# UNIVERSITY OF CALIFORNIA

Los Angeles

Learning from Profound Intellectual Disability

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Philosophy

by

Alexandra Hope Peabody Smith

© Copyright by

Alexandra Hope Peabody Smith

## ABSTRACT OF THE DISSERTATION

Learning from Profound Intellectual Disability

by

Alexandra Hope Peabody Smith Doctor of Philosophy in Philosophy University of California, Los Angeles, 2021 Professor Daniela J. Dover, Co-Chair Professor Alexander Jacob Julius, Co-Chair

Profound intellectual disability, the most severe form of intellectual disability, has long been left at the margins of philosophical thought. Further, many accounts of the grounds for human moral standing rely on the possession of higher-order capacities of mind that serve as status-conferring attributes to the exclusion of human beings with more significant intellectual impairments. This dissertation advances three main theses responding to three main questions regarding the lives of those with profound intellectual disability. First, with regards to the question of how we should conceptualize profound intellectual disability, that we should think about it as a disability characterized by the impossibility of successful, mutual linguistic communication rather than solely as extreme cognitive deficit. Second, with regards to the role of heterogeneous forms of communication that are available to non-speaking intellectually disabled persons, that there is ubiquitous form of communication I call relationship-constituted and constituting meaningful expressions (RCMEs). RCMEs are morally significant in their relying on the fabric of a particular relationship for their use, and they are particularly salient for pairs of profoundly intellectually disabled and non-intellectually disabled communicators. Third, with regards to human moral standing and the historical philosophical exclusions of intellectually disabled lives, that the grounds for human moral equality lie in our ability to employ RCMEs to develop and deepen relationships – a capacity whose possession in one individual presupposes its existence in others.

The dissertation of Alexandra Hope Peabody Smith is approved.

Susan Brison

Samuel John Cumming

Joshua David Armstrong

Daniela J. Dover, Committee Co-Chair

Alexander Jacob Julius, Committee Co-Chair

University of California, Los Angeles

For my brother, Travis Peabody.

TA	BL	E	OF	CC	)N7	ΓEN	JTS

Ac	Acknowledgements	
Vita		X
0.	Introduction	1
1.	Chapter I: How should (and shouldn't) we think about profound intellectual disability?	11
2.	Chapter II: Relationship-constituted and constituting meaningful expressions	40
3.	Chapter III: Toward basic equality of human moral standing	71
4.	Conclusion	107
5.	Works Cited	122

## <u>Acknowledgements</u>

No dissertation was written alone. Without the help of the following friends, this project would not be what it is.

Thank you, first, to my excellent committee. Daniela Dover has exceptional insight and has always believed in me and provided just the feedback I needed precisely when I needed it. AJ Julius' perception never fails to amaze me, and his influence is evident in what I've written. I am so grateful for my many conversations with my co-chairs over the years. Joshua Armstrong and Sam Cumming assisted in areas outside of my typical scope of inquiry, greatly strengthening the breadth of this project and challenging me in fruitful ways. Susan Brison's thoughts are among the most philosophically and interpersonally perceptive of any philosopher I know, and I'm so glad she was willing to join the team. I look forward to many more conversations over croissants with her in the future.

To my writing partners, sounding boards, and helpful peer-pressuring motivators: thank you for making writing more fun. This process was a lot less lonely thanks to my dear friends Theodra Bane, Jenna Donohue, Amber Kavka-Warren, Ayana Samuel, and Aarthy Vaidyanathan. Thank you as well to Sarah Buchanen and Taylor Schooley for their friendship and their eagle-eyed proof-reading skills.

I have had wonderful role models and mentors. Supporters like Alice Crary, Eva Feder Kittay, Victoria McGeer, Sara Protasi, Joel Michael Reynolds, and Joseph Stramando made me feel like I had something worth saying in a sometimes hostile philosophical world. Thank you for believing in my project and for your work in philosophy of disability.

My colleagues-turned-lifelong friends at UCLA include a few folks mentioned above, but I would be remiss to fail to mention my brilliant friends Sarah Beach, Jae Choe, Catherine

vii

Illingworth, Jung Suk Lee, Torsten Odland, Daniel Ranweiler, and Kyle Scott. I learned a lot from faculty members including Katie Elliot, Barbara Herman, Pamela Heironymi, Sherri Roush, and Seana Shiffrin, and I greatly benefited from feedback received during Albritton presentations and in Pamela's Ethics Writing Seminar. Another UCLA connection, Ashley Feinsinger, gave me the push I needed to get this thing done, and I look forward to being her colleague at UCLA's David Geffen School of Medicine in just one short month.

To Brendyn Adams, Joni Anderson, Esme Croonen, Micah Feiring, Lance and Kirsten Gilliam, Gerdi Kanzler, Kaitlyn Kerhart, Mark Lavoie, Niall Lessard, Cameron Lussier, Sarah Millar, Holly and Ruben Petersen, Jamila Rizvi, Julian and Jeremy Smith, Rachel Wenitsky, and Verena Zurakowski – you are among the best friends a girl could wish for and your support and interest in my work means the world to me.

To Ellie Anderson, Christina DiDonato, and Susan El Khoury: I do not know where to start but thank you for keeping me sane, loving me, loving my daughter, and inspiring me in various ways. You are each so impressive in your passions and accomplishments. If it's true that we become the people we surround ourselves with, I'm going to become a brilliant, astute, hilarious, hard-working, compassionate, amazing friend/mom/sister amalgamation of you three. I will also be *exceptionally* well-dressed.

Thank you to my parents and in-laws. Monica and Michael Smith are giving, incredible grandparents who raised three wonderful sons. (I even married one of them!) I hope that, like Monica, I always maintain a sense of wonder in the world for both its beauty and its injustices. I hope that, like Michael, I see academic philosophy as quite a wonderful career path that is to be balanced with more important endeavors like friendships and families. Eric and Patti Peabody,

viii

who we do not see nearly often enough, inspire me with their ability to actually relax (it's hard!) and their non-judgmental support of their children.

My mom, Paige Petersen, has been the most influential person in my life. Her strength is truly a marvel. I cannot imagine what it was like to raise my brother prior to the advent of the internet or the purchase of a Tineco (imagine how much less horrible those 2am accidents would have been!). Anyone who has met my mom has been touched by her warmth, style, intelligence, and loyalty. You are amazing.

To my step-dad, Curtis Jordan: your generosity is unsurpassed and there are many reasons Sam and I often pause and ask, WWCD? I hope you understand how powerfully influential your deep kindness has been to me.

To Bowie: \*all\* the special treats.

To Sam and Etta Smith: I love you.

Finally, to my brother Travis Peabody – thank you for inspiring me. This is all you!

# <u>Vita</u>

## EDUCATION

University of California, Los Angeles Doctoral Candidate, Philosophy (Degree to be conferred 12/10/2021) Masters in Philosophy (Conferred May 2017)	Sept. 2016- Present			
University Center for Human Values, Princeton University Visiting Student Research Collaborator	Oct. 2019-Jan. 2020			
Trinity College Bachelor of Arts in Philosophy with Honors	Sept. 2007- May 2011			
<b>PUBLICATIONS</b> "Patient-centered communication, profound intellectual disability, and COVID-19 triage protocols" <i>Disability Justice in Emergency Conditions</i> (edited volume), forthcoming				
Review: Routledge Handbook of Disability Law and Human Rights Disability Studies Quarterly, forthcoming				
<b>ARTICLES UNDER REVIEW</b> "Profound Intellectual Disability as Neutral Simpliciter" Draft available upon request				
"Conceptualizing profound intellectual disability" Draft available upon request				

### WORKS IN PROGRESS

"Neurodiverse Communication, Autistic Cognition, and Wiggenstein" *Cripping the Canon* (edited volume), abstract available upon request

"Relationship-constituted and constituting meaningful expressions" Draft available upon request

"Patient-centered communication and non-speaking intellectual disability" Draft available upon request

"Profound intellectual disability and human equality" Draft available upon request

"Speaking for those who cannot speak" Abstract available upon request

### PRESENTATIONS

"Patient-centered communication, profound intellectual disability, and COVID-19 triage protocols" Disability Justice in Emergency Conditions, Georgetown University (Nov. 2021) American Society for Bioethical Humanities (Oct. 2021)

"Risks, Benefits and Values: Patient Participant Perspectives on Basic Intracranial Human Research" (with Feinsinger, Pouratian et. al.) International Neuroethics Society Poster Session (Nov. 2021)

"Conceptualizing profound intellectual disability" Ethics Workshop, University of California, Los Angeles (Oct. 2021) "Patient-centered care and profound intellectual disability" (with Ashley Feinsinger) Bioethics Research Group, University of California, Los Angeles (May 2021)

"Informed consent, autonomy, and paternalism" Bioethics Research Group, University of California, Los Angeles (April 2021)

"Relationship-constituted and constituting meaningful expressions" Prospective Graduate Student Visits Talk (invited) (March 2021) Ethics Workshop, University of California, Los Angeles (Feb. 2021) Albritton Workshop, University of California, Los Angeles (Jan. 2021)

"Lessons from Profound Intellectual Disability in Human Life: Communication and Relationship-Forming Capacities as Key to Moral Standing" Ethics Workshop, University of California, Los Angeles (May 2020)

"Profound Intellectual Disability as Neutral Simpliciter" MAP Flash Talks, MAP International (April 2020) <sup>3rd</sup> Biennial Philosophy of Disability Conference, University of North Carolina, Asheville(March 2020) Albritton Workshop, University of California, Los Angeles (Feb. 2019)

"Speaking for those who cannot speak: Advocacy for profound intellectual disability" Atypical Agencies Works in Progress Group, Princeton University (Dec. 2019)

"When is it okay to say that disability is not okay?" Proposition Series, University of California, Los Angeles (Jan. 2019)

"Cognitive Disability and the Space for Moral Standing: Foot's Answer to Aristotle" APA Eastern Poster Session (Jan. 2018)

"Rationality's Exclusions in Virtue Ethics" American Comparative Literature Association, Utrecht University (July 2017)

"*Becoming* Political: The Metaphysics of Agency in Nietzsche and Arendt" Southwestern Seminar in Continental Philosophy, California State University, Northridge (June 2017)

"Would De-ableizing Thought Experiments Destabilize Philosophy?" philoSOPHIA, Florida State University (March 2017)

"Aristotelean Natural and Social Hierarchy: An Abridged Genealogy" New Frontiers in Ethics, University of Toronto (April 2014)

#### HONORS, GRANTS AND AWARDS

International Neuroethics Society Annual Conference, Best Abstract Nov. 2021 For "Risks, Benefits and Values: Patient Participant Perspectives on Basic Intracranial Human Research" (with Feinsinger, Pouratian et. al.)

UCLA, Yost Prize for Excellence in Teaching	2019-2020
UCLA, Graduate Student Research Award	Summers 2016 and 2017
NSSR, Double High Pass in Oral Exams	Nov. 2013
NSSR, Merit-Based Scholarship	Sept. 2012-Aug. 2016

# Learning from profound intellectual disability

by Alexandra Hope Peabody Smith

# **Introduction**

This dissertation was inspired by three things: a memoir I read in college, an interaction between Eva Kittay and Peter Singer, and my relationship with my brother. Each of these brought to the surface the salience of important philosophical questions about what it is to come to know a person, how we can justify human moral standing, and the natures of communication and equality for a particular group of human beings: those with non-speaking, profound intellectual disabilities. My brother Travis has a non-speaking profound intellectual disability and we have always had a special relationship that I felt was not, despite appearances, all that different from the relationships between my friends and their non-disabled siblings. Yet I've spent much of my life justifying why that is the case. When mentioning my brother, I'm constantly met with comments along the lines of, "wow - that must have been so hard," or "what a burden for your family, you are so strong." To quote my Gen-Z students, that is to me, so cringe. But there is some truth to these comments. My brother and others like him are different and require more work than a lot of other people. But at the same time, the assumption that they are merely burdens with whom families and intimates will never share deep and meaningful relationships is totally off base. And the deeply rooted philosophical assumption that they lack those attributes that typically make humans unique is troublesomely pervasive and, to my eye, also incorrect.

My questions became more succinct after reading a 2009 memoir by Karl Taro Greenfeld, a journalist, novelist, and writer, about growing up with a profoundly intellectually

disabled brother. At the time I was in college, a junior and a philosophy major, and I happened to be enrolled in an excellent course with Professor Diana Paulin of the English Department. The class was called "The Spectacle of Disability" and it was the first place where I engaged intellectually with disability theory. This wound up plotting the course for my career thus far, and at the time it was very eye-opening for me, as the sibling of a profoundly intellectually disabled (henceforth, PID) man. It was for my final paper in this course that I read Greenfeld's *Boy Alone: A Brother's Memoir*.

The synopsis on the book's jacket indicates its grappling with significant philosophical questions, among them one that will be of principal interest in my first and second chapters: can relationships exist without language? I remember reading this and thinking, as I still do, that of course they can. Yet for many, this is not obvious. The memoir opens:

A boy sits by himself on a stained white carpet, the corner of a frayed blanket stuffed into his mouth, his head bobbing, the fingers of both hands twiddling at ear level. He seems neither to miss company nor to show any eagerness to seek it. If you say hello, he will not look at you nor turn in the direction of your voice. If you take up position in his line of sight, he will look away. (Greenfeld 2009, p. 3)

This rather bleak description sets the stage for the tale of Greenfeld and his brother Noah's upbringing. The memoir is a difficult and triggering read for me to this day, not least because of how much this scene resembles some of my own realities. Greenfeld recalls an incident from his childhood where he overheard his parents recounting that Noah used to talk. He goes to Noah, shocked. "'Talk!' I order Noah. 'Talk. You can talk.' He doesn't acknowledge me. He doesn't really look at me. He never really looks at me" (ibid. p. 4). My brother also doesn't talk or make much eye contact.

But Greenfeld's later experience differs from mine dramatically. Writing about his adolescence, he remembers thinking that it was "impossible for [him] to dismiss how deformed

our family has become by Noah and our response to Noah" (ibid., p. 249). Noah, like my brother, became violent and increasingly withdrawn during puberty. The effect on Greenfeld was anger, resentment, and an increased reliance on drugs to cope. Eventually, after years of bad and often abusive care, Noah landed in a good group home. They tried – and succeeded in using – facilitated communication, which led to Noah finally engaging in some limited verbal communication. Despite these wonderful advances in Noah's life, Greenfeld wound up in rehab, and it was an interaction with Noah that finally cemented his path to recovery. In family therapy, Greenfeld remembers the monumental moment:

"You're my brother." Noah began. He had neglected to prepare a list. "I'm his brother. And I am here, you came here, because I love you." He stopped rocking back and forth and nodded his head once, and then several more times. "Karl? I need you. I need my brother."

... In our room, we sat silent, and for the first time between us brothers, I was the one who couldn't talk. (ibid., p. 299-300)

Greenfeld eventually married, moved to Hong Kong, and had children of his own. The section of

the memoir where he discusses Noah's developing verbal communicative capacities and his own

recovery is titled, aptly, "A Brother."

But then, a chapter titled "Reality" follows.

A middle-aged man sits by himself on brown lawn outside a run-down house in South Central Los Angeles. He seems neither to miss company nor show any eagerness to seek it. If you greet him, he will not look at you nor turn in the direction of your voice.

Noah is still alone... Noah never spoke... I did go to rehab. I did get married. We did move to Hong Kong. But Noah never spoke.

I dreamed that happy outcome. I imagined the life I wanted for me, for Noah, for our parents. I conjured it, as therapy, as a study in what if, as an attempted answer to the great question in our family: What if Noah could talk? What if Noah were normal? What if? What if? (ibid., p. 329) Greenfeld laments, "I don't know Noah. He is, I suspect, unknowable. Yet he remains the center of my life. I hate him for that" (ibid., p. 331). This, and the implied sentiment that Noah's inability to talk makes him incapable of any meaningful communication, is where Greenfeld's and my experience of life with PID brothers comes apart. I do not find my brother incapable of communication just because he cannot speak. I do not think he is unknowable in a way that differs in kind from the more general unknowability of others.

Eva Feder Kittay, philosopher and parent to a PID woman, addresses coming to know her daughter. "It is through my daughter's body that I come to know her. That I come to know another through her body is an epistemic claim. It is in one sense true for all subjects of human knowledge, and in another, it is particular to people such as my daughter, that is, to people who are restricted in their movements and who have no (or little) expressive language" (Kittay 2019, 249). Ordinarily, Kittay explains, our epistemic access to others is linguistic and behavioral, as well as material. And yet, even language is a manifestation of voice, and so of the body. This suggests that we always ultimately come to know one another via bodies, though we tend to grapple with that fact less in the case other language-users, where our focus is oriented towards their (often perceived as distinct-from-body) neurologically abled minds.

I understand where Greenfeld is coming from, and I think his sentiments capture a particular interpersonal challenge that many who share their lives with PID persons face. Of course, we want to know who our siblings, children, and friends are as individuals. When we cannot communicate via language, it is difficult to know who someone is, let alone how much of an inner life exists for that person. These questions regarding the potential of coming to know, communicating with, or using communication to come to know persons incapable of linguistic communication deserve close philosophical attention. As Kittay's remarks suggest,

communication is not only embodied, but it draws upon the multitude of tools available within the body, not just the capacity to use natural language to speak. Communication can be nonlinguistic and is at its core a multifaceted and heterogeneous phenomenon. Chapter II will address one way in which meaningful communication between individuals with PID and those close to them can occur. This will imply that coming to know a person with PID is possible, though perhaps more challenging, than it is to come to know other sorts of persons.

By "coming to know" I mean something quite broad and intuitive. Like Kittay, I perceive the epistemic aspect of the claim that I can "come to know" another person, but in what follows I am focused on its practical and ethical dimensions. Admittedly, the epistemic and ethical can be quite tightly wound here, so rather than attempt to unravel them I will say a bit about what I mean when I mention "coming to know" and its value: to "come to know" in this sense is to understand one another with some degree of accuracy that allows a relationship to form. That relationship will allow additional aspects of the other person to come into view, because part of that relationship is its use of past interactions in which individuals came to understand one another as fodder for additional understandings to come into play. When people are friends, siblings, parents and children, and so on, part of what they do together that is good vis-a-vis the relationship is to come to know one another better and better, using past interactions as part of their knowledge base for getting to know one another better and better. One aspect of the good of any relationship is understanding one another in iterative steps of coming to know one another that rely on past interactions for new ones to form. Communication is central to coming to know, so the major roadblock between pairs of PID and non-PID persons is their extremely different access to natural language-type communication. This is clear in the portrayal of Greenfeld and

Noah's relationship, and it is something many of those who share their lives with PID individuals experience.

At a conference held at Stony Brook University in 2008, Peter Singer and Eva Kittay engaged in a line of questioning following his talk, "Speciesism and Moral Status."<sup>1</sup> Kittay, the conference organizer, a founder of philosophy of disability, and the mother of an intellectually disabled daughter, found Singer's comparisons between non-human animal minds and those of intellectually disabled humans problematic.<sup>2</sup> Singer's comparisons centered on capacity-based considerations about individuals. He argued that a significantly disabled human mind may function more like a parrot or dog than other human beings, and that significantly intellectually disabled human beings have moral standing beneath non-intellectually disabled human beings because of their lacking certain morally relevant capacities of mind. Kittay remarked on how, to the parents of such a daughter, comparisons between such individuals and non-human animals were offensive, poorly founded, and cruel. Further, Singer's thesis – that the moral status of human beings with profound intellectual disabilities was beneath that of non-disabled humans – seemed to Kittay, and seems to me, to be an unacceptable conclusion.

