized.¹⁷² The Waiting List Campaign wrote in 2015: “Each person on the Waiting List has waived their right to institutional care, saving the commonwealth and the taxpayers billions of dollars over their lifetime, yet they languish on long waiting lists for home and community based services. If they choose to exercise their entitlement, the state would be required to serve them immediately and at a much higher cost in both dollars and freedoms. We need to close our State Centers and reinvest the funding into a robust, flexible, and responsive Community Based system.”

¹⁷³ The Waiting List Campaign, through a variety of strategies, including lobbying, has made significant gains in the number of waivers available for community-based services. Deinstitutionalization doesn’t work unless home and community-based services aren’t available and fully funded.

A recently settled lawsuit would force the Department of Human Services to make significant changes to the state hospital system with regard to forensic cases. “Because of a lack of treatment opportunities, these individuals have been detained in Pennsylvania’s county jails, often in solitary confinement, for months and in some cases over a year awaiting treatment as their mental health deteriorates further. The two state hospitals, Norristown in the east and Torrance in

¹⁷¹ 2014-2015 IDEA Data, author’s personal correspondence with Nancy Murray, President of The Arc of Greater Pittsburgh, December 1, 2016.

¹⁷² PA Waiting List Campaign, “PUNS,” August 31, 2016, <http://pawaitinglistcampaign.org/wp-content/uploads/2016/10/PUNS-as-of-8-31-2016.pdf>.

¹⁷³ Ibid.

the west, currently have a wait list of 220 people for about 190 slots.”¹⁷⁴ The lawsuit will require an additional 120 slots for placement in hospitals, among other changes.¹⁷⁵ A federal judge made a decision in a case regarding Washington deeming “unconstitutional Washington’s practice of holding mentally ill people in jails while they await competency evaluations and treatment.”¹⁷⁶ Only time will tell if this decision will set a national precedent.

While this may be a slight help to forensic patients on the waiting list, it does little to resolve the large number of civic cases awaiting a waiver slot. Carol Beatty notes in her article in the *Tulsa Law Review*, “Disability advocates have convinced many states to close public institutions but have been less successful in establishing essential community supports.”¹⁷⁷ Beatty further suggests that the *Olmstead* decision should be interpreted in such a way as to outlaw waiting lists for services.¹⁷⁸ Previously, *Olmstead* had been interpreted to allow waiting lists under certain criteria, but in response to a new lawsuit, *Ball v. Kasich*, the Justice Department filed a statement of interest: “Non-institutionalized individuals with disabilities who are not currently receiving state-funded home- and community-based services may bring a claim that a public entity has placed them at risk of institutionalization or segregation in violation of the ‘integration mandate’ of Title II of the Americans with Disabilities Act.”¹⁷⁹ It seems individuals with

¹⁷⁴ ACLU, “ACLU-PA Settles Lawsuit Over Unconstitutional Delays in Treatment for Hundreds of Defendants with Severe Mental Illness,” January 27, 2016, <https://www.aclupa.org/news/2016/01/27/aclu-pa-settles-lawsuit-over-unconstitutional-delays-treatme>.

¹⁷⁵ Ibid.

¹⁷⁶ Martha Bellisle, “Federal Trial to Tackle State’s Mental Competency Wait-Lists,” March 14, 2015, <http://www.seattletimes.com/seattle-news/health/federal-trial-to-tackle-states-competency-wait-lists-2/>.

¹⁷⁷ Carol Beatty, “Implementing *Olmstead* by Outlawing Waiting Lists,” *Health Law Policy* 49,3 (2014): 35.

¹⁷⁸ Ibid.

¹⁷⁹ Michelle Diament, “Waiting List Placements May Violate ADA,” August 30, 2016, <https://www.disabilitycoop.com/2016/08/30/waiting-list-may-violate-ada/22685/>.

intellectual/developmental disabilities have waited long enough. Yet again, none of the advocacy behind these changes come from within medicine, nor is the activism spurred by changing philosophies of medical ethics; rather, the changes are spurred, like before, by community activists, parents, self-advocates, and lawyers.

I would hope, I would wish, that as societal attitudes toward people with disabilities continue to become more positive, that institutionalization of those with mental illness or disabilities would continue to decrease. Though the horrors of the institutions no longer make the nightly news, advocates are still engaging in strong efforts toward community-based care. Outcomes post-Pennhurst looked good for Pennhurst Class Members, as evidenced by the Pennhurst Longitudinal Study: “The overall results of five years of investigation into the behavioral consequences of deinstitutionalization are clear: in terms of adaptive behavior, the average person who left Pennhurst is better off.”¹⁸⁰ “They are doing things now that at Pennhurst would have been impossible.”¹⁸¹ I can only hope that current activism results in positive quality of life outcomes for those still trapped in institutions or living in the community without necessary supports. Over 16,000 citizens of the state of Pennsylvania have waited long enough. End the waiting lists and close the institutions. It. Is. Time. The State of Pennsylvania has a moral, ethical, and, soon-to-be legal obligation to fund community-based, integrated care.

¹⁸⁰ “The Pennhurst Longitudinal Study,” p. 64.

¹⁸¹ Mike Freeman, 1980, “‘Ex-Pennhurst Residents 'Benefiting' in News Lives”,” *Archives of the Disability Advocacy Movement*, accessed November 17, 2016, <http://uwac.omeka.net/items/show/881>.

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