<sup>&</sup>lt;sup>1</sup> "Cognitive Disability: A Challenge to Moral Philosophy" was hosted by the Department of Philosophy at Stony Brook University on September 18-20, 2008. The proceedings eventually became an edited collection of essays (Carlson and Kittay 2010).

I originally came to know about this interaction through a conversation with Kittay. Later, I learned more through a series of papers and responses between Kittay, Singer, and Crary (Crary 2018, 2019; Kittay 2017, Singer 2017).

<sup>&</sup>lt;sup>2</sup>I use the term "intellectual disability" rather than the perhaps more common "cognitive disability" throughout this paper. In the taxonomy of disability I prefer, I take disability to divide into [physical, cognitive], and then cognitive to include the subsets [psychiatric, intellectual, learning]. Psychiatric disabilities are those things we think of as mental disorders or illnesses, like schizophrenia, depression, or bipolar disorder. Learning disabilities are things that affect an individual's capacity to acquire or retain information, as in attention deficit disorder or dyslexia. Intellectual disabilities affect a person's functioning across multiple domains, and include things like Down Syndrome, autism, and mental retardation.

In Kittay's view, her daughter, Sesha, has a host of uniquely human attributes that set her moral standing above that of a non-human animal. Singer asked Kittay to explain these attributes to him. Kittay cited a few examples, like Sesha's love of classical music, but Singer wanted more. From Singer's perspective, Kittay's inability to respond to that request constituted an admission of precisely what her daughter lacked. Singer wanted to hear an account beyond what Kittay had already told him, because, after all, non-human animals can appreciate music too. He wanted something like a set of facts that would illustrate what attributes distinguish Sesha and those like her from the non-human animals he cited.

Kittay invited Singer to come meet Sesha and other individuals with intellectual disabilities at her daughter's group home, which was not a far drive (two hours and twenty minutes, give or take) from Singer's home institution at Princeton University. Singer declined her invitation, insisting she explain what he would learn there that Kittay could not simply tell him here and now. He expected a piece of propositional content he could assess from afar. Kittay, at a loss, moved on – though discussion of this interaction continues to this day in her own work.

During this question-and-answer session, Singer seemed to have thought that he could learn all that he needed to for the sake of comparisons between the intellectually disabled and non-human animals at second hand: via empirical studies, the testimony of others, through observation, and through the transmission of descriptive facts about capacities of mind. Kittay's invitation implies that she disagrees: her invitation illustrates how Kittay recognizes that there is more to be learned by meeting Sesha, by interacting with Sesha, or by witnessing Kittay interact with Sesha. While Singer evidently agreed that Kittay has a significant amount of knowledge about her daughter, the sort of knowledge he was looking for to understand Sesha as compared to

dogs, apes, or parrots had to be objectively discernible, transmissible as a piece of propositional content, and thus describable in a conference setting. Kittay recognized that there is something additional to be learned by meeting her daughter that she could not describe in these terms.

I believe that this morally saturated thing to be learned has to do with the significance of the capacity to participate in the kind of communication that builds relationships and the kind of relationship that allows for certain kinds of communication. One theme of this dissertation is the suggestion that interaction between Singer and Sesha itself would have been precisely what mattered in Singer forming opinions about the moral standing of those with intellectual disabilities. In opposition to the Singerian grounding for moral status, individualized capacities of mind assessed in isolation of others, my overarching argument and the focus of Chapter III will be the idea that relational capacities of communication and relationship-building determine moral standing.

Singer's mistake was interpreting Kittay to be claiming that there was some piece of propositional content or a general truth about PID that he would see if he would just meet Sesha. It is not that there is some ineffable bit of knowledge to be had by interacting with her, but rather that that interaction is precisely what matters in a different view of moral standing. Kittay's responses suggest – and I will argue – that we should understand human moral standing not by trying to figure out what each human is like, so that we can compare their natures in isolation from one another. Instead, we should think about our commonalities within the context of our relationships with one another. This will happen at least in part by thinking about the very inequity of certain facets of our natures, and what these inequities reveal about what we owe to one another. The capacities that all human beings share are not rational, self-conscious, or linguistic ones, but are rather our relational capacities. These might instead ground moral

standing. Of course, I am not the first to suggest a relational view of moral standing: my contribution will be unique in its reliance on a form of communication I'll term relationship-constituted and constituting meaningful expressions.

Finally, my brother. As I said, he is largely non-speaking, and has a profound intellectual disability, the specific diagnosis for which has been rather nebulous over the years. But that does not matter much: what matters is that he is a human being for whom things matter, and with whom close and meaningful relationships are wholly possible. He has desires, preferences, and a wicked sense of humor. He suffers. In many ways, he is just like everyone else, but in others, he is dramatically different. Like many other older siblings, I am very protective of him, and have been told that perhaps my judgments surrounding PIDs are obscured by facts of our relationship. In response to a paper on conceptualizing communicative limitations as central to characterizing profound intellectual disability, I once had a supervisor tell me that it sounded like the people I was describing "lacked what we typically call personality." What this person lacked, and, unfortunately, what many people lack is interpersonal relationships with non-speaking intellectually disabled people. Anyone who has taken the time to get to know such a person knows this sentiment to be exceptionally poorly founded. And anyone who has spent much time among philosophers knows its reprehensible ubiquity.

The motivation of my dissertation is thus inspired by and focuses on three questions, in this order: how we should think about profound intellectual disability? What is the moral significance of non-linguistic forms of communication? And what are the grounds for human moral equality? These three topics are, to my mind, intimately connected. I also think they give some answers to where Greenfeld and Singer's thinking about PID persons runs into problems and how our reflections on these lives might be improved. Much of the dissertation will focus on the nature of interactions and relationships between PID and non-PID persons. Ultimately, I'll advance three related theses: first, that we should conceptualize PID as a disability characterized by the impossibility of successful, mutual linguistic communication; second, that there is ubiquitous form of communication consisting of what I will call relationship-constituted and constituting meaningful expressions (RCMEs) that is particularly salient for pairs of PID and non-PID communicators; and third, that the grounds for human moral equality lie in our ability to employ RCMEs to develop and deepen relationships. My hope is that my arguments will convince folks lacking PID intimates that it's worth developing relationships with and coming to know such persons, as they can be as good of friends as anyone else can be. I will close the dissertation with some thoughts on the lingering issue of the unique asymmetries between PID and non-PID persons, and what this might mean for disability advocacy in this sphere.

# <u>Chapter I: How should (and shouldn't) we think about Profound Intellectual</u> <u>Disability?</u>

## **Introduction**

Cases involving the interactions between profoundly intellectually disabled (PID) individuals and non-PID individuals are unique. One person has significant cognitive impairments; the other does not. One person speaks; the other does not. One person relies on higher-order cognitive functions to make judgments about the other; the other likely does not. Significant differences in mental functioning make the pair particularly dissimilar and make it the case that they face all sorts of difficulties in interacting with one another.

Most disability rights advocacy centers on the implications of the slogan, "Nothing about us without us" (Charlton 2000). With most groups of people – deaf people, wheelchair users, black people, straight people, men, or women– it would be condescending and circuitous to ask the question, "how should we treat them?". It would be more respectful and more efficient to just speak with them directly about matters pertaining to interpersonal interactions. Yet, as I will argue, we should think about those with PID as distinctive in their inability to communicate verbally.<sup>3</sup> This makes asking PID people how we should treat PID people difficult. However, as with others, the formation of the question itself – "how should we treat them?" – belies its patronizing nature. The better question to ask is "how should we interact together?" And yet, asking how we ought to interact with those with PID is unlike asking the same question with

<sup>&</sup>lt;sup>3</sup>I mean to exclude those who either previously had or will come to have verbally communicative capacities, such as people with dementia and infants.

other groups of human beings, because unlike other groups of human beings, we cannot have a conversation with them about that – or about any other topic.

The most prevalent understanding of PID is one where it is understood solely as a severe cognitive deficit. By the predominant view, PID involves the lack of some of the attributes we typically take to distinguish human beings from other animals: superior mental functioning, rationality, language, self-consciousness, and the like. By the criteria listed in many philosophical accounts, those with PID are defective human beings, more like animals than humans (Foot 2001; McMahan 1996, 2002, 2009; Singer 1993, 2008, 2009); they lack what is necessary to live well as a human being, as in Aristotelianism; or they lack the quintessential human attributes that explain our moral preference for other human beings as opposed to nonhumans, as in views like Williams' in "The Human Prejudice" (Williams, 2006). At worst, philosophical systems place those with PID outside of the category of humanity. At best, the topic of intellectual disability is left to the margins of philosophical thought, whether as a challenge case, thought experiment, or brief aside to be dealt with hurriedly at the service of some grander point. Many accounts of moral standing end up excluding those with PID from the category of full human moral standing. To my eye, PID deserves its own careful philosophical attention: not just to avoid problematic conclusions but to think seriously about the lives of a great many human beings and the relationships they share with others.

In this chapter, I will first trace the connection between the characterization of PID as cognitive deficit and the conclusion that those with PID have diminished moral status by looking to the work of Peter Singer. Moral standing matters for my present purposes because it has implications for our interpersonal interactions. Singer's tack involves assessing the comparative cognitive capacities of different individuals and species. By Singer's line of thought, possessing

particular capacities results in particular moral treatments.<sup>4</sup> If we discover that cognitive capacities are of a certain kind, we will have an answer about what we owe to those with capacities like that; if cognitive capacities are different, we'll have a different answer about how to treat that sort of individual. Insofar as we buy into this type of picture, we will emerge with a particular view about PID and what we owe PID individuals due to their relative moral status.

Singer famously approaches the question of moral standing with the treatment of nonhuman animals in mind, a compelling and altruistically motivated concern. I, too, am concerned with questions whose stakes are practically oriented. I am interested in improving interactions with PID human beings in a way that is respectful of their humanity and sensitive to the fact of deep relationships existing between pairs of PID and non-PID persons. However, my methodological approach will differ from Singer's. Singer's order of explanation begins with an assumption about how we should characterize PID, where it is exclusively thought about in terms of particular diminished capacities of mind. From there Singer assesses abstracted notions of moral standing, which are then applied to particular cases so that we might determine what we owe particular groups. My approach will be to begin by questioning the practical treatment and characterization of PID in order to eventually develop an inclusive view of human moral equality.

To that end, a word about my assumptions in what follows: I begin with an understanding of what the basic desiderata of relationships with PID persons should look like, assuming that

<sup>&</sup>lt;sup>4</sup>Of course, this is not the case for all accounts of the moral standing of PID persons or for all accounts of moral standing that center on the possession of particular capacities of mind. Diminished standing does not always entail lesser moral solicitude. It may make lesser treatment appear more permissible. I focus on Singer because he is quite explicit about the connection between capacities of mind and entailed guidelines for interpersonal interaction, and I leave the question of implied treatments in other accounts resulting in diminished moral standing open.

these relationships should not be derogatory, abusive, condescending, subjugating, or anything else along these lines. History provides many obviously horrific and many more banally bad examples of ways that folks with PID have been treated. That relationships between those with PID and those without PID should be, in this minimal way, well-motivated, un-cruel, and respectful is to me an assumption, and I will devote no further argument to it. As such, my audience is likely those who recognize the value of and are motivated to help promote the sorts of relationships that, for example, Kittay has with Sesha. The fact that relationships like theirs exist motivates my commitment to some very basic form of human equality, where people like Sesha are not left in the margins. It will become clear in what follows that the fact of human equality is itself my most basic assumption: I take it to be self-evident. Any argument that arrives at inequalities of human moral status errs. (The details of these claims will become more apparent in Chapter III, where I will propose an alternative view of the nature of human moral equality.) For now, I'll stake myself to what looks to be an abstract philosophical guess at the fact of human moral equality and invite my readers to explore what that (and its alternatives) might look like.

Singer's rock-bottom looks quite different. He treats medical diagnostic criteria and assumptions about cognitive capacities as his most basic assumption, deriving what I take to be unacceptable conclusions about moral standing and what we owe persons lacking certain capacities. His view implies that there are few compelling reasons to get to know people with PID. However, to my eye, the most obvious thing is that we should try to get to know and have good relationships with individuals with PID. I will begin with the fact of existing deep, meaningful relationships between pairs of PID and non-PID persons. I assume that these are

worth emulating. I aim for a characterization of PID conducive to the kind of treatment that I am assuming is good.

It could be that everything Singer thinks about the cognitive capacities of PID persons is true, but this would be difficult to prove; likewise, it would be difficult to prove it is false. Pinning the question of what we owe one another on such an unstable foundation is problematic. So, I take the possession or lack of possession of particular, individualized capacities of mind to be a rather tenuous bedrock, whereas something along the lines of facilitating good and worthwhile relationships or (at this point) a guess at the fact of human moral equality is less dependent on the tides of empirical inquiry.

In what follows, I will suggest that current practices involving care and interpersonal interaction are negatively affected by a view of PID in which it is understood solely in terms of cognitive deficit. My reasons for dismissing this view are twofold: on the one hand, there are many things we do not know about the inner workings of those with PID; and on the other, the associated practical interactions between PID and non-PID persons fall short of where they might be. I will move from my discussion of Singer and the sorts of practical consequences implied by his views to propose an alternative understanding of PID: one where PID is characterized by the impossibility of successful, mutual verbal communication. Verbal communication is otherwise typical of human life and is the primary means by which we establish and deepen our relationships. This means that the looming practical problem is communicating with PID persons. I will then investigate several successful cases of relationships between PID and non-PID persons forming. Here I will assess what makes them cases worth emulating: the development of atypical means of communication to come to know one another.

The final section of this chapter will look to the implications of my view for improved interpersonal interactions between PID and non-PID persons.

The question of moral standing will be addressed in more detail in Chapter IV. However, a preview: by my view, the moral equality of any set of beings is a function of their having shared capacities for shared activities, most centrally the activities of forming and deepening relationships with one another. Here, communicative capacities will be key. But, in this chapter, I begin on the ground in an effort to build up to this view. The focus of what follows will be characterizing PID in such a way that motivates improved interpersonal interactions such that we might understand PID persons better, and then in turn to think about questions of moral standing in ways that are ultimately more well-founded.

## I. How we shouldn't think about PID

Approximately 1% of the population has some form of intellectual disability. Of that 1%, six in one thousand have a severe to profound intellectual disability (Patel et. al. 2018). That means, at a current population of close to 330 million individuals, there are nearly 20,000 individuals with severe to profound intellectual disability in the United States. This is not a huge number, but it is significant.<sup>5</sup>

Clinicians diagnose intellectual disabilities in terms of their gravity, ranking them in ascending order as mild, moderate, severe, or profound (DSM-V 2013). The DSM-V, the manual that medical professionals use to diagnose the entire range of cognitive, personality, psychological, and intellectual disorders, requires three conditions be met in order to diagnose

<sup>&</sup>lt;sup>5</sup>To attempt to contextualize this number: the total enrollment at the University of California, Los Angeles hovers just shy of 44,000 students, and just over 550 people have been to outer space. The definition of an area's being rural is a population beneath 20,000 whereas a town has 20,000 or more inhabitants.

intellectual disability: diminished cognitive capacity (IQ of 70 or below), decreased adaptive functioning (the skills needed to live independently or as appropriate for one' age, as those skills pertain to daily living skills, communication, and social skills),<sup>6</sup> and that the disorder be present from childhood (DSM-V, 808). Diagnostically, PID requires an IQ of below 20 and a mental age of under three years old (ibid.). I will rely on this terminology because it largely extensionally overlaps with and names the category that interests me here: *profound* intellectual disabilities.

Let me briefly characterize profound intellectual disabilities (PIDs). PIDs cause many restrictions: they render an individual incapable of independent living, prevent them from working a job without constant assistance, bar almost all verbal communication, and limit engagement in many complex human activities. Individuals with PID always require supervision to ensure their safety and the safety of those around them. At the same time, people with PIDs do have a significant level of interaction with other beings and activities in the world. Those with PID often enjoy relationships with immediate family and primary caretakers, but beyond that, their engagement with the social world is limited. Unlike those in vegetative states, people with PIDs move through the world, perceiving and interacting with others in ways that convey certain mental states. Many individuals with PID show signs of enjoying music, nature, food, affection, and so on. They are also unlike those with significant psychological disorders because from what we can glean, their perceptions and reaction to stimuli are connected appropriately to their actions. Finally, those with PID differ from other cognitively limited human beings because,

<sup>&</sup>lt;sup>6</sup> Adaptive functioning assessments tend to be made via behavioral studies of what the individual can and cannot do independently (DSM-V). For those with PID, independent living is typically impossible, and as such, their adaptive functioning assessments reflect the extent of their disability.

unlike infants, children, or those with various forms of dementia, they never will be nor were they previously fully capacitated agents.

Popular depictions of those with PID make them out to be burdens to their families or life-long sentences of care for someone who will never reciprocate.<sup>7</sup> Individuals with PID have historically been institutionalized, sterilized, abused, treated with neglect, and even killed because of their perceived mental insufficiencies (Crary 2018; Porter and Wright 2003; Trent 2016; Wehmeyer 2013; Wolfensberger 1969). Fortunately, our practices have improved from their horrific pasts. However, very few of us interact with individuals with PID with any regularity. As such, very few of us have the kind of relationship that would allow us to know much about such persons.

In hypothesizing potential ways to think about PID and the interpersonal challenges it brings, I see three basic criteria worth examining.<sup>8</sup> I will set aside one for future work and discuss the other two in this chapter. On the one hand, we have claims about what goes on inside the heads of those with PID. These sorts of claims are things that have to do with missing or diminished cognitive capacities as compared to non-PID persons. On the other hand, we have two observable, obvious facts about such persons. First, they are dependent on others for nearly

<sup>&</sup>lt;sup>7</sup>Some examples from popular culture include "What's Eating Gilbert Grape," "Rain Man," "I am Sam," "Love Actually," *Of Mice and Men*, "There's Something About Mary," *Boy Alone*, and the list goes on. Other frequent tropes include mental difference vilified or as comic relief, and in any case, always as supporting rather than lead characters. Importantly, groups are organizing to confront these representations in interesting ways, particularly via self-narration. One such group, Sprout, promotes social inclusion and transformation of societal preconceptions of developmental disabilities through film festivals that exclusively show films that challenge these assumptions. See <u>http://gosprout.org/</u>.

<sup>&</sup>lt;sup>8</sup> These alternatives are the ones I could, with reflection based on personal experience and exposure to individuals with PID, identify. Psychiatrists diagnose intellectual disability via a combination of cognitive capacity (typically estimated IQ) and independence in daily living skills. Philosophers tend to assume lack of rationality or cognitive abilities more similar to animals.

all facets of their daily lives and care. This is the criterion I will set aside – rigorous attention has already been devoted to the nature and ubiquity of dependency in human life (see for example Kittay and Feder 2002). Second, those with PID are unable to communicate using language beyond a few basic words or phrases and may or may not comprehend the utterances of others. I'll approach each of these considerations (cognitive capacity and communication) in turn.

## How we shouldn't think about PID: Cognitive deficiencies

An opposing view characterizes PID solely in terms of cognitive deficiencies, and often concludes diminished moral status based on those deficiencies. While it is admittedly quite plausible to conceive of PID as constituted primarily by a lack of or deficit in certain cognitive capacities – after all, PID is the most severe form of intellectual disability and cognitive functioning is a large component of how it is diagnosed – conceptualizing PID in terms cognitive deficiencies alone harms our approaches to engaging with such persons.

Some examples of what capacities might be absent are rationality,<sup>9</sup> theoretical or practical reasoning capacities, or meta-representation (Baron-Cohen et. al 1987, Baron-Cohen 1995). The claim might also be that PID persons have cognitive similarities that are more like non-human animals than they are to other human beings (Foot 2001; McMahan 1996, 2002, 2009; Singer 1993, 2008, 2009). These characterizations are not unrelated. Non-human animals are also typically taken to lack, for example, rationality.

Peter Singer's work on moral standing is perhaps the most well-known example from philosophical ethics of comparisons between the cognitive capacities of PID human beings and

<sup>&</sup>lt;sup>9</sup> For critiques of the assumption of rational capacities in human life, see Berube 2010; Carlson 2010; Davy 2015; Kittay 2010; Kittay and Feder 2002; Wong 2010; Stubblefield 2007; Taylor 2013.

non-human animals.<sup>10</sup> The idea at stake is that humans have certain capacities of mind that nonhuman animals lack, and those capacities grant human beings their superior moral status. Singer's argument concludes that those human beings lacking certain attributes of mind lack full personhood and thus full moral standing (Singer 1993, 76).<sup>11</sup>

This line of thought occurs in "Speciesism and Moral Status," the paper Singer presented at the 2008 Stony Brook Conference mentioned at my outset. Singer cites IQ and language comprehension in great apes, dogs, and grey parrots in order to compare their capacities to the American Association on Intellectual and Developmental Disabilities' diagnostic criteria for severe intellectual disabilities.<sup>12</sup> The animals tend to come out ahead in terms of their cognitive and linguistic capabilities (Singer 2009, 570). Since not all humans have cognitive abilities above all non-human animals, we cannot ground humans' superior moral standing on the claim of superior cognitive capacities. Since Singer is interested in what grants humans or non-human animals their moral status, he goes on to discuss the foundations of distinctive human moral

<sup>&</sup>lt;sup>10</sup> As far as the permissibility of animal comparisons goes, a quick word: it seems to me that if one has a certain level of respect for non-human animals this sort of comparison could be neither here nor there. However, I disagree with Singer that "these comparisons are unavoidable if we are to clarify the basis of moral status" (Singer 2009, 568). They are, in my opinion, only unavoidable if we insist moral standing depends on some sort of status-conferring attribute of mind. Yet to remain on topic, I will bracket these issues and focus instead on the epistemic validity of presumed cognitive attributes. For more on the debate regarding these types of comparisons, see Crary 2018; Kittay 2010, 2017; Singer 2010, 2017. My main conclusion here is something like Crary's: if we set aside the Aristotelian normative ordering of life forms that informs social Darwinist-types of thought, there's no normative pecking order to worry about (Crary, 2018). The comparisons may never be purely descriptive but they can be made respectfully.

<sup>&</sup>lt;sup>11</sup>Following Locke, Singer defines a person as rational and self-conscious, with awareness of its past and future. Unlike Locke, Singer's view does not defend basic human equality: "there could be a person who is not a member of our species. There could also be members of our species who are not persons" (Singer 1993, 76). Personhood is key to full moral standing.

<sup>&</sup>lt;sup>12</sup> It's worth noting that the criteria Singer used in 2009 have since been altered to mirror the DSM-V criteria I cited above. However, even with different diagnostic criteria, his conclusions would stand.

standing (religious, speciesist, and superior cognitive ability), only to debunk each option (ibid.,

571-4). Singer concludes:

So, to reiterate: because of the overlap in cognitive ability between some humans and some nonhuman animals, attempts to draw a moral line on the basis of cognitive ability, as Kant and the contractarians try to do, will require either that we exclude some humans—for example, those who are profoundly mentally retarded—or that we include some nonhuman animals—those whose levels of cognitive ability are equal or superior to the lowest level found in human beings. Hence, we must conclude that the standard ethical view that we find expressed in the statement by John Paul II—the view that all human beings, irrespective of their cognitive abilities, have equal moral status, and that this status is superior to the moral status of the most intelligent nonhuman animals—cannot be defended (ibid., 574).

In other words, Singer thinks we must sacrifice both distinctive human equality and equality

across humanity. He presents a picture of graduated moral standing that applies inter- and

intraspecies, considering three possibilities for how that might pan out.

1. preserve equality by raising the status of animals, granting them the same status we now grant to humans; or

2. preserve equality by lowering the status of humans to that which we now grant to animals; or

3. abandon the idea of the equal value of all humans, replacing that with a more graduated view in which moral status depends on some aspects of cognitive ability, and that graduated view is applied both to humans and nonhumans. (Singer 2009, 574-5).

He rightly rejects (2), admits some sympathy to (1), and ultimately defends (3). In Chapter III,

I'll propose an alternative version of (1) in which the status of non-human animals is left open-

ended, but in which all humans have equality of moral standing. The version of (1) in which we

preserve the equality of all humans and perhaps raise the status of some animals seems more

attractive to me than (3) does.

To defend (3), Singer's next move involves the claim that moral standing requires certain capacities, and in particular, the capacities for pleasure and pain (Crary 2017, 2019; Singer 1975,

1993, 2010, 2017). But his position also admits that capacities like rationality are morally relevant to personhood, and as such they inform his own graduated view of moral standing (Singer 1993).<sup>13</sup> He argues that for consistency's sake, any solicitude we have for other human beings based on particular capacities ought to be extended to non-human animals with similar capacities. Rational capacities, when taken as a morally relevant, status-conferring attribute, place humans at the top, with non-rational humans and certain non-human animals with comparable capacities following behind. Singer's broader picture requires us to ask whether those humans with similar cognitive attributes to some non-human animals deserve the same sort of diminished consideration. Singer concludes that those humans lacking particular attributes cannot possibly require additional moral consideration than comparable non-human animals because of the lack of morally relevant capacities of differentiation (Singer 2009, 576).<sup>14</sup>

### <sup>13</sup> From Singer 2009, 576:

We could problematize the factual claim that pain and pleasure are experientially similar across species, but the point here is that there are additional morally salient features of mind that inform graduated moral standing (like quality of life or being able to think about the future). <sup>14</sup> Here, Roger Scruton's defense of killing animals for eating motivates Singer's thought: if we agree that it's less had to kill a cow than a human because they lack the capacity to have goals.

agree that it's less bad to kill a cow than a human because they lack the capacity to have goals for their futures (we cannot "cut short" a cow's life), then we have to admit that a human who lacks the capacity for conceiving of her future might be justifiably killed. Of course, we could reject the claim that conceiving of one's future is morally relevant, but this is not the path Singer takes.

That there is some significance, as far as the wrongness of killing is concerned, in whether the being killed can think about the future, seems to me defensible. How much significance there is in this is a more difficult question, to which I have no clear answer. But I think we can conclude that pain and suffering are equally bad—and pleasure and happiness equally good—whether the being experiencing them is human or nonhuman, rational or nonrational, capable of discourse or not. On the other hand, death is a greater or lesser loss depending on factors like the extent to which the being was aware of his or her existence over time, and of course the quality of life the being was likely to have, had it continued to live.

As mentioned at my outset, this conclusion is problematic. It blatantly and brusquely gives little cause to develop better practices to improve interactions between non-PID and PID persons. We merely have to treat those with PID humanely, as we would pigs or monkeys. And for those of us committed to some basic understanding of equality across all forms of human life, it simply will not do to exclude any group of human beings, particularly based on their having or lacking x, y, or z.

Philosophical views like Singers that centralize capacities of mind as status-conferring tend to present a package view where the question of how we should treat others is matter of equality or inequality of capacity. Moral status attaches to kinds of beings according to possession of those cognitive capacities. Non-human animals and PID persons are types of beings who have less cognitive capacity and are therefore not equals in way that matters to how we treat them. The entire opposing view has issues. It seems obviously wrong at the level of interpersonal interaction between human beings and in its proposed inequalities of human moral status.

Beyond that, those sympathetic to my way of thinking about human equality may agree with the abstract philosophical onus against concluding that how we treat one another ought to be determined by a view of moral standing which can either be equal or unequal, depending on what sorts of capacities one happens to possess. Think of it this way: imagine a party whose attendees either can or cannot sing well.<sup>15</sup> Imagine dividing the party into singers and non-singers and giving singers large slices of cake and non-singers mere slivers. We could think about what's wrong with this in a few ways: we might think cake distribution shouldn't be proportional to singing ability, and that we need to rethink what attribute to base cake distribution upon –

<sup>&</sup>lt;sup>15</sup> Thank you to AJ Julius for the seeds of this example.

perhaps drawing, or painting, or writing. Or, we might insist everyone can sing equally well, refusing to distinguish between the tone-deaf and the Pavarotti's in our mix. Finally, we could refuse to accept the idea that dividing people by singing ability is actually carving anything at the joints or making a difference in determining kinds of persons. We might say the same thing about drawing, painting, or writing. I'll be working to convince my readers of a view like the latter. I believe that we should not try to divide humans at all based upon their possession of particular attributes of mind or any other individualized attribute, the possession of which is assessed in isolation from other people.

Beyond that, I am not trying to arrive at an effective welfarist ethics where we fairly allocate cake or divvy up care. Rather than asking "how should we treat them?" or "how can we help?" I ask, "how can we become closer?" so that we can come to understand one another better. So, the capacities that matter are the ones that we share and the ones that allow us to come to know one another better, perhaps something like certain forms of dance that draw partners – both capable of dancing, though perhaps in different ways or with different degrees of aptitude – together in deep and meaningful ways.

I suggest that to motivate my view, we attempt an alternative tack. Since we arrived here using assumptions that were made on the basis of the possession of certain capacities of mind, my first strategy will be to consider what we know and do not know about the capacities of mind of those with PID. This will connect to the ways in which conceptualizing PID solely as cognitive deficit has led to the subpar treatment of PID persons. My second strategy will be to suggest that at a practical level, we need not overemphasize capacities of mind, but instead look to illustrative examples emerging from positive relationships that exist between PID and non-PID persons; by doing this, we'll land on the significance of communication rather than that of

possessing similar capacities of mind. My third strategy, in Chapter IV, will be to insist that particular individuated capacities of mind are not what are relevant to moral standing – rather, the shared capacities to communicate in the ways necessary to form deep interpersonal relationships are what matter. We should be looking for qualities we share and ones that unite us, insofar as we are committed to some basic idea of human equality. Attributes that differentiate us and are assessed in isolation of other people only serve to stratify.

# Cognitive capacity and poor interpersonal interaction: Assuming more, not less

There's a lot we don't know about the inner workings of those with PID, and there's a lot we cannot know because PID persons do not communicate with the same immersion into natural language that non-PID persons possess. The fact that there may be more happening than meets the eye motivates my suggestion that we should assume more rather than less about the potential cognitive functions of those with PID, whether or not this winds up being empirically correct. Consider the following: a position of humility regarding the cognitive capacities of people with PID might support the view that some cases of PIDs are more like people with Locked-in syndrome than people with severe cognitive deficits. Cases of facilitated communication are fodder for these sorts of concerns.<sup>16</sup> The idea behind facilitated communication is that some

<sup>&</sup>lt;sup>16</sup> Facilitated communication is a sensitive topic. Readers may be familiar with the 2015 legal investigation of Professor Anna Stubblefield's relationship with her facilitated communication patient, who went by the moniker "D.J." in court (for an overview, see Engber 2015, 2018). Stubblefield engaged in a sexual relationship with D.J., an intellectually disabled man who could not verbally communicate without her guidance using facilitated communication. Stubblefield was convicted on rape charges because the court found D.J. incapable of consent. Their facilitated communication transcripts were deemed inadmissible as evidence by the courts due to scientific doubt about the veracity of facilitated communication practices. There has been a heated debate about the trial and its implications for the status of facilitated communication, the guiding belief of the court that D.J. could not possibly have the mental capacities required to fall in love or consent to sexual acts, and many other related issues. I will here remain agnostic about the possibility of a romantic relationship between Stubblefield and D.J. I do grant that other issues, like power dynamics between a therapist and a patient, make the relationship morally

people with intellectual disabilities are somehow communicatively trapped. As with Locked-in syndrome, they are merely unable to speak to convey what is inside their minds.<sup>17</sup>

Take, for example, Carly Fleishmann. Carly is a woman with PID who appeared to be incapable of communication for most of her childhood and adolescence (Fleishmann 2012). At age sixteen, her family decided to try facilitated communication as an effort to connect with her. It worked, and Carly can now communicate by typing with the support of a therapist.<sup>18</sup> Facilitated communication has revealed that she has plenty to say and that she has understood a lot more of what was going on around her than those who knew her had recognized.

While this is wonderful for the Fleishmann family, many have doubts about the veracity of facilitated communication.<sup>19</sup> The main concern is that the facilitator may be guiding the patient's arm, to communicate on their behalf, whether they are aware they are doing it. Think of a Ouija board, where the mystical force guiding the answers to the questions posed is most likely one of the participants' hands. Setting this issue aside, even if facilitated communication is illegitimate, the fact that it may not be is enough to make us pause.

problematic, and that the possibility that D.J. could not consent worsens these issues. However, I leave further discussion about this case and the empirical salience of facilitated communication to future philosophical work and, of course, to additional empirical investigation.

<sup>&</sup>lt;sup>17</sup> Those who use facilitated communication are taught to read letters, form words, or use images to communicate. Because many intellectual disabilities are coupled with physical ones, particularly motor skill deficiencies, the individuals who are candidates for facilitated communication require assistance picking out the letters or images displayed before them in order to convey their thoughts. In therapy sessions, a trained support person guides the forearm of the individual over a keyboard so that they can improve their dexterity and select the letter or image of their choice in order to communicate.

<sup>&</sup>lt;sup>18</sup> See Carly's YouTube channel here:

https://www.youtube.com/channel/UCeKKQIMB1NeOLN31\_CSJFRQ

<sup>&</sup>lt;sup>19</sup> See, for example, the American Psychological Association's position at <u>https://www.apa.org/research/action/facilitated</u> or the American Speech-Language-Hearing Association's position at <u>https://www.asha.org/policy/PS2018-00352/</u>.

This pause is where my point lies. We *should* wonder how much those with PID do comprehend and how much they might have to communicate. This is something many of us are familiar with doing: parents constantly wonder how much their infants understand, as do the friends and loved ones of those suffering from neurodegenerative disease. Following traumatic brain injury, much effort goes into diagnosing just what patients still comprehend. This kind of wonderment is central to many of our loving or caring relationships, and it is foreclosed if the entire way we think about people with PID is grounded in a dogmatic assumption about their capacities.

Assuming for the sake of my argument that Carly and others like her can communicate with help, imagine the Fleishmann's' realization that Carly had understood so much more of what was happening around her than they had assumed for more than a decade of her life. They believed what doctors told them – that Carly was profoundly intellectually disabled, that her level of understanding of the world around her was likely equivalent to that of a 6- to 12-monthold, and that she would never be able to communicate for herself or understand others (Fleishmann 2012). Imagine how they may have acted accordingly. In Carly's case, evidence emerged of a history of sexual abuse.<sup>20</sup> Her abuser believed she had no capacity to expose his crimes and likely believed she did not understand their harm.<sup>21</sup> The thought that PID individuals

<sup>&</sup>lt;sup>20</sup> The rates of sexual and physical abuse of PID individuals are incredibly alarming, with studies estimating as many as 90% of intellectually disabled persons experiencing some form of sexual abuse during the course of their lives (Sobsey 1994, 2004; Valenti-Heim and Schwartz 1995). This is particularly horrible when we note how many more cases slide under the radar due to the inability of the victim to communicate the wrongs they have suffered.

<sup>&</sup>lt;sup>21</sup>Of course, one does not have to understand *how* violence wrongs them for that violence to cause significant harm, but it quickly became apparent that Carly did grasp the egregious harm that had befallen her.

have little to no cognitive functioning is what allows abusers to assume they will get away with their crimes or that their victims cannot comprehend what is happening.

Still, we do not have to look to violent crimes to understand this aspect of my argument. We can all relate to how frustrating it is to be underestimated. Feminists have highlighted the unique epistemic injustices that occur via "mansplaining" and gaslighting; non-white folks in the USA have historically been put down as less intelligent than their white counterparts and treated as such; ageism causes epistemic injustices to both younger and older generations alike. Certain child-rearing practices also make this mistake – adolescents treated as children become incredibly frustrated by the lack of freedom and trust placed in their ability to accomplish things independently. If those with PID turn out to understand more than we think, we can imagine how degrading many of our interactions have been. A lifetime of assumed incompetence, of one's vocational activities being limited to Play-Doh and nursery rhymes when one is capable of much more, evokes a Kesey-esque nightmare. It is no wonder that Carly was so eager to express how much she understood and how much she wanted to be treated like her twin sister, not like a toddler.

The point of this consideration is to emphasize how, by assuming more rather than less, we avoid potential interpersonal harms in our interactions with those with PID. Beyond that, we create the space to work on the itself worthwhile project of coming to know one another better. Why bother trying to get to know someone you see as lacking all the attributes central to personality, to an inner life, to being human? Those outside of immediate family and caretakers lack an impetus when PID is taken to be constituted solely by cognitive incapacities. However, if we leave some room and act as if there may be more complexity than meets the eye – whether or not we one day determine the empirical truth of the matter – our actions and interactions begin to

be shaped by better ways to come to know those that appear to be dramatically different than ourselves.

### II. How we should think about PID

I will now shift gears and motivate an alternative view of PID. We typically think about PID in terms of cognitive deficit, but this has a negative impact on our interpersonal interactions with PID persons and on our assessments of their moral standing. These concerns motivate my practically oriented conception of PID's distinctiveness that is based on the impossibility of successful, mutual, language-based communication.<sup>22</sup> Unlike cognitive capacity, I take the inability of those with PID to communicate using natural language to be obvious and observable. I also take it to be more salient than comparative capacities of mind to the looming question of improving interpersonal interactions between PID and non-PID pairs of persons. Whether or not a person can, for example, reason practically or theoretically seems less important than whether I can somehow communicate with them.

By "the impossibility of successful, mutual language-based communication," I mean that those with PID lack the sort of communication that goes beyond ostensive definition or utterances of basic needs ("yes," "no," "go bathroom," "water," etc.). Successful, mutual language-based communication requires a certain level of verbalization and comprehension. A minimally sufficient degree of such communication would allow for the type of two-way conversational exchange involved, for example, in the claim of a native English speaker who

<sup>&</sup>lt;sup>22</sup> I use the term "language-based communication" in this paper to capture the natural-language based communication that humans typically use. Some may prefer "linguistic communication" or "verbal communication." I intend to rule out utterances that are not part of common languages. I am agnostic on the distinction between these two options, and will stick to "linguistic" or "language-based communication," by which I mean communication that requires language and words, and which does not include non-verbal utterances, made-up words, or gibberish.

says she is "conversational" in French. Maximally, it allows for the sort of rich discourse and depth of meaning we see in literature, poetry, or philosophical exchange. This sort of immersion in language allows a person to communicate beyond things like basic requirements. Many individuals with PID can state a few dozen words or phrases, but their ability to communicate verbally does not exceed this baseline. While they may have more to say or be able understand much more than we can perceive, their linguistic incapacities make it challenging to discern the degree or depth of their immersion in language.

For what it is worth, empirical studies on the communicative skills of individuals with intellectual disabilities find a lot of variation in both expressive and receptive skills. In general, individuals with PID are found to have fewer communication skills than those with less severe forms of intellectual disability (Cascella 2004); in many cases, they are perceived to have very little ability to communicate in a way that is translatable by anyone outside of their group of immediate caretakers, and even then, the rate of translation is highly unreliable or efficient (Adeli et. al. 2016). I will take the humbler route and assume that more rather than fewer communicative events can be considered intentional, largely based on the experiences of those close to individuals with PID. Overall, though, those with PID are only capable of using a few dozen words in natural language, most of which have some sort of practical function having to do with basic needs and desires like bathroom use or food acquisition. Most communication, if we are open to perceiving certain actions and utterances as such, takes place in highly atypical and idiosyncratic manners unique to the individual.

In any case, researchers largely agree that a greater degree of communication correlates positively with a higher quality of life (Light and McNaughton 2014). Conversely, researchers have also found a strong correlation between diminished quality of life and inability to

communicate in the sorts of cases I am interested in (Garcia et. al. 2020). Higher communication support needs and fewer successful communicative acts negatively affect quality of life across eight standard markers derived from the San Martin Scale, a set of quality-of-life domains designed specifically for non-speaking intellectually disabled persons (ibid., 4). More complex communicative purposes, like storytelling, talking to family and friends, and forming new relationships are the most strongly affected by higher communicative support needs and these higher needs have stronger correlations with more complex quality of life dimensions like self-determination, emotional well-being, interpersonal relationships, and social inclusion (ibid., 6-7). So, insofar as we are interested in practical considerations like improving the quality of life of those with intellectual disabilities, improving communication takes on a central role.

Of course, it may well be the case that cognitive deficiencies explain the lack of language-based communication distinctive to PID. For now, I will remain agnostic on this causal question and continue to urge humility with respect to what does or does not happen within the minds of those with PID. A focus on communication will be sufficient to think about PID for the purpose of exploring the nature of our interactions and for beginning to think about questions of moral standing. I will now turn to several examples of deep, meaningful relationships between PID and non-PID persons to illustrate the role of atypical means of communication in relationship-building.

## **Relationships worth emulating**

Susan Brison, a longtime friend of Eva Kittay and her daughter, Sesha, describes getting to know Sesha as at first intimidating, but then wildly worth it:

I knew *of* Sesha—that she had very significant cognitive and physical disabilities; that she lived with Eva, Jeffrey, their son Leo, and a full-time care provider, Peggy; that she required assistance with just about everything; that she could not

talk—but I didn't know what to expect. How would I introduce myself? Should I shake her hand? Would she be able to clasp mine? What would I say—and in what tone of voice? She was nineteen years old at the time, but with no discernible IQ. Should I talk to her the way I'd talk to an adult? Or to a toddler?

After I said some sort of greeting, Eva and I went for a walk, with Sesha in her stroller, and I sang a Scottish lullaby, "Rocking the Cradle," not because I thought of Sesha as a baby, but because it's fun to sing *a cappella* and it had gotten a good reception when I'd sung it for friends before.

Sesha listened, politely, but I could tell she wasn't really into it. I started to panic, thinking "Oh, no, this isn't working. She doesn't like my singing. She doesn't like *me*!" Although she's able to be entranced by music she's never heard before, Sesha prefers—especially when encountering a stranger—music that's familiar, something from her vast repertoire of favorites... Eva suggested we sing something by Elvis Presley, so we knelt down to Sesha's level and started singing "Love me tender, love me sweet, never let me go" and by the time we got to "tender," Sesha was beaming at me. (I think I had her at "Love.") What had seemed to me to be an unfocused, uncomprehending stare became a delighted, adoring gaze. And then she reached out and hugged me! (She also grabbed my hair and pulled me into her, but I'd been warned about that and quickly extricated myself.) I'll never know what she was thinking, but I was smitten. From then on, I was never at a loss for things to do with Sesha. (Brison 2019, xi-xii)

Brison's openness to relating to Sesha on her own terms and to perceiving communication conveyed in atypical manners allowed the two to develop a now decades-long friendship. Brison approached Sesha assuming she was approaching a communicator and a potential friend, not a very disabled person incapable of conveying meaning of her own; they forged their relationship bearing in mind that doing so may require atypical means and creative ways of communicating with one another.

Children affected by the Rubella epidemic of the 1960's were sometimes born deaf, blind, and intellectually disabled. Sociologist David Goode's work with these children highlights the ways in which unconventional forms of communication allowed such children to come to communicate with their caretakers (Goode 1994). When Goode conducted his research, clinicians and care workers tended to diverge on many aspects of a PID individual's perceived personality – characteristics, competencies, incompetencies, needs, and so on. After all, the clinicians working with patients like those in the 1960's intellectual disability wards typically only met with children once a year, diagnosing the children and moving on. Direct-care staff, on the other hand, had the sort of intimate knowledge that ground-level, day-to-day care of their charges enabled. They tended to have more reliable and concrete knowledge of the children because of their ongoing care (ibid., 12). However, staff turnover was high as the demands of caring for so many children with such profound impairments caused employees to burn out quickly. So, although direct care did grant those staff privileged perspectives on the needs and personalities of individual children, the finite resources of staff members led to stunted one-on-one relationships that were curtailed by limited time and energy.

Goode's research orientation shifted when he began to focus his investigation on one child in the ward, a girl named Christina who had been institutionalized since age six. He realized that focusing on individual children and individual relationships would create an "opportunity to socially reconstruct [that child] in a fashion truer to their actual human qualities and capabilities" (ibid., 17). With Christina, Goode endeavored to establish the sort of close interpersonal relationship that would allow for the pair to understand one another in some meaningful sense so that Christina's more genuine self could become clearer (he later describes this motive as understanding "with" the child, on her "own terms") and so that her care could improve as the result of that understanding.

Goode also studied another PID and deaf-blind child, Bianca, who remained home with her family. In both cases, he observed unique communicative practices that developed within the fiber of particular relationships. He noted that for Christina and Bianca, communication was available via touch, proprioception, and most significantly via "the engagement with their society

that their senses and the structures of their societies permitted... through the mutual production and interpretation of 'indexical expressions'" (ibid., 100).<sup>23</sup> Indexical expressions are particular to dyadic pairings or small groups of users who rely on the context and history of a relationship to communicate successfully and idiosyncratically.

Goode and Christina, as well as Bianca and her parents, were able to communicate with one another in various ways. For example, Goode would greet Christina by placing his hand on her face, and she would respond by gesturing to be picked up or by placing her right (less impaired) ear on his mouth, indicating she wanted him to sing to her (ibid., 111). Goode's central observation was that the communication between the pairs consisted exclusively of "conversations with our bodies... constructed of nonformal-language-related bodily expressions or gesticulations, produced by particular bodies, with specific biographies, at some specific time, in particular relationships, as part of a historically specific scene, and interpreted as such" (ibid., 119). They were able to establish effective communication precisely because of the relationships that existed between the pairs, and then their relationships became the basis for additional successful acts of communication to occur.

One of Goode's conclusions was that the microsocieties between PID and non-PID individuals challenge prevailing biases about the role of natural languages in human life by exposing the ways in which symbolic language is rooted in practices of bodily intersubjectivity (ibid., 97). Infants and their primary caretakers develop their relationships without natural language serving as the primary means of communication; here too the body plays the

<sup>&</sup>lt;sup>23</sup>Goode uses 'indexical expressions' to refer to the "essentially situated, or occasional, character and interpretation of expression." It is not merely that an indexical expresses context sensitivity in these cases, in the way a statement like "I am here" expresses both a linguistic and a respective meaning depending on the utterer. Instead, he is referring to the sense in which these expressions are contextualized within relationships.

foundational role for the relationship to form. Further, as Brison's friendship with Sesha suggests, humans do not always require similar capacities or attributes of mind to come to know one another. Regardless of capacities, relationships can center on shared joys, like music, or shared interest in and affection toward one another.

Even though the pairs described above could not speak to one another, they came to know one another in rich and meaningful ways. I think this has to do in large part with Brison and Goode's approaches towards Sesha and Christina: they saw the girls as persons with whom it was worth forging friendships. The front-and-center concern for Brison and for Goode was not how to grapple with cognitive deficiencies, but rather how to communicate despite apparent barriers. To contrast their approaches with Singer's, Brison and Goode implicitly rejected Singer's bedrock of assumed capacities or capacities of mind in their attempts to get to know Sesha and Christina. The intuition that it seems wrong to relate to another person based on a fixed guess about what they are like in the way that Singer does relates to their attempts at communication. Though we often do and sometimes must operate based upon certain assumptions about other people, it does to some degree seem bad to relate to someone (or refuse to interact with them, like Singer) based upon a fixed notion of what the other person is like or what they can do. This very intuition is the one I am trying to interpret and give expression to in my view, particularly in Chapter III where I propose a relational, communication-based grounding for human more equality. One of the thoughts to bear in mind as I make my way toward that view is that the way that Brison relates to Sesha, the way that Goode related to Christina, and the way that I relate to my brother is exactly by trying to figure out what the other is like without the baggage of Singerian-style assumptions.

#### III. Improving interactions between non-PID and PID persons

When we think about PID in terms of the impossibility of verbal communication rather than solely as a deficiency in some other attribute of mind, the nature of our interactions with those with PID shifts accordingly. We're motivated to seek alternative means of communication, and to approach PID persons as individuals with whom we may be able to form meaningful relationships. Significantly, we begin to ask, "how should we interact together?" as opposed to "how should we treat them?".

This is not to say that our interactions with PID persons will be the same as they are with other types of human beings. Of course, the nature of their disabilities makes it the case that some level of supervision, guidance, and care will be needed, as it is with other human beings whose mental capacities, maturity, or disability makes it the case that they require assistance from others. PID persons are unlike children in that we do not expect them to one day become independent adults; nor are they like the elderly, who were once more autonomous than they may become. However, this does not mean that PID persons do not have preferences, goals, and the ability to form friendships, as a view of PID in which it is primarily thought of as significant mental impairment would have us assume.

Insofar as we seek to improve relationships between PID and non-PID persons, the tangible goal of seeking alternative means of communication seems to my eye to be the best starting place. The goal in improving interactions with PID persons would not, for example, be respecting their autonomy. A quick anecdote about why this would not do: my family once stayed overnight in a hotel that had a tray of cookies in the lobby. We had a two-bedroom suite with my parents in one room, my brother in the other, and me on the pull-out couch. My mom rushed in on me showering, asking where my brother went. When she ran down to the lobby,

there he stood in his underwear with a panicked receptionist and two police officers, calmly eating the cookies while they tried to ask him questions. We are lucky that he had not been apprehended or harmed. My brother also had a phase of waking in the middle of the night and eating entire sticks of butter while we slept. Non-interference therefore would not work, barring extreme shifts in attitudes towards PID, public awareness of PID, and facts regarding cholesterol.

So, we are not looking to find a way to interact with individuals with PID as we do other adults; nor are we looking to take on what would be a patronizing attitude of stewardship. We are seeking a way to interact with them in a way that respects their individuality as human beings and their capacity to form deep, meaningful relationships with other individual human beings. Judging by Goode's work and Brison's description of her friendship with Sesha, and thinking of my own experiences with my brother, the common denominator looks to be finding atypical means of communication to come to know one another. The existing or developing relationships between PID and non-PID persons that I have described use non-language-based communication to get off the ground. So, figuring out how to communicate with those whose primary means of communication differ dramatically from our own will be the next step.

By thinking about PID in terms of the inability to successfully, mutually communicate using language, we leave open the door to discovering heterogeneous forms of communication. We begin to perceive those with PID as potential interlocutors, rather than as persons so damaged so as to not bring much to the table. Even though the cause of an inability to communicate using language may well be cognitive deficiency, the presence of even a profound cognitive deficiency does not disbar potential friendships and it certainly should not impact the way we assess moral standing. Instead of seeking differences, we should be on the lookout for the things we have in common, including our shared capacities to communicate in a variety of

ways in order to come to know one another. The continued emphasis on cognitive deficiencies in PID points us in the wrong direction in terms of perceiving the potential for PID persons and their lives; it encourages the propagation of prejudices regarding what sorts of relationships PID persons could be capable of. When we focus instead on a communicative barrier, we begin to think about the possibilities of our lives as lived together. We seek ways to communicate successfully. These improved practical outcomes seem to me to be a good reason to begin to think about PID differently.

An additional reason to rethink PID will come to the surface in Chapters II and III, and especially in Chapter III where I will argue for an alternative grounding for human equality of moral standing. Having raised the question of capacity, and the fact that we do not know for sure what occurs in the inner of lives of those with PID, I should emphasize again that my interest moving ahead is not purely motivated by this epistemic humility but instead in the possibilities left open by remaining agnostic in the interest of moving ahead in forming a relationship by trying to communicate with one another. In Chapter II, I will argue that despite apparent asymmetries, there is a way to communicate where both parties are doing the same thing. The question of how two participants – one with a PID, one without – can be exercising the same capacities is an important one, because at the surface this seems rather dubious. After all, one person can talk, possesses higher-order attributes of mind, and observes and interprets the other by employing these capacities. It appears that other does none of these things. It would be implausible to make light of these issues and to argue that the type of communication that occurs is the same as linguistic communication.

However, in conceptualizing relationship-constituted and constituting meaningful expressions (RCMEs) in Chapter II, I will argue that the function of RCMEs can be like that of

natural language and that RCMEs have salience in thinking about PID persons and their relationships with others. Further, RCMEs are not just a means to overcome the practical problem of developing and deepening relationships with PID persons. Ultimately, the possession of the wholly relational capacity to develop and employ RCMEs will play an important role in my alternative view of the grounds for human moral equality. Their very existence and use presupposes their existence and the capacity for their use in other people. The role of RCMEs in developing and deepening relationships will be the grounds for moral equality in Chapter III. The possibility to have communicative relationships is a capacity possessed by all human beings, and this relational capacity will serve to motivate an egalitarian view of human moral status.

# **Chapter II: Relationship-Constituted and Constituting Meaningful**

# **Expressions**

I also have a sibling with intellectual disabilities. She experienced brain damage (lack of oxygen) during birth. What I learned, as a younger sister, in the process of adapting to her mind, continues to impact my relating to everyone else. I am certain that understanding her differentness honed my abilities to perceive people in a way that allows them to release self-consciousness. I automatically integrate how we exist on broad spectrums. It is simply realistic to confront how delicately far out on these spectrums we all, often surprisingly, exist. Abstraction in painting allows these strains of difference to be seen and identified without words constraining those qualities. My interest is in discovering more about how deliberate we are in explicitly communicating these nuances to each other in forms that one might imagine as dreamlike landscapes of the present moment of relating. (Personal correspondence with Prudence Whittlesey, artist, 2021)

# **Introduction**

Here is how Eva Kittay describes her relationship with her daughter Sesha:

It is through my daughter's body that I come to know her. That I come to know another through her body is an epistemic claim. It is in one sense true for all subjects of human knowledge, and in another, it is particular to people such as my daughter, that is, to people who are restricted in their movements and who have no (or little) expressive language (Kittay 2019, 249).

Ordinarily, Kittay notes, our epistemic access to others is linguistic and behavioral, rather than

material. And yet, even language is a manifestation of voice, and so of the body. This suggests

that we always ultimately come to know one another via our bodies, although we tend to grapple

with that fact less with other language-users.

People who share their lives with one class of non-speakers,<sup>24</sup> profoundly intellectually

disabled (PID) persons like Sesha, face unique interpersonal challenges in these relationships.

<sup>&</sup>lt;sup>24</sup> I use non-speaking and non-natural language-using throughout this paper to refer to individuals who do not use natural language as their primary means of communication. I do not use non-verbal or non-linguistic because many of these individuals do communicate verbally, using

Those of us who love people with PIDs want to know who our siblings, children, and friends are as individuals. And yet when we cannot communicate with another person via language, it can be difficult to feel that we know who that person is.

As Kittay's remarks suggest, communication is not only embodied: it draws upon the multitude of tools available within the body, not just the capacity to use natural language to speak. Communication can be non-linguistic and is at its core a Janus-faced phenomenon. While my focus in what follows will not be the role of the body in communication *per se*, it will be on a form of communication that does not necessarily require language to get off the ground. In what follows, I will illustrate how what I will term *relationship-constituted and constituting meaningful expressions* (RCMEs) can allow us to come to know – among others – those incapable of using language to communicate.

RCMEs are a form of communication unique in their reliance upon shared histories of a relationship, and for their continued role in developing that relationship. Their meaning, value, and use are all situated within the context of a particular relationship between a pair or small group of communicators. They range from inside jokes between pairs of language users to unique bodily gestures or non-natural language utterances that have a particular meaning to a pair of persons, and perhaps even to certain types of non-human animal communication such as the alarm cries of vervet monkeys. I will argue that through the employment of RCMEs, coming to know a person with PID is possible, albeit significantly more challenging than it is to come to know other sorts of persons.

sounds and varied vocalizations, and because as a matter of principle, I do not make judgments about what may constitute a linguistic practice for certain persons.

By "coming to know" I mean something quite broad and intuitive. Claims of knowledge of course have an epistemic dimension, but like Kittay, I am focused here on their practical and ethical contours. To "come to know" another person in the sense I will be exploring here is to understand them in a way that allows a relationship to form. That relationship will in turn allow additional aspects of the other person to come into view, because part of what constitutes a relationship is the use of past interactions in which individuals have come to understand one another as fodder for additional understandings to come into play. When people are friends, siblings, parents and children, and so on, part of what they do together that is good *qua* the relationship is come to know one another better and better, using past interactions as part of their knowledge base for continuing to get to know one another.

Communication is central to the process of coming to know another person. This means that the major roadblock between pairs of PID and non-PID persons has to do, most obviously, with the PID's person's lack of access to natural language-type communication. It also has to do with the asymmetry between the two, both in terms of their modes of communication, their expectations of one another, their responsibilities towards one another, and their cognitive capacities, among other things. My present inquiry will focus on how RCMEs can make use of certain symmetries between these sorts of pairs and what this means practically for guiding our interpersonal interactions with PID persons.

In this chapter, I will begin by characterizing *relationship-constituted and constituting meaningful expressions* (RCMEs). This form of communication is relationship-*constituted* in that its use requires a preexisting (or developing) relationship in order to be successful; without the relationship, an RCME or its significance might not be understood. RCMEs are also relationship-

*constituting* in that their use allows for additional successful acts of communication to occur, which aids in the development and deepening of that relationship.

I will illustrate the commonness of RCMEs using both language-based and nonlanguage-based examples. My focus throughout will be on PID and non-PID pairs of human beings, where the primary mode of communication of each person differs dramatically. Using anecdotes from my personal history and evidence from a study conducted with Rubella patients by sociologist David Goode in the 1960s, I will show how pairs of PID and non-PID persons can rely on RCME use to come to know one another. I will close the chapter with a sketch of two resulting communicative virtues that RCMEs point us towards: hermeneutic openness and willingness to translate.

In conceptualizing RCMEs, my claim is not that all communicative difficulties between PID and non-PID persons can be transcended. My claim is also not that the ways we might know an individual with PID are identical to the ways we might know a non-PID person. Many interpersonal difficulties will remain, and I will explore the nature of these in due course. However, what philosophical inquiry can provide us here is a way to revise the expectations that non-PID persons bring to relationships with their current or potential PID intimates.

### I. <u>Relationship-constituted and constituting meaningful expressions</u>

For years, at least once a day, my brother Travis would direct the following utterance at me and my family members: "Becket. Be-be-be-beck-becket. Becket." My family would ask him what he meant, or we would urge him to show us, to find it. Professionals told us it was echolalia, or meaningless verbal repetition. But the way "becket" tended to lead towards thrown glasses of water, attempts to hit or bite us, and incidents of self-harm pointed to a failure to understand something significant. He was trying to communicate something. I would try giving him things that sounded like "becket" (ticket? biscuit?). Still, insistent "becket" utterances ensued. Violent outbursts would follow. At this point in his life, physical outbursts that lead to broken dishes, bruises or even stitches were not particularly unusual. Understanding what "becket" meant was not just important interpersonally, or to figure out what Travis needed; successful interpretation could prevent a trip to the emergency room.

My brother cannot speak beyond a few basic words and phrases. It is unclear how much he understands others. We rely on attempts at gestural communication, talking to him and hoping that he understands, and behavioral study to figure out who Travis is and what matters to him. However, we have always felt that Travis tries to communicate with us, despite the gloomy outlook of therapists and medical professionals. It seems obvious to me and to many people close to individuals with PID that my brother does communicate both gesturally and via verbal utterances which are, admittedly, different from the English ones that I use.

Empirical studies of the communicative skills of individuals with intellectual disabilities find a lot of variation in both expressive and receptive skills. In general, individuals with PID like my brother are found to have fewer communication skills than those with less severe forms of intellectual disability (Cascella 2004); in many cases, they are perceived to have very little ability to communicate in a way that is translatable by anyone outside of their group of immediate caretakers, and even then, the rate of translation is highly unreliable and inefficient (Adeli et. al. 2016).

While these are important empirical discussions, they must be interpreted cautiously. In particular, they have to be interpreted alongside the experiences of the people who are most closely attuned to individuals with PID. There is ample testimonial evidence that many of the non-linguistic acts and non-standard utterances (like saying "becket") of people with PID are

predictably related to particular outcomes. The presence of *some* form of targeted communication and its successful uptake between PID and non-PID persons is, to my mind, beyond dispute, and I will assume it in what follows. My aim is not to prove that some such communication is possible but to explore *what sort* of communication that is, and what distinctive ethical challenges it poses. This is an important task, since researchers largely agree that a greater degree of communication correlates positively with a higher quality of life (Hatton 2009, Light and McNaughton 2014, Miranda 2014): understanding others and being understood increases anyone's well-being, intellectually disabled or not.

Here is the sort of thing I have in mind when I appeal to testimonial evidence of "successful communication" with people with PID. One morning, my family went to a diner. It happened to have pictures on its menu. Travis opened the menu to a page with dozens of breakfast options pictured and said, "Becket." We all inwardly groaned and braced ourselves for what would be a hasty departure. But then Travis kept talking, gazing intently at the table next to us. "Becket."

A lone diner sat with her meal. It was pancakes.

What was dismissed by many professionals – teachers, therapists, doctors, psychologists – meant something, and it meant something important to my brother. That day we ordered him pancakes and he was happy. Our translation was a success that we rely on to this day – in fact, we rarely call pancakes "pancakes" anymore. Travis was indeed telling us something; the problem between us was not meaninglessness but a case of something being lost in translation.

When Travis successfully asks for "becket" now and my family and I fire up the griddle, we are using *relationship-constituted and constituting meaningful expressions*. We can think of a non-PID case that functions similarly to the "becket" scenario when we think about inside jokes.

Inside jokes occur when a pair of friends share a funny experience or have similar senses of humor, and they arise on specific occasions that are memorable for whatever ostensibly hilarious reason. They are often not funny to those who were not present from their outset ("I guess you had to be there!") and can often take on additional life or snowball as the friends refer to the joke and riff on it. Inside jokes both help develop relationships between friends and strengthen them as they become a part of the texture of the relationship itself. They are unique to the pair, and they become a part of their shared history in a way that allows additional instances of joking to occur. They have value as an aspect of the way the pair communicates and as a token of that friendship. In a sense, an inside joke begins to have its own value that is not purely instrumentalized as a means of making the other laugh. Rather, it becomes a part of what friends do together that is good as an aspect of the friendship and the activity of being friends. Likewise, with "becket:" it had instrumental value as a means to understand one another, but it took on non-instrumental value as an instance of us working to understand one another because of our commitment to one another and to our relationship.

RCMEs can be linguistic or non-linguistic, verbal, or gestural, and can express informative or phatic meaning. For example, verbal, phatic cases of RCMEs are also quite common. Infants and their caretakers will often enter a mimetic game, making cooing sounds, blowing raspberries, or imitating one another's utterances. This is typically done with steady eye-contact between the pair, which highlights its targeted character and its audience-specificity. As far as I know, the purpose of making these sounds is largely phatic, as the sounds are not made to convey any specific pieces of information.<sup>25</sup> A similar phenomenon occurs between PID

<sup>&</sup>lt;sup>25</sup> In fact, targeted responses like continued eye-contact or the caretaker's copying the infant stimulate additional mimicry and the development of the superior temporal sulcus, a region of

persons and those with whom they share their lives. Individuals with PID make sounds to capture the attention of family members or friends, and the receptive interlocutor will engage in social interaction in a way appropriately tailored to that individual. For example, my brother likes to exclaim "ay-oh" loudly while going for walks outside. He will sometimes look at me and smile when he does it. To me, it has always seemed to be an expression of joy and shared appreciation of our activity. So, when he says it, I say it back.

Since RCMEs do not necessarily require language or linguistic capacities on the part of the agents involved, they become particularly important in the context of relationships where language is not the primary means of communication. As mentioned, this is the case in pairs of PID and non-PID persons, as well as in many other important relationships, such as those between pre-linguistic infants and their caretakers. The use of RCMEs still relies on the existence of a dyadic relationship for their success, and the value of their success has to do with those relationships having value of their own. Before spelling out why this is the case, I will characterize RCMEs more precisely so that we have a working concept in view.

In what follows I will refer to two parties involved in RCME use as A and B. RCMEs are:

- 1. either verbal utterances or non-verbal gestures that express a particular informative or phatic content (their meaning),<sup>26</sup>
- 2. at least part of which is derived from the unique context of a pair or small group of communicators' relationships,

the brain that has been found to be significant in social cognition (see, for example, Simpson et. al. 2014 or de Klerk et. al. 2018).

<sup>&</sup>lt;sup>26</sup> I use the term "meaning" or "meaningful" in as broad a sense as possible. I want to capture the sense in which there is some particular informative or phatic content conveyed by the communicative act. Whereas sentence meaning is typically taken to carry certain features like truth or falsity, synonymy, or contradiction, I do not take this broader sense of communicative meaning to require meeting so many criteria. Rather, I intend to use "meaning" to capture the very general sense in which communicative acts, linguistic or otherwise, can express content, intentionally or not. The meaning of a hug may be its expression of affection, or it may be consolative. The meaning of "becket" was pancakes. The meaning of a mimetic game played between an infant and her caregiver may simply be a purely phatic desire to connect.

3. and at least part of which aids in deepening the pair's relationship;

### RCMEs:

- 4. rely on A's willingness to attempt to understand B's act or utterance's meaning,
- 5. and rely on as well on A and B's trust in one another, derived from the context of the relationship, that the act or utterance will be
  - a. interpreted as having meaning, and that
  - b. the act or utterance's meaning will be interpreted successfully.

This list is not a set of necessary and sufficient conditions, but rather a rough characterization meant to identify the central features of certain communicative phenomena that we see happening across many forms of life in a variety of manners.<sup>27</sup> Further, RCMEs may also be prevalent in non-human animal life.

Now that my target concept is in view, I will devote the remainder of this chapter to first discussing how RCMEs function similarly to natural language, despite some limitations. This will aid in framing the role RCMEs can play for PID and non-PID pairs of human beings. I will then present a case study that will emphasize the significance of recognizing and developing RCMEs for PID persons. Finally, I will explore the ethical character of RCME's as a distinctive form of human communication before turning towards the communicative virtues of hermeneutic openness and willingness to translate.

<sup>&</sup>lt;sup>27</sup> Here are some additional examples of RCMEs that may help illustrate their ubiquity. In gestural, phatic cases we may imagine something like a secret handshake between friends as a typical example. Secret handshakes do not convey some particular content, but rather they are an expression of a particular social bond and its shared history. In terms of a PID example, my brother and I often play a game where one of us sticks out their tongue at the other, and then the other repeats it back. We've done this as long as I can remember, and continue to do so both in person and over FaceTime now that we live on different coasts. In all of the cases I have mentioned, communication successfully takes place. This communication serves a purpose, whether that purpose is informative or purely social. These cases are all directed towards some form of connection between the communicator and the observer, and they rely on the existence (or intended development) of a relationship for their uptake. The relationships that are present make the communicative acts more seamless.

### II. The function of RCMEs

It is likely that many cases of non-natural language based RCMEs occur in non-human animal life. While non-human animal communication may lack the accuracy or efficiency of human languages, it certainly allows non-human animals to convey information and to form and deepen social bonds – outcomes that natural language also fosters. Rather than lay out potential examples here, I will avoid potential anthropomorphization of intraspecies communicative acts by instead thinking about an interspecies case that captures an important facet of PID and non-PID pairs of human beings.

In cases between two different species, the individuals involved rely on different modes of communication as their primary means to communicate, just as with PID and non-PID human pairs. Companion animals provide a useful comparison. Think about the distinction between the following sorts of cases. Imagine I place before my dog, at equal distances, a steak and a bowl of kibble. It is no shock that my dog goes immediately to the steak rather than to the kibble. On the other hand, imagine my dog nudging a doorknob with her nose and looking directly at me, whining until I get up and let her go outside. The former case may be merely a reaction to a better smell – an impulse, surely not something minded or intentional in any thick sense. However, we can imagine the dog having some sort of inference process where she has learned that certain gestures and vocalizations bring about desired results, like me letting her out into the yard when she nudges the doorknob. Both cases are such that any person who knows a bit about dog behavior could interpret their meaning.

Then imagine a third case. My dog is fairly lazy. She gets tired earlier in the evening than I do, and she has a certain tell when she is ready to go to bed. Usually, we will be sitting in the living room across the house from the bedroom in the evening. First, my dog will walk to the

side of the room that is nearest to the bedroom. She'll sit, look at me, and whine a bit. She will continue to edge closer to the door that is nearest to the bedroom, stopping to look at me and whine. It's as if she wants me to follow her. When I do get up and go over to her, she will wag her tail and walk to the bedroom, looking back behind her every few steps to make sure I'm following. When we get to the bedroom, she stands near the foot of my bed, which is high, and waits. She needs help to get up due to a hip surgery last year. Then, I pat the edge of the bed, she puts her front paws up, and my job is to lift her rear so that she can settle into bed for the night.

Those who share their lives with individuals with PID are familiar with all these kinds of cases. The steak case and its analogies are an easy read for anyone, whether they have spent much time with individuals with PID. Simple behavioral studies, like a person with PID accepting a cookie over a plate of steamed broccoli, are transparent. It's unclear whether the person with PID accepting the cookie does anything along the lines of thinking to herself, *"cookies are so much better than broccoli,"* but it's obvious that she is reacting to something desirable in the way that the dog is with the steak. The steak and cookie cases are, to their observers, informative about the preferences of the individual.

The doorknob nudging case can be read as an attempt at communication between two individuals, rather than merely an informative action. An individual with PID might analogously engage in an action where he picks up the remote control and hands it to his caretaker when he wishes to watch a television program. He understands the connection between the remote and the program and he recognizes that his caretaker will interpret the action and carry out his desired outcome in the same way that the dog knows nudging the doorknob will lead to her owner letting her go outside. Unlike the steak and cookie cases, this sort of action is targeted and audiencedirected in that there is an intended viewer of the act. However, this type of case does bear some

similarity to the steak and cookie cases. In both types of cases, it would not take an expert on the individual's idiosyncrasies to interpret what is happening.

The last case is more interesting in that it is not necessarily transparent to a non-expert in my *particular* dog's communications. If a guest was over who did not know my dog very well, they might think she went towards the exit of the living room because she wanted to go outside, or because she was hungry, or for no reason at all. They would most likely infer that she was just being a dog. I also have reason to doubt that my dog would engage in this behavior at all with someone other than my husband or me – the last time a friend dog-sat, my dog merely fell asleep on the rug in the hallway. It is because I know my dog, and I know her patterns of behavior, that I can see:

- 1. that she is communicating something,
- 2. that that communicative act is targeted and audience-specific, and
- 3. what that particular communication means.

Without my established relationship with her, I would have no reason to know that this particular action indicated a desire to have my help so that she could go to bed. Further, she has some sense that engaging in this behavior with me will lead to the same routine each time. There is some sense in which she is aware that the fact of our relationship and its history will lead to my trying to understand her needs in a way that someone else would not.

A PID individual might have certain behaviors that look meaningless to an outsider but that are in fact attempts at communication. There may be certain utterances or actions reserved for particular contexts with particular persons that the PID persons trusts to attempt to understand. A person who shares their life with a particular PID individual develops the interpretive tools to understand that, oftentimes, there is a lot more communication happening than meets the eye. The hermeneutical skills developed through relationships with non-speaking

persons (or non-human animals) grant privileged access to often overlooked acts of communication. If one engages in a sufficient number of interactions with a non-speaking person, one often develops the ability to interpret within a seemingly meaningless action criteria (1), (2), and (3) mentioned above.

Of course, in the case with my dog in the evenings or in the "becket" case, a stranger might stumble upon the correct meaning of the action/utterance. A waiter may have passed by, seen Travis gazing at the pancakes on the next table while uttering, "becket," and said to us, "he wants pancakes." Or a dog-loving friend might be over for dinner and see my dog sitting and staring from across the room and suggest that my dog is tired, and that she seemed like she wanted to go to bed. Certain context clues help those without preexisting relationships interpret cases of communication that constitute RCMEs for the parties involved. But does this make the lucky guesser privy to the RCME, too?

My answer to this question is "no," for two reasons. First, the lucky guesser is not the intended audience. RCMEs as I have been describing them are directed towards a specific observer. In this sense, the lucky guesser is also an eavesdropper. Second, the lucky guesser lacks the fabric of the relationship which makes RCMEs both relationship-constituted and relationship-constituting. The waiter is not friends with or close to my brother in any way. His guess has nothing to do with the shared history of a relationship. So, the lucky guesser lacks the relationship-constituted aspect of RCME use. On the flip side, the lucky successful translation on the part of the waiter would not have the same weight for Travis that translation from his loved ones bears. Without immersion in the history of the relationship, they cannot fully grasp the significance of successfully translating "becket" after years of trial and error, physical injury, and the accompanying emotional distress that arose from not being able to understand someone we

love. Guessing what "becket" meant might, in the best of cases, lead to the pair wanting to develop a friendship, but this is admittedly unlikely. A lucky guess is just not, in most cases, relationship-constituting.

In a funny scene in the mockumentary television show *The Office*, office manager Michael Scott sits speaking to the camera and to his imagined interviewer in his office. Though his jokes nearly always fall flat, Michael takes himself to be quite the comedian, constantly offending others and making a fool of himself with his attempts at humor. The interview has to do with an inside joke between two of his employees that Michael had tried to riff on. "I love inside jokes," Michael says wistfully. "Someday I'd love to be a part of one."

Guessing the meaning or context of, or hearing second hand about some other pair's inside joke just isn't the same. Like Michael, you might try to work your way in. The pair might even try to explain it to you so that you might be included, but if you were not present from its outset the joke just would not have the same bite. It would not have the same role as an expression of a shared history, of your relationship, and of the joke as part of the fabric of that relationship. Hearing about someone else's inside joke is not going to be relationship-constituted or constituting in the way that it is when it is your *own* inside joke.

A further concern may arise from a behaviorist perspective. Perhaps what is occurring between my dog and I at bedtime, or my brother in repeating "becket," is the employment of some all-purpose capacity to use information about a relatively stable environment and the responses certain behaviors elicit towards the end of accomplishing certain goals. While there is a clear difference between the inferences I make about my (or any) dog's tastes in food and the inferences I make about my particular dog wanting to go to bed, or my brother's passing the remote versus his saying "becket" to me, the type of inference I use does little to advance the

theses that "becket" and bedtime are examples of RCME employment and that RCMEs are in fact a form of communication that functions similarly to other forms of communication. To assess this challenge, I must first say a bit more about more typical forms of communication and what they can accomplish.

Communication has many forms and functions. I have said a bit about forms of communication – language, gesture, verbal, non-verbal – but of course this category also includes things like written and visual communication. I will remain open about the scope and heterogeneity of forms of communication. In terms of function, my focus has been on intersubjective understanding. This can include things like information gathering and sharing, which themselves apply more broadly than intersubjective understanding. RCMEs both arise from and serve to deepen relationships in which intersubjective understanding is a crucial end. So, I will continue to think about the myriad forms of communication that serve the end of intersubjective understanding, or, in a phrase I've used before, coming to know one another.

We can tell a story about the evolutionary underpinnings of communication that leads towards intersubjective understanding. Here is what I have in mind. Vervet monkeys have several distinct warning cries they will sound to alert their group to the presence of different predators: one for snakes, one for birds, one for predatory cats, and so on (Cheney and Seyfarth 1980, Dunbar 1997). Further, vervets will only sound these alarms if they take themselves to be within earshot of other vervets (ibid.). Dorit Bar-On seeks to establish the origins of expressive communication in non-human animals, exploring the implications of this case. She argues that theory of mind, the cognitive capacity that enables us to discern the states of minds of others, is not necessary to the spread of information via communicative acts (Bar-On, 2013). Expressive communication, by her view, "means that [non-human animals] show to their designated

audience (without intentionally telling)—and their designated audience recognizes (without rationally inferring)" (ibid, 342). Joshua Armstrong also argues that while there is not necessarily evidence that vervet monkeys are capable of the higher-order mental states that some theories of communication require for intentional information-sharing to take place, they do engage in robust forms of social cognition that allow for meaning to be communicated in targeted, audience-specific ways between individuals (Armstrong forthcoming). He defines the iterative updating of common informational grounds that develop amongst individuals as "mutually responsive attitudes," a social capacity that is distinct from a cognitive one in that it does not necessarily require higher-order mental capacities.

We might think about the pervasiveness of relationally-oriented, meaning-conveying forms of communication by looking at an even simpler communicative act. The grooming practices that take place amongst some species of primates are similarly communicative and meaningful, though they play a more phatic role. Robin Dunbar gives a compelling overview of the role grooming plays in the evolution of language, providing evidence of the ways in which grooming establishes and cements social bonds between pairs of primates (Dunbar 1997). Deeply rooted alliances are formed through grooming practices that facilitate the development of trust between pairs and by extension tightly bonded, multi-individual coalitions. Dunbar's primary thesis is that grooming provided the evolutionary stepping-stone to language, which serves many of the same purposes grooming did – language is merely a more efficient means by which we achieve the same rudimentary goals of survival, protection, and the social connection that serves these ends (ibid., 120-8).

If grooming can provide some of the same functions that language can, it seems plausible that RCMEs can, too. As a form of communication, RCMEs function to form and deepen social

bonds so that individuals can come to know one another in meaningful ways. Beyond survival and protection, RCMEs can allow us to understand one another's goals, preferences, needs, desires, quirks, emotions, characteristics, etc. – they permit us to come to know other individuals as individuals, using our relationships with one another as the very means to come to know one another. Inside jokes, with the way they allow us to glimpse humor and what makes both members of a pair tick, use language and a developing shared history as the means to serve the end of intersubjective understanding. Repeating "becket" was a verbal act of communication that relied on preestablished trust between Travis and the rest of my family to achieve a similar understanding. While natural language is certainly more expedient, this does not mean that other forms of communication like alarm cries, grooming, or non-linguistic RCMEs cannot function in similar ways.

In sum, we have cause to think that non-linguistic RCME use is not merely the employment of some all-purpose capacity to connect certain behaviors to particular outcomes. Specific interpersonal relationships are required for them to get off the ground. Further, in the case of a PID and non-PID pair, the non-PID person's interpretation of particular behaviors is not mere behavioral study. If it were, this would take us back to our lucky guesser case, where the lack of a preexisting or developing relationship deprives RCMEs of their ethical, relationshipconstituting character.

It is undeniable that significant asymmetries exist when one member of the relationship relies on natural language as their primary means of communication and the other does not, or when one interprets the other using higher-order cognitive attributes and the other likely cannot. And yet, the fabric of the relationship that both rely on to employ RCMEs remains the same. This is part of what makes RCMEs unique and particularly salient for certain types of

relationships. I will now turn more squarely to the ethical character of RCMEs. This will point us towards two things: first, what they can allow us to know about our non-speaking friends and loved ones, and second, what their non-instrumental value might tell us about relationships where significant asymmetries exist.

### III. <u>The value of RCMEs</u>

I have suggested that part of the value of Goode's work was its role in allowing him to get to know Christina, beyond the clinical and direct-care identities transposed on her by the medical institution where she lived. Getting to know Christina had instrumental value as a means to allow her to communicate her preferences and to improve her overall quality of life. However, I want to argue that part of the uniqueness of RCMEs lies in their non-instrumental value as an expression of the value of the relationship itself. Every time Goode and Christina succeeded in getting something across or picking up what was being communicated, they relied upon and discharged the trust one placed in the other to apply the history of their relationship, just as a pair of language users might. This happens with inside jokes, too. When a pair of old friends references a joke from their past, they do so trusting the other will remember that moment, its context, and its humor. Because of the value of their relationship that is in part constituted by this moment in the past, the joke remains funny to them, and this fact deepens their bond. Any particularized knowledge of how a pair of persons has communicated so far allows the pair to engage in additional successful communicative acts. The pair of language-using people might build on the joke, or a pair of PID and non-PID persons might use past bodily interactions to develop new ones. In this way, every time a communicative act succeeds, it has the value of the two people demonstrating to one another their mutual knowledge and commitment to their relationship.

The less interesting way that we can instrumentalize knowledge based on past interactions might happen between two people who do not know each other, who are not trying to get to know each other better, and for whom communication is primarily for information gathering and conveying. They will use what they have learned so far and leverage it as the basis for guessing which gestures, jokes, and references the other person will pick up on and interpret correctly (and vice versa). However, this way of using knowledge of past interactions lacks the value of the relationship's history that I'm using as the basis of interpretation for RCMEs because this type of past knowledge use is purely instrumental. A key component of RCMEs is that they are not purely instrumental; they are an expression of an intrinsically valuable relationship.

RCMEs rely on the rich, storied fabric of relationships for their meaning to be interpreted. Travis said "becket" trusting us to eventually understand what that meant, even if that trust was not characterized by the thought, "they will eventually understand what I mean." While my inference may not have been expected by Travis in an intellectualized sense, it was expected because of the fact of our relationship. It seems that Travis sensed that the fact of our relationship and our commitment to understanding him, specifically and as an individual who mattered to us, would eventually make possible our interpretation.

Despite many deep asymmetries, there is a certain symmetry between interlocutors party to RCME use. Despite the one using language and the other not, the members of the dyadic relationship that exists in PID and non-PID pairings rely on the same base of knowledge that is the product of their relationship and its history in order to communicate successfully with one another. The mutually responsive attitudes that RCMEs employ allow for iterative updates of the common knowledge ground that is the context of a relationship. The more success a pair has

communicating, the greater the opportunity for more RCMEs to come into play in the varied, idiosyncratic communications that exist between pairs of persons. This shared set of data that is the relationship's history, the associated commitment each individual has to the relationship, and their desire to deepen the relationship by communicating together account for the unique ethical character of RCMEs.

The respect in which the two parties to RCMEs are each relying on the fact of the relationship is precisely that they are friends, or they love each other, or they are brother and sister, and so on. Communicating is a part of what they do together that is good as an aspect of that relationship. Each individual uses the pair's past interactions as the basis for what they can expect to be successful communication in the next round of communication. This uptake is good as such, as an aspect of their intimate relationship. Communicative capacities here serve as capacities for making use of the history of a relationship through their ethical function in deepening that relationship. RCMEs do not merely function, then, for getting meaning across – they function to continue and deepen the intrinsically valuable thing that is the relationship itself. There is a level at which each individual, regardless of capacity, is doing the same thing: using the relationship to deepen the relationship.

While we may not know individuals who cannot speak in the same way, with the same depth, or with the same accuracy that we know those with whom we can converse, things look less stark for our relationships with our PID intimates once we have RCMEs in view. Patience and persistence, as well as the communicative virtues I will describe in the close of this chapter, can aid in our coming to know such persons. Our expectations for such relationships will admittedly be different than our expectations for non-PID folks. However, we can see that there is not *nothing* to be known or *no* means that can bring about meaningful communication.

RCMEs can allow us to know even those who cannot speak in a way that allows for a deep, unique, specific relationship to form.

This brings us to the virtues that might guide our use and development of RCMEs. Insofar as we recognize the value, instrumental and not, of RCMEs, and insofar as we are committed to developing them so that we might come to know in particular our non-speaking intimates better, we can work to develop certain communicative virtues so that RCME use can be its most effective.

### IV. Hermeneutic openness and willingness to interpret

If RCMEs are to be successfully interpreted and employed in pairings where at least one individual does not use natural language, two virtues might guide the sense in which we approach them: hermeneutic openness and willingness to interpret.<sup>28</sup> Listeners must first have some degree of hermeneutic openness. By this I mean that the observer must view the actor as attempting to communicate. This will involve a certain degree of epistemic humility in terms of what types of persons may be capable of communication, and what types of acts might count as communicative ones. Too often, with the unfamiliar forms of communicative acts present in PID persons, attempts to communicate are dismissed, ignored, or are not perceived as forms of communication. For interpretation to occur, an observer must be willing to see the act as

<sup>&</sup>lt;sup>28</sup> Without getting into the weeds of the distinction between translation and interpretation, I will use "interpret" here to designate the largely epistemic process of attempting to correctly arrive at the meaning of a communicative act whose meaning is initially opaque. The "correct" meaning is the one intended by the actor. There often may not be a one-to-one matching of communicative act to word, concept, or phrase as is the case in the ways we typically understand translation to happen. Some cases of translating RCMEs or the communicative acts of non-neurotypical human beings may be more like translating "schadenfreude" or "hygge" to English: the concept does not map neatly onto a single term. Some meanings may be purely phatic. This is another case where hermeneutic openness serves both parties well in prescribing a stance of openness to multifaceted forms of meaning being derived from communicative acts.

something they might be able to interpret, and so they must be open to finding meaning in unlikely or unusual sources.

Second, from that openness must come a willingness to try to interpret. This is an epistemic project in that it requires the employment of epistemic faculties like creativity and rational interpretation. For the PID person, it may require a different type of perception or interpretative work, which will be determined by their unique cognitive capacities. Yet on either side, the work will come from a commitment to the development and deepening of the relationship, so it is morally motivated by that commitment. Only those involved in relationships or attempting to develop relationships will likely have the drive to put in the work to try to understand one another. The degree of effort a person is willing to put in is likely tied to the degree to which they value the relationship. Because it is interpretive work, it requires engagement with knowledge of the relationship's history, and particularly with knowledge about communication that has taken place in the past.

Those who share their lives with PID individuals tend to take on more of the heavy lifting because of their relationships with those sorts of persons. To return to an example I mentioned in my taxonomy of cases, my brother and I will sometimes shout "ay-oh" on walks together to express our enjoyment of the activity and our time together. I doubt that a person who did not know my brother would exclaim "ay-oh" back at him with equal enthusiasm. I'm not sure that beyond my immediate family, anyone would know to recognize "ay-oh" as a communicative act. In cases involving PID, we have cause to think that the closer the relationship, the more successful the translations might be. Those close to individuals with PID are more invested in understanding the person with PID, and they also have a host of background knowledge that

grounds their ability to recognize acts of non-traditional forms of meaning-conveying communication.

In contexts where relationships do not yet exist, a strance of hermeneutic openness significantly alters the course events can take. Where no relationship exists, or where the potential communicative acts of another individual (human or not) are quite unlike one's own, adopting a stance of hermeneutic openness is less automatic and thus less likely. This is because the fact of a relationship renders the observer more sensitive to the potential communicative acts of the actor, and because the fact of the relationship makes both parties more trusting, willing, and desiring of communication between the pair. When strangers can approach one another with hermeneutic openness, there is a higher likelihood that communication will occur and that a relationship might get off the ground. Recall Sesha and Brison's relationship: both parties approach of openness made that relationship possible.

Trust that an act will be perceived for what it is – communication – likewise renders the actor more able to attempt to communicate. As with "ay-yo" and "becket," the fact of the relationship instills some degree of trust on the part of the actor to try to communicate, confident that their acts will be received with a willingness to regard or listen, so that they might eventually be interpreted successfully. Even when the communicative act remains opaque, the hermeneutic openness of both parties serves both as a vehicle that expresses a willingness to listen. This itself solidifies the pre-existing relationship or creates the foundation for a new one to form. Here, too, Brison and Sesha's relationship evidences the fruits of their hermeneutically open stances: describing their shared passion for music, Brison writes "She was, and is, the best audience I've ever had and that's because, I came to realize, I'm not performing *for* her when I sing. Music is something we do together... Singing with her is like singing with a jazz combo in that it's a kind

of improvisation and she's totally present in the moment" (Brison 2019, xii). Later, Brison cites an inside joke of their own: "She thrills to Beethoven's Ode to Joy and, at times, finds the frenetic protracted finale of his Fifth Symphony hilarious, as do I" (ibid., xvi). Brison and Sesha's hermeneutic openness have allowed them to develop a deep friendship centered on shared pleasures and appreciations – much like many non-PID friendships.

Like RCMEs, the virtue of hermeneutic openness has both instrumental and noninstrumental value. Instrumentally, it affords the means to begin to communicate in meaningful ways. Its non-instrumental value has to do with its being a facet of any good relationship that requires communication to function well: in any communicative relationship, the willingness of each party (and their shared recognition of that willingness) to listen to the other make that relationship stronger. If a person refuses to perceive my communicative acts as communicative acts or if they refuse to try to interpret them correctly, whether or not that person correctly identifies the actual meaning of my communicative act, then they do not display the hermeneutic openness necessary to get our relating to one another going. A person who is not hermeneutically open shuts the door to the possibility of the other conveying something worth listening to. This can happen consciously, if a person outrightly says or thinks that PID persons cannot communicate, or implicitly, if a person merely assumes they cannot or does not challenge this assumption.

We see this happening in medical contexts like those described by Goode. The clinical identity of the children that Goode identified was the one that corresponded to the assessments practitioners made on the basis of very little interaction with each individual child. Goode discusses how, for both Bianca and Christina, it was often the case that direct-care, parental, and Goode's own testimony were overshadowed by what was taken to be "the truth" about the

children – that is to say, the diagnostic decisions and IEPs written by clinicians (Goode 1994, 58). This curtailed the ability of those who had experience recognizing and interpreting the communicative acts of Bianca and Christina to advance each child's own interests effectively. Instead, Bianca and Christina (and many like them) were perceived as lacking any kind of communicative competence whatsoever (ibid.).

When in place, hermeneutic openness can lead to willingness to interpret. Without a stance of hermeneutic openness, it would be hard to get to this second step of attempted translation. Here, agents attempt to correctly identify the intended meaning of the other's communicative acts. Of course, a person could be willing to interpret without adopting a stance of hermeneutic openness; for example, in only recognizing or accepting particular types of utterances as potential conveyors of meaning, and being willing to try to understand those and those alone, even when the meaning is opaque. (Some poetry comes to mind here – readers recognize the existence of meaning, even if its content can be difficult to derive or translate with certainty.) However, in interpersonal contexts, particularly where one person communicates in a non-standard manner, the practical correlate of hermeneutic openness is willingness to interpret.

Willingness to interpret, then, is an epistemic commitment deriving from the recognition of meaning in various communicative acts that are initially opaque to an agent. It is the practically-oriented upshot of hermeneutic openness. In many cases, it may require significant effort on the part of the observer. This will likely occur in both directions, and in PID cases, may occur in two very different manners. It will often require creativity and non-traditional means in order for its outcome to be successful.

Employing these virtues, as those who already share their lives closely with PID individuals do, will drive up success rates for RCME use. These are precisely what allow us to

come to know those who communicate atypically. What does coming to know someone with PID look like, then? Coming from inside of a relationship with a PID person, my own testimony here may fail to convince those who lack these sorts of built-in, familial relationships. However, Kittay's extended family provide several anecdotes that illustrate how coming to know a nonspeaking, intellectually disabled person looks remarkably similar to coming to know a speaker. It may take more time, hermeneutic openness, willingness to translate, and a healthy amount of creativity, but the development and recognition of RCMEs can lead to deep and meaningful relationships between PID and non-PID pairs.

### V. <u>Coming to know</u>

While I do think a PID and non-PID pair of persons can come to know one another in a meaningful sense, there are clearly dramatic differences present in certain pairings of RCME users. Ignoring this fact would not do justice to the uniqueness of the relationship and its particular challenges. In PID and non-PID pairings, we must take seriously the asymmetries that exist if we are to understand the potential RCMEs have for allowing the pair to come to share a deep and meaningful relationship. One individual does in fact rely on and employ higher-order cognitive capacities and rational inference to interpret the other. She uses natural language as their primary mode of communication. The other does not. In emphasizing the shared knowledge base that allows for RCME usage, should it not bother us that some humans will be engaging with others only through the second, less intellectualized way and never the first? That some will never have the type of relationship that natural-language based communication allows?

This worry could be directed towards the instrumental aspect of communication, where we aim to convey bits of information to one another, or, in the PID case, where we attempt to interpret non-natural language utterances or gestures with the goal of providing better care. Of course in this instrumentalized aspect of communication there will be significant asymmetry whenever one interlocutor has very different capacities or modes of communication from the other.

And yet, this worry has more ethical substance to it than the mere discrepancies mentioned above. It's not just that we have trouble interpreting one another when one person uses language to communicate and the other does not, it is that language is the primary and distinctive means we have to get to know one another. We facilitate, form, and deepen relationships using language as our primary tool. When one person in a dyadic relationship uses language to communicate with most other people and engages higher order capacities of mind to interpret others, including those who cannot use language to communicate, there is a deep dissonance in the sort of symmetry we might hope to attain in the sorts of pairs with which I am concerned. Our relationships with those with whom we cannot speak begin to appear less deep, more impoverished, both in terms of their possibilities and their substance.

At the conference held at Stony Brook University in 2008 mentioned at my outset, Peter Singer and Eva Kittay engaged in a line of questioning following his talk, "Speciesism and Moral Status."<sup>29</sup> Singer seemed to have thought that he could learn all that he needed to for the sake of comparisons between the intellectually disabled and non-human animals via testimony. Kittay's invitation implied that she disagreed. Her invitation showed that Kittay recognized that there was and is more to be learned by meeting Sesha, by interacting with Sesha, or by

<sup>29</sup> "Cognitive Disability: A Challenge to Moral Philosophy" was hosted by the Department of Philosophy at Stony Brook University on September 18-20, 2008. The proceedings eventually became an edited collection of essays (Carlson and Kittay 2010).

I originally came to know about this interaction through a conversation with Kittay. Later, I learned more through a series of papers and responses between Kittay, Singer, and Crary (Crary 2018, 2019; Kittay 2017, Singer 2017).

witnessing Kittay interact with Sesha. This morally saturated piece of information has to do with the significance of the capacity to participate in the kind of communication that builds relationships and the kind of relationship that allows for certain kinds of communication. I do not think it's a stretch to suggest that Kittay hoped Singer might witness or develop some of his own RCMEs to use to get to know Sesha and others like her. Their meeting would not have been about Singer uncovering that bit of propositional content Kittay could not tell him, but instead about what he would be *doing* if he were to meet Sesha. Meeting her, developing communication, *not* holding fixed guesses about her capabilities, and instead attempting to come to know her would have been constitutive of the real equality between them.

Brison did in fact get to know Sesha over the course of the past three decades. She writes, "Getting to know [Sesha] has taken time, as getting to know someone always does. I had to learn how to listen to her various silences, how to read her expressions and her movements, how to tell when she's not feeling well, when she's not in the mood for me to sing..." (Brison 2019, xiii). But despite what this quote implies, it is not one sided. Brison cites a host of things she and Sesha do together, such as the music examples cited above, and things Sesha has taught her. I have a friend who, in our twenties, often joked that the girl she met in the bathroom at the bar was her new best friend. But beyond these trivial encounters, having a friend always takes time. Getting to know someone always takes time.

Brison concludes a reflection on coming to know Sesha, "I'm grateful to have been given the opportunity to get to know Sesha and I want to try to give those who haven't had the opportunity or taken the time to get to know her a sense of who (I think) she is and of what it's like to be her friend. Sesha has an unusual capacity for paying attention, for being wholly present in the moment, but, in order to notice this, one has to pay attention to her, rather than ignoring

her or making assumptions about her" (ibid., xii). The suggestion here is that many people do not take the time to get to know individuals with PID because they assume that there is not much to know. This is reflected in Singer's refusal to come meet Sesha and in the fact that very few people lacking immediate interpersonal bonds with PID persons take the time to get to know them. Those with PID are not typically perceived as communicators. Communication is necessary to coming to know someone, so perhaps the thought that those with PID are in a certain sense unknowable connects to this assumption about their communicative capacities. However, my contention, corroborated by the various testimonies cited throughout this chapter, is that RCMEs can function similarly to other commonly recognized forms of communication. As such, we can use RCMEs to come to know those who cannot communicate using natural language.

Is knowing someone with PID the same as knowing someone without it? Of course not. But knowing one person is never like knowing another. Further, the fact that communicative possibilities may be more limited does not impoverish the sorts of relationships that are possible. Infant-caretaker relationships are very different from child-caretaker relationships, because the caretaker can speak to the child and know different parts of them than they can about the infant. But insofar as the function of a child-rearing relationship is the facilitation of love, care, growth (on both parts), and the richening of lives, the infant relationship does not strike me as in any sense lesser than the one had with the older child.

Likewise, knowing someone with PID may look very different than knowing someone without it. I cannot discuss works of philosophy with my brother. (Then again, I cannot discuss them with my very stubborn husband, either.) But there are many unique and rich things we can do together, which I value just as much as I value conversations with friends. I know him in a

distinct way but I know my husband, my best friend, and my mother in distinct ways too. The things that I do not know about him analogize to things we never know about the inner workings of others. By this I mean that there is a sense in which we never fully know other people, we never truly comprehend how their minds work. I also mean the less deep thing, that there are plenty of things I do not know about my brother due to our communicative asymmetries (for instance his favorite color), but likewise there are many friends about whom I lack this inconsequential knowledge. I do know his character: his silliness, his gentleness with my daughter, his anger and frustration, his gourmet tastes, his love of the outdoors, and so on. These strike me as the things that matter in knowing a person. And so, I do not take it to be the case that he is unknowable in a way that impoverishes him or our relationship. As with any valued friend, our relationship takes time, openness, creativity, and generosity.

One significant difference between my relationship with my brother and my relationships with non-intellectually disabled friends has to do with an example I mentioned above, childrearing. The fact that child-caregiver relationships spring to mind when thinking about the relationships between PID and non-PID persons is no accident. The type of dependence one person has on the other, the expectations each brings to the relationship, and the cognitive and moral faculties employed in assessing and understanding the other, all differ quite strikingly. Given that my primary focus has been the possibility of coming to know a person with PID, the question should then be whether or not these things affect our ability to come to know one another, or, more precisely, whether they affect our ability to communicate via RCMEs and to come to know one another through their use.

Given all I have argued thus far, it seems safe to conclude that the cognitive differences between a non-PID and PID person and all that they imply in terms of expectations, dependence,

interpreting one another, and so on, make a difference in terms of the scope of types of RCMEs available and the ease at which they can develop and be deployed. On the one hand, RCMEs like verbal inside jokes will not be available, but many other non-natural language RCMEs will be available between pairs. On the other, developing RCMEs and getting to know one another may take considerably more time between PID and non-PID pairs of persons than it would between two non-PID ones. When Dunbar showed primate grooming to be the evolutionary ancestor of language that serves many similar functions to language, he acknowledged the superior efficiency of language in accomplishing those ends. Likewise, RCMEs between pairs where language is not an option will require substantially more time and effort than it will in pairs where language can be employed.

Still, this does not mean that RCMEs cannot serve the functions between non-language speaking pairs that they do with language-users. More efficient does not always mean better, and in this case, does not necessarily imply deeper. Language can aid in allowing us to get to know one another a lot faster than we would without it, but this does not imply that the depth or value of the relationships emerging between pairs of language-users surpasses that of pairs without language at their disposal.

# Chapter III: Towards basic equality of human moral standing

In fact, much of philosophy depends on being able to make such claims about distinctive human capacities, and many claims of political ideals of justice, autonomy, and equality are grounded on a set of competences or potentials, many of which my daughter most likely does not possess. As a critique of philosophy based on my experience as a mother of a cognitively disabled daughter is a critique that touches on foundational concerns, I could expect that this road would be full of landmines, some of which could be anticipated. Others would be discovered only after I had already stepped on them. Unsurprisingly, I have stepped on several, and it has at times prompted me to ask the question: Should I continue? What is to be gained? (Kittay 2009, 607)

### **Introduction**

In Chapter 1, I argued that we should think about profound intellectual disability (PID) in terms of communicative difficulties as opposed to cognitive incapacities. I was motivated by the idea that doing so would yield preferable practical outcomes and that focusing on communication left open any conclusions about the moral standing of PID persons when moral standing requires the possession of particular attributes of mind. I contrasted my view with Peter Singer's account of PID and moral status. Singer presents a philosophical package where (1) the question of what we owe one another is a matter of equality or inequality of particular capacities assessed at an individual level; (2) those with PID are a kind of being who have lesser cognitive capacities; and (3), therefore those with PID are not morally equal to non-PID human beings in a way that matters to how we treat PID persons. Singer takes for granted (2), assuming that PID *just is* a lack of those attributes that morally distinguish non-intellectually disabled human beings from other forms of life. I pointed out that, given all that we do not know about the inner lives of those with PID, perhaps it is a mistake to begin with and hold evidentially fixed hypotheses about the capabilities of different types of people. Further, even if (2) were correct, we would not necessarily arrive at (3). The purpose of this chapter will be to illustrate an alternative view of the grounds for moral status in which (1) is false, and therefore, (3) does not follow.

What of (2) and the actual capacities of mind of those with PID? We do, after all, have good reason to believe that there are significant cognitive impairments present. Many PIDs are caused by traumas that occurred during pregnancy or birth; psychological and neuroscientific evidence points to distinct physical differences in brain structure and function. But, it is not as though my view suggests that the vast array of empirical studies regarding the brains of PID human beings have been suddenly called into question. If we had definitive science proving that those with PID lack attributes like rationality or whatever capacities of mind we think differentiate human beings from other living creatures, I would feel the same way about the upshots of my view. My practically-oriented conception of PID is motivated by the thought that the basis of our interactions ought to be nothing other than the hope of communicating and becoming closer to one another so that we can understand each other better and so that we can understand the PID persons with whom we share our lives. My communicative conception of PID differs in not taking cognitive capacity as its basis, because it is all about trying to find out what people are like as opposed to taking presumed capacities for granted. From its beginning, as a matter of principle, my conception refuses to act as settled the question of what different types of people are like or what they are capable of.

Plus, if we were, like Singer, to assume (2) and arrive at (3), we have reason to think that (3) would be at least somewhat self-fulfilling, because human cognitive capacities are developed socially (for a philosophical account of the import of this sentiment, see Dover, "The Conversational Self," forthcoming). Think about data regarding female students: if their teachers assume they are less talented, they won't get the same attention, and the language used to describe and interact with them will lead to negative educational outcomes (see, for example, Leslie 2015). Likewise with the clinical care of patients with neurodegenerative diseases like

Alzheimer's disease: one of the first courses of action to prevent the hastening of a person's decline is to increase their social stimulation. Cognitive capacities are at least in part the product of how other people interact with a person.

For these reasons, my view about the characterization of PID centralizes the challenges we face in doing the thing we should be doing, which is trying to get closer and attempting to understand each other better by interacting together. My view is distinguished by the hope to understand better what Singer's takes as known. My view is all about doing the *opposite* of assuming anything about others, and instead working to try to get to know one another better. That is why communication became key.

In Chapter 2, I conceptualized a form of communication I call relationship-constituted and constituting meaningful expressions (RCMEs). I argued that despite very different cognitive capacities and very different forms of communication, pairs of PID and non-PID intimates find ways to communicate effectively using heterogeneous forms of communication unique to their particular relationships. In the case of PID and non-PID pairs, RCME use is of course asymmetrical in many ways. One person uses language and higher-order cognitive capacities and the other likely does not. Yet, I argued, there is a sense in which both persons are doing the same thing. In my hunt for symmetry, I suggested that there was a surprising way in which PID and non-PID persons are drawing upon the same data set in order to work towards a shared end when they use RCMEs to communicate with one another. Their doing so presupposed the possibility of the other doing the same. They draw upon a shared history, itself valuable as the fabric of their relationship, in order to communicate effectively.

In this chapter I will suggest that it is our shared capacities for shared activities (most centrally, the capacity to communicate in the ways necessary to establish and deepen

relationships) that ground our moral status. I will defend a view of basic equality of moral standing in which equality is not a matter of possessing particular attributes assessed at an individual level, but rather of relational capacities to come to know one another that presuppose the very same capacity in others. Equality will thus become a matter of sharing a nature where the nature of each person presupposes the like nature of the other. The shared nature is simply the nature of one possessing the ability to communicate in order to form relationships. RCMEs are helpful tools that allow us to see how this nature is shared by all human beings, not merely those with perceivable higher-order capacities of mind.

Beyond this, my view will be unique in refusing to see any given episode of communication as a means to the distinguishable outcome of a valuable relationship; rather, I will blur the means/ends distinction by insisting the relationship is what we use to produce the outcome of the relationship. Employing RCMEs – which are both relationship-constituted and relationship-constituting – allows individuals to draw upon the same communicative toolbox to engage in the shared activity, despite dramatic asymmetries in communicative modes or intellectual capacities.

I will arrive at my inclusive view of equality of human moral standing by assessing other views of human moral status: first, those that exclude the intellectually disabeld, and then, two that intend to capture even those with PID. In working towards my own picture, I will assess their shortcomings. I will present my positive view in the second half of this chapter. Finally, I will conclude with some thoughts on the moral status of non-human animals.

# I. <u>Human equality of moral standing</u>

Now, I turn to what Chapters 1 and 2 might imply for the way we think about human equality of moral standing, particularly as it affects the moral status of those with severe- to

profound intellectual disabilities. I will discuss moral status in two ways: human's distinctive standing and basic equality of moral standing. By human distinctiveness, I mean the idea that human beings have a unique, higher moral standing as compared to other living beings. By basic equality of moral standing, I mean something along the lines that Jeremy Waldron does: that humans are one another's equals with no morally significant divisions in their standing (Waldron, 2008). My concerns in what follows are twofold: first, that typical philosophical accounts of human moral status attempting to defend both basic equality of moral status and human distinctive moral standing are extensionally inadequate; and second, that these accounts tend to be grounded by some sort of individually possessed status-conferring attribute. In other words, the first problem is that accounts of human moral status that attempt to defend basic equality of moral standing and human distinctiveness tend to run into one of two problems. They either exclude certain classes of human beings (with the intellectually disabled often being the limit case), thus failing to defend basic equality of moral standing, or they inadvertently include certain non-human animals, thus failing to defend humans' distinctive moral standing. The second issue has to do with attempting to ground moral status in capacities assessed at an individual level. I think this approach is wrongheaded: insofar as we seek to ground moral status for *all* human lives, our focus should not be on what sets us apart, but rather on what we share and what we can do together.

I will not survey the vast history of accounts of moral status in too much detail. But it is worth rehearsing a few remarks on the typical approaches taken. Those concerned with explaining human moral standing have historically attempted to seek some explanatory or grounding feature that distinguishes and elevates humans above other living (and non-living)

beings.<sup>30</sup> Examples of status-conferring attributes are things like rationality, self-consciousness, or linguistic capacities. The grounds for moral standing might rely on some other descriptive similarity between human beings, or it might have to do with our being created in God's image. Rawls suggests that basic equality is a range property based on our sense of justice; Kant took it to be based on moral capacities; many others have taken it to be grounded in our higher order capacities of mind. Variation of course occurs across these properties, yet they are taken to exist across human life to at least some degree.

Of course, these status-conferring attributes all have notable exclusions. Note that thinkers like Rawls' and Kant's grounds for basic equality of moral standing simultaneously serve to ground human distinctiveness. Yet clearly there are human beings without a sense of justice – what of these groups? Exclusions sometimes occur subtly or accidentally, or they can be more blatant. Aristotle and his followers quite clearly do this, as the Aristotelian focus on human distinctiveness is meant to leave certain groups by the wayside. Of course, Aristotle's empirical data was quite off in thinking that only property-holding, non-enslaved males had full rational capacities. But even with women and propertyless males included, the account will not include all human beings. And, depending on how we define something like rationality, some non-human animals may be included, too.

Beyond their extensional shortcomings, the status-conferring attributes that philosophers have typically landed upon are capacities that are assessed at an individual level, independently and in isolation of other persons. These are the sorts of things one either has or does not, though occasionally status-conferring attributes will be assessed in a more gradient-like manner. So long

<sup>&</sup>lt;sup>30</sup> I will focus on non-utilitarian grounds for moral standing – the sorts of status-conferring attributes that are prior to having one's interests factored into an overall calculus of utility.

as a person has some discernible presentation of the status-conferring attribute, they have moral standing akin to others who possess it. Possession of the attribute gives us some clue regarding treatment – those with equal standing deserve equal consideration. The inference's problematic conclusion is that those who lack the necessary attributes lack the same moral status and therefore do not require the same moral solicitude.

Then, the trouble with the theoretical ideal of equality of moral standing is that it does not by itself serve to ground human moral standing, nor does it by itself explain the reason for any equality in that standing. If we do wind up landing on a status-conferring attribute that is extensionally adequate, the fact (or at least the regulative ideal) that humans are in some basic sense one anothers' equals does not tell us why humans have moral status, or what that status is. Think of it this way: I can easily tell you that every one-dollar bill has the same value, but this tells you little about what one dollar is worth, why it has that value, or what to do with it.

Not all philosophical accounts of basic equality have the same objectives. Some philosophers explicitly attempt to deny distinctive human moral standing, albeit at the expense of basic human moral standing. As cited in Chapter 1, Peter Singer's explanation of moral standing proposes that the status-conferring attribute with the most moral relevance is sentience (Singer, 1989). While this denies any unique human moral status, it extends the grounds for a basic moral status to all with the capacity to suffer. However, Singer contends that there are other morallyrelevant status-conferring attributes, and in particular, rationality grants a higher standing to those who possess it. His argument results in a view of graduated moral standing in which certain non-human animals have status equal to certain human beings, and certain human beings have lower status than other human beings. The intellectually disabled hence have a standing more akin to higher-order mammals.

Eva Kittay responds to Singer's willingness to exclude the intellectually disabled and tries to maintain our grounds for both basic human equality of moral standing and of human distinctiveness by seeking an alternative status-conferring attribute. Her feature of choice is being some mother's child (Kittay 1999). I will return to her ethics of care in a moment to illustrate how, though relational, her proposed grounds for moral standing remain one-directional in a way we might fare better to avoid. A later revision of her account attempts to resolve this one-directionality but again locates the grounds for moral status in what I take to be the incorrect place: she argues that we are all only temporarily-abled and that we should thus see care as a bi-directional and all-encompassing practice (Kittay 2011). But for many pairs, there is no potential for any symmetry in relations of care. While I take Kittay's view to have made significant progress, I will argue that the symmetry that grounds our equality of moral standing is to be located elsewhere: in shared capacities for shared activities that presuppose the ability of the other to do the same.

I will move forward assuming that basic human equality is a philosophical ideal worth defending. I also take it to be a normative ideal because of what it would prescribe for what we owe one another. As such, my focus will be on finding an explanation for basic equality of moral standing across human life. I have less concern with defending human exceptionalism, and would be glad to accept that my account winds up including some forms of non-human animal life. My hunch is that claims to basic equality of moral standing must focus on seeking grounds that do not bear the brunt of attempting to simultaneously defend our distinctive moral standing. Before putting forward my positive account, I will explore the limitations of two arguments that explicitly work to include severely to profoundly intellectually disabled persons within their

account of equality of basic human moral standing: Kittay's relational account of moral standing and Jaworska and Tannenbaum's account of person-rearing capacities.

### II. <u>Alternative relational accounts: Kittay, Jaworska and Tannenbaum</u>

### II.i Eva Kittay and being some mother's child

I want to start with my worry about the sorts of capacities that matter in assessing moral standing. Most accounts of basic and distinctive moral standing rest upon a similar assumption: that the explanatory criterion for moral standing will be a status-conferring attribute or some kind. The possession of this capacity is assessed at an individual level, in isolation of others. Though individuals may have more or less of that capacity, and though they may be better or worse at deploying it, its possession grounds the moral standing of any individual with at least some evidence of it. The impetus to ground moral status in an individual's own capacities can be contrasted with more relational accounts, particularly those popular in feminist ethics.

Let's return to Eva Kittay's account of moral standing, in which it matters whether an individual is a human mother's child. In *Love's Labor*, Kittay reflects upon how claims that "'After all, I am some mother's child,' or 'he, too, is some mother's child' can be heard as 'we are all – *equally* – some mother's child'" (Kittay 1999, 24). Childhood highlights dependency on the parent and Kittay's claims rest upon the centrality of dependency and vulnerability. A virtue of her view is that these characteristics affect all of us at different stages of our lives, as opposed to higher order attributes of mind, which some humans do not possess (ibid., 29). Her proposals can help us to see how a fully relational alternative – in this case, one centered on dependency and care work – might capture a broader extension of human life (Kittay 1999, 2009). Moral significance is located in the relationship of dependency as opposed to the capacities of either individual involved.

Kittay's relationship with her own intellectually disabled daughter, Sesha, motivates her arguments. Her career as a philosopher was shaken by the birth of such a profoundly disabled child. Shifting gears from philosophy of language to ethics, she realized how much moral theory depended on the possession of uniquely human attributes of mind her daughter lacked.<sup>31</sup> This reckoning was the starting point for her work in ethics of care. When she discusses as foundational to moral theory the notion of being some mother's child, she grants that the nature of the care directed toward intellectually disabled children may differ in mode or intensity or expected outcome from the nature of care directed toward a non-disabled child. Nonetheless, she argues, the obligations a parent has for *any* child of theirs include socializing others to see that child's value in the way that they do. A family does not exist in a vacuum: parents desire for their perception of their child's worth to be affirmed by others (Kittay 2009, 623; see also Kittay 2019, Chapter 3). Kittay expresses the special challenge for the parents of PID children, particularly those enmeshed in a career where one's colleague's core assumptions routinely degrade one's child:

When Sara Ruddick describes the practice of mothering, a central feature is socializing the child for acceptance into society. The mother with a disabled child hears this requirement somewhat differently from most (Ruddick 1989). For her, socialization for acceptance means that you have both to help the child make her way in the world given her disabilities and to help shape a world that will accept her. My daughter, Sesha, will never walk the halls of academe, but when what happens within these halls has the potential to affect her, then I as an academic have an obligation to socialize academe to accept my daughter. Such "care" may seem to be far from the daily care that her fully dependent body requires, and it may appear to be far-fetched to call this "care," but it is part and parcel of that labor of love that we do as parents, especially parents of disabled children—more still in the case of those who are so disabled that they cannot speak for themselves, a defining condition for those who are severely intellectually disabled. (Kittay 2009, 611)

<sup>&</sup>lt;sup>31</sup> This sentiment is recounted in the epigraph of this chapter.

To challenge the assumptions of typical accounts of the grounds for moral standing, Kittay advances the proposition that the personal-is-political-is-philosophical and that hence, her experiences as the mother of a PID person give her both epistemic priority and moral knowledge to advance an improved account that would be extensionally adequate (ibid.).

Being a human mother's child is a property that necessarily involves more than one individual to derive its moral significance. Although it rests on a biological fact and may be subject to concerns with essentialism, Kittay's reference to being a mother's child means to capture the loving *relationship* between a caregiver and her child, not their mere species-membership. It is this love and care that grants moral significance to the subject of the love and care (Kittay 1999, 2009, 2011, 2019). It is dependency, a facet of all human lives at different points in time, that makes the caregiving relationship unique. Plus, barring technological advances, being some mother's child successfully captures all human beings, and it requires no further status-conferring attribute as its foundation: the love central to parenting morally saturates the grounds for moral standing.

However, receiving one's moral status due the love and care typically conferred by a primary caregiver is subject to two main criticisms: relativism and asymmetry. First, it looks like it might relativize moral status. The grounds for moral standing depend on the care one person has for another, making it seem as though the moral standing of the latter is dependent on the presence of that relationship. Lacking that caregiving relationship, a person may lack full moral standing. There is a way of reading Kittay that makes this claim appear all the more problematic. Topics like transpregnancy, surrogacy, adoption, or male parents make the idea of being some mother's child appear to naturalize the nuclear family to the exclusion of other types of families. It may also seem to romanticize the mother-child relationship in a way that does not reflect the

lived experiences of many children. However, I do not take Kittay's claims to be so literal. Her nod to the old adage instead means to capture facts about care and facts about all children deserving the same sort of moral attention a mother ideally devotes to her child. But this care can come from others, and in the unfortunate cases where children do not receive that care, the fact of their needing or deserving it in better circumstances captures their moral standing, too. Dependency is meant to capture the scope of those included within the fold of full moral standing. All people are dependent at one point or another. This fact renders a person deserving of moral solicitude.

However, the sense in which all people are dependent reminds us of the fact that most people are at some point *independent*. Reflecting the value of independence, a large faction of disability rights literature urges giving people the tools they need to become more independent. Disability advocates may then take issue with Kittay's centralization of dependency. In a later paper, Kittay contends with this criticism, suggesting that the contrast between dependency and independence (and disability and "temporary ability") amount to a red herring:

Instead people with disabilities have wanted to insist on their right to live independent lives and to be granted the same justice that is bestowed on people without disabilities, that is, the "temporarily abled." The need for care, or as many would rather say "assistance," is viewed not as a sign of dependence but as a sort of prosthesis that permits one to be independent. Judy Heumann, one of the founders of the Independent Living Movement, wrote influentially: "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body" (cited in Stoddard 1978, 2)...

I believe there is much that is problematic in an approach that extols independence as the route to a dignified life and sees dependence as a denigration of the person. I worry that the emphasis on independence extols an idealization that is a mere fiction, not only for people with disability, but for all of us. The emphasis on choice leaves out many people with disabilities for whom making choices is problematic as their cognitive function may be seriously impaired. And the denigration of care and dependency tends toward an attitude that makes the work and value of the carers invisible, thus creating one oppression in the effort to alleviate another. Instead I want to suggest that an ethics that puts the autonomous individual at the forefront, that eclipses the importance of our dependence on one another, and that makes reciprocal exchanges between equals, rather than the attention to other's needs, the model of ethical interaction is not one to be preferred in the construction of an ethics of inclusion—at least not without the correction of an ethic of care. (Kittay 2011, 50-1).

By focusing on the (perhaps fictional) ideal of the independent, autonomous individual, we lose sight of alternative models of interaction that might be more inclusive – kinder. Moral status is not, for Kittay, relativized to the presence of a relationship, or the constancy of dependency, or to one's abilities. It is a product of the facts of human lives: that we are all dependent at certain times, and that we are all only temporarily-abled, and that we all must rely on one another to get by in life. Kittay thinks that ethics should center on meeting needs that are a product of that dependence, as opposed to reciprocal interactions between equals.

This quote points to another issue. The second problem with Kittay's account has to do with the one-directionality of the caregiving relationship and the effort to locate equality in a relationship that is, in essence – and by her own admission, inequal. Kittay notes this inequality of power, arguing that an inequality of power is distinct from a relationship of domination – the former being morally unproblematic and common, the latter more fraught (Kittay 1999, 34). She thinks that a system attuned to creating the conditions for better dependency work will seek to empower care workers, so that paternalism and domination occur less frequently (ibid., 37). However, I am not sure that this assuages my worry. We are, after all, seeking the grounds for equality of basic moral standing. Locating this equality in an inherently unequal relationship curtails the possibility of uncovering capacities that are equally evidenced in all parties to a relationship. Kittay seems to overlook this potential locus of the grounds for moral status.

While moral standing is not grounded in capacities that are ultimately the individual's own, it is instead relocated to a caretaking relationship. The fact that a person matters to another in the way unique to how a child matters to their parent, and the fact that we are all at some point dependent in the way a child is to their parent, grants our moral status. Aspects of this picture are quite attractive, as it captures a moral fact – loving attention and care – that exists between two or more persons. No further fact is needed to explain why this sort of relationship is morally significant. And, because it is relational, we are not left wondering about the move from the possession of some sort of individualized status-conferring attribute, this being a descriptive fact, to the moral significance of that status-conferring attribute.

But Kittay's picture, in its emphasis on the caregiver's valuing of their charge, overemphasizes one side of a two-sided relationship. She seems to think that ethical theories based upon "reciprocal exchanges between equals" must situate moral status in the possession of individually-assessed capacities. However, there is room for a relational account of moral standing that is at the same time based upon these "reciprocal exchanges between equals" as opposed to asymmetric relationships of dependence and care. But before I propose such an account, I turn to an attempt to extend a capacity of mind-based account of moral status to the intellectually disabled. This account is partially relational, and partially individualized. But it follows the same order of explanation as the Singerian account of moral standing and thus lacks the ideal of symmetric capacities I seek.

# II.ii Jaworska and Tannenbaum on sophisticated cognitive activities

The second account I'll look at begins with the expressed purpose of including those with intellectual disability within the fold of full human moral status, while still situating the grounds for moral standing within a capacity that is possessed at the level of the individual. Agnieszka

Jaworska and Julie Tannenbaum attempt to broaden sophisticated cognitive capacity accounts (SCC accounts), a form of an individualized status-conferring attribute account (Jaworska and Tannenbaum 2014). Jaworska and Tannenbaum also remain committed to distinctive human moral standing, working to defend the intuition that a human's moral standing is greater than that of a dog's. They argue that moral status can be accounted for by the human ability to learn by practice in the context of a person-rearing relationship (ibid., 253). This seems to head in the right direction – person-rearing is, after all, in some sense relational as opposed to individualized. However, Jaworska and Tannenbaum are nonetheless guided by the goal of illustrating that it is an agent's *own* capacities that ground her moral standing.

Jaworska and Tannenbaum assume that SCCs have the sort of moral weight necessary to ground moral standing. They argue that the elevated status of a human being has to do with her ability to participate, even just as a rearee, in what they call a *person-rearing relationship*. Person-rearing relationships involve being raised to become a self-standing person and ostensibly explain the difference in moral standing between, for example, a human infant and a dog, despite their otherwise similar cognitive capacities (ibid., 244). Rearers can be persons other than biological parents, but the relationship between a nine-month old infant and her parent is their paradigm case. The authors argue that when infants engage in certain activities in person-rearing relationships, this transforms the nature and moral relevance of the relationship in a way that explains their special moral status.

In order to explain the significance of person-rearing relationships, the authors show how the end of an action affects its nature and value. In some cases, an end can transform an activity into the very realization of that end. Jaworska and Tannenbaum cite writing a dissertation, where the end of writing the dissertation characterized by the generic activity of writing sentences can be transformed into writing sentences for the dissertation, thus bringing about the end (ibid., 246). Activities and ends are connected in ways in which the nature of the connection matters to our moral evaluation of the nature of the action.

This leads to the suggestion that the ability to learn by practice is the capacity analogue to an action bringing about a completed end (ibid., 249-252). If one performs an activity, then one has the capacity to do that activity, regardless of whether or not the intended end of the activity is brought about. If I have the end of becoming a great philosopher, and learn and study to become a great philosopher, all while failing to become a great philosopher, I will have incompletely realized my end. Nonetheless, I can be viewed as possessing the capacity to become a great philosopher despite that capacity (and my end) being incompletely realized. And my actions directed toward my end will have the value conferred by that end, regardless of whether I actually become a philosophical great.

Incompletely realized capacities are central to Jaworska and Tannenbaum's account of person-rearing relationships. Their key moral insight is the relevance of the ability to learn by practice in a person-rearing relationship, where the rearer's end is their rearee eventually becoming a self-standing person. When a rearer engages in activities directed towards the end of developing the rearee into a flourishing human adult, their actions take on a different sort of moral weight. Many of the activities the rearer engages in involve extensive interaction with the rearee, who is an active participant, and who learns by example over the course of their development. The moral weight of the interactions grounds the moral significance of the rearer's actions. This transforms the actions performed for the sake of the end of developing a self-standing person into the end itself.

If the end of developing the rearee into a self-standing person is not brought about, the moral significance of the actions towards the end and of the end itself do not change. The end is merely incompletely realized (ibid., 253-4). Even if a rearee lacks particular SCC's central to becoming a self-standing person, the nature of the interactions between the rearer and the rearee do not lose their moral significance, either. They are, again, merely incomplete realizations of self-standing person activities (ibid., 254). Just as self-standing persons have particular, distinctive moral status, rearees enjoy special status because their (incomplete) capacities have a special value (ibid., 257). Non-human animals are not granted this same status, by Jaworska and Tannenbaum's light, because "few animal owners (and no animal parents) intend to turn the animal into a self-standing person, the moral weight of the activities involved and of the end itself are lost.

The final component of Jaworska and Tannenbaum's account is the idea that, in a case where the end-aim of developing a rearee into a self-standing person is impossible (as in the case of certain severe genetic disabilities) the rearer may reasonably hold an alternative "end-standard" (ibid., 260). An end-standard is a "next best option" to the ideal of the end-aim, which in person-rearing relationships is the eventual self-standing personhood of the rearee. An end-standard can also serve as a guide to selecting appropriate sub-ends and as a basis for judgments about which sub-ends or goals are as close to the end-standard as possible, given that the "current situation [of the impossibility of eventual self-standing personhood] is unfortunate" (ibid.). In other words, in cases where the rearee cannot develop into a self-standing person due for example to severe- to profound intellectual disability, the rearer holds onto the end as a

standard guiding their actions in ways that as closely as possible resemble cases where it is an actualizable end-aim.

Here is the problem, as I see it. In this account, it is not just that rearer and intellectually disabled rearee are not relating for the sake of a relationship that would ideally be directed toward the development of self-standing personhood. Jaworska and Tannenbaum seem to be thinking that for value to be credible in a case where the rearer knows this, the standard that is conferring value on the relationship activity is the imported second-best end. The ideal remains self-standing personhood, but if the rearer is aware that will not happen they should still act in ways that resemble what they would do to rear for self-standing personhood. This is the business with the "next best option" meant to serve as guidance to the unachievable end-standard. This is to my eye an implausible account: the value of rearing should be realizable through the relationship itself and not be wholly contingent upon having an end-standard that guides rearers to select sub-standard (though as close to ideal as possible) ends for a rearee incapable of eventual self-standing personhood. When it comes to PID persons, the account manifestly does not take moral standing to be the product of a person having the *same* capacities for relationship forming and deepening as other people with whom they could share relationships.

To summarize: Jaworska and Tannenbaum's goals are to preserve both basic and distinctive human moral standing and to show that it is the individual's own capacities that explain her moral standing, all while being sure to capture the severely- to profoundly intellectually disabled within their account. This is explained by four main claims: that the nature of the ends of activities explain their value (at least in part), that an incompletely realized capacity has the same value as a completely realized one, and that an incompletely realized capacity is the capacity to engage in an incompletely realized activity, and that in certain cases,

the typical end-aim of rearing (self-standing personhood) becomes instead a guiding, though unattainable, standard that confers value on this next-best sort of rearing relationship (ibid., 268). If we agree with the idea that the value of a capacity has to do with what that capacity is for, then we see that even a severely intellectually disabled individual has the incompletely realized capacity to engage in the incompletely realized activity of participating in person-rearing relationships. Further, these (incomplete) capacities are her own. So, by Jaworska and Tannenbaum's account, even the profoundly intellectually disabled have the SCCs necessary to ground their full, uniquely human moral standing.

So, why not locate moral status in something foundational and early in the course of a person's life, like the capacity to participate in a person-rearing relationship? Jaworska and Tannenbaum's proposed grounds for moral standing are, in a way, capacities for a relationship. For them, moral equality is relocated from self-standing personhood or capacity of mind to participation in a rearing relationship. Jaworska and Tannenbaum's account is a good deal more relational than many accounts of moral standing, but in the end the authors are nervous about the relational character of their view and argue that the capacities for person-rearing are ultimately located in the individual. Although moral equality is fully actuated within the rearing relationship and within the self-contained, morally complete deeds of attempted rearing, they balk at presenting the grounds for moral status as a capacity that is purely relational. The final paragraph of their article addresses this challenge, briefly. They write:

The capacity we appeal to is relational in the sense that its exercise requires active participation of another being. Many authors assume relational features cannot ground moral status, and the popular relational views currently on offer do face serious criticisms. For instance, treating a morally relevant relationship itself (A's bond with B) as a source of A's moral status (for B) has been criticized for depriving moral status of impartiality. And treating membership in a category whose typical members possess morally relevant features as a source of moral status has been criticized for ultimately relying on morally irrelevant features. Ours is, in one sense,

a more deeply relational account than the popular alternatives, since the capacity we emphasize requires for its exercise not only the existence, but (a specific kind of) active participation of another being. And yet, this deep relationality is really a central strength of our account because, as we show, the possible participation of others (rearers) can alter what the individual herself (the rearee) can do. Thus, when a relational feature is a capacity for relational activity, this can be a deep trait of the individual herself, allowing us to retain the idea that the resultant moral status is impartial (must be respected by all moral agents). Moreover, this altered capacity itself is correctly considered morally relevant to higher moral status since it is an incomplete realization of the very capacity that explains why self-standing persons have higher moral status than dogs. Thus our proposal meets key criteria for a successful account of moral status.

The authors worry that a purely relational account of moral status may wind up making moral standing non-objective. I imagine they have something like Kittay's account in mind. But, on Jaworska and Tannenbaum's terms, if self-standing personhood can be incompletely realized, why can't relationships? A fully relational view need not be based on actualized relationships, but perhaps might seek its grounds in potential ones.

Furthermore, Jaworska and Tannenbaum believe that an extensionally coherent account of human moral standing must preserve both human's distinctive standing and basic equality of moral status. But it's hard to see why a rearee *must* be human. We all know some pet parents who imagine their charges to be analogues to human children. Deluded as they may be, it seems as though these very coddled pets may worm their way into Jaworska and Tannenbaum's category of full moral standing. As I briefly discussed above with regards to non-human animals, it's hard to avoid bringing some non-human animals into the picture when the basis is a statusconferring attribute, even person-rearing capacities; unless, of course, we are to give a purely essentialist account, which would leave us asking why exactly being biologically human matters. Perhaps, as Singer has suggested, distinctive human moral status is speciesist and rests on prejudice as opposed to some morally-salient fact. However, as argued in Chapter I, Singer's account fails to preserve basic equality of human moral standing, a conclusion I find unacceptable.

Jaworska and Tannenbaum's account ultimately faces a similar issue to Kittay's. At the relational-level, it is plagued by a deep-rooted asymmetry between the rearer and the rearee. Even if Jaworska and Tannenbaum were to go fully relational, overcoming their worry of impartiality, the sheer passivity of the relationships described would make it hard to locate equality within the relationship, after all. To my eye, their view is an unstable stopping point between a fully individualized, capacity-of-mind type view and a relational view of the grounds for moral status. The means by which Jaworska and Tannenbaum relocate equality of moral standing into a rearing relationship leads to trouble identifying precisely what the equality is, because they fail to locate any type of symmetry or equality in capacities to participate in the relationship on both sides. This leads to a rocky compromise between a relational view in which individuals are ultimately doing the same thing, that thing serving as the grounds for their equality, and the typical philosophical account in which the capacities that matter are wholly located in the capacities of the individual. While Jaworska and Tannenbaum are able to avoid something like the relativism or contingency of some relational views, like Kittay, they fall short of a bi-directional form of equality of moral status where the relational qualities that matter are ones that presuppose the existence of the same in others. It turns out that their account follows the typical philosophical order of explanation: the fact of moral equality derives, ultimately, from the capacities of the individual, and our assessment of which individuals are our equals as determined by their possession of that capacity determines our treatment of one another.

### III. Shared capacities to establish and deepen relationships

I will now turn to my positive view. My thesis is that the grounds for basic human equality of moral standing is relational and bi-directional. Present in my account of relationshipconstituted and constituting meaningful expressions, my insistence on basic equality of moral standing for all human lives, and my characterization of PID are the seeds for an egalitarian account in which the possession or attribution of individually-assessed capacities do not determine moral status and treatment. Rather, it is the shared potential to come to know others, a capacity that presupposes its existence in those others, that determines moral standing. Specifically, I will argue that the grounds for moral status is our shared capacity for communication that is used as a means to establish and deepen relationships.

The initial reason for my favoring of this kind of relational capacity is that it is already firmly embedded in an ethical realm. We saw this with Kittay's account of dependency and care. Unlike individualized status-conferring attributes like the capacity to reason, which are descriptive facts about an individual, relational capacities inherently involve the interactions between people and are thus often already morally embedded. Like Jaworska and Tannenbaum, I take it to be the case that the end of an action affects its nature and value, and that ends can transform activities into the very realization of the end. This seems to be true of establishing and deepening relationships via communication. However, the sense in which communication is employed to develop relationships, and the manner in which the context or past of the relationship affects the type of communication available, transcends a means-ends distinction. Instead of having communication serve purely as a means to the end of building or deepening a relationship, we have a feedback loop where the fabric of the relationship is the fodder used to build the relationship, and where communication (as a facet of the relationship) employs the context of the relationship in developing the relationship.

With relationship-constituted and constituting mutual expressions (RCMEs), the concept I proposed in Chapter II, we employ a form of communication that essentially uses the relationship to deepen the relationship. I illustrated the ubiquity of RCMEs in order to show how their use ranges from typical natural language cases, like inside jokes, to non-linguistic forms of communication that occur in pairs such as PID and non-PID human beings. I suggested their use may also occur in non-human animal life. What matters is the sense in which the RCME emerges from the context of a particular relationship, the way in which its use deepens the relationship, and the manner in which the moral significance of RCMEs has to do with their role in developing and deepening relationships. Even when one person has a significant intellectual disability and thus cannot use speech and may not employ higher-order capacities of mind to interact with the other, there is an important symmetry in RCME usage: each party trusts in the other to understand their meaning, and each relies on the shared history of their relationship to bring that understanding about. I suggest here that the capacity to develop and deploy RCMEs as a means to form and deepen relationships should play a role in understanding basic equality of moral standing.

One way of thinking through how this might happen emerges in A. J. Julius' thoughts on recognition (Julius, 2016). Julius contrasts his view of mutual recognition with a more intellectualized understanding of how recognition might occur. In the alternative account, equality is a matter of shared moral status, and shared moral status implies certain answers to the question of what we owe one another. By many of the accounts I've assessed or gestured to, moral status finds its grounds in capacities, located in the individual, which are for one reason or another deemed to be morally relevant to moral standing. If an individual possesses the relevant

status-conferring attribute(s), she has moral status equal to others who also possess that attribute; as such, she will be treated as an equal, as her status implies she ought to be.

Julius proposes a different understanding of what it is to share a nature, in which equality is located in the sharing of a nature where the capacity of each individual presupposes that capacity in the other. When we think about the practical use we make of equality in moral status, the standard formula involves an inference of what to do from the fact of equality, or the lack thereof, as in Singer's graduated account of moral standing. Julius argues that it is illuminating to contrast that type of picture to his proposed alternative way an egalitarian insight might factor into practical questions: with the insight that we are in fact equals, and as a matter of knowing there are things I can do as a response to your invitation of doing them back to me and viceversa, our equality is self-contained in our shared capacities for shared activities. Conversation is key to Julius' understanding. By knowing that we can converse together, we are equals in the sense of being two people who can converse together. Rather than our equality being something inferred to on the basis of our individual capacities, which then becomes a restraint upon what we cannot or cannot do with or to one another, our equality simply is our capacity to share a relationship and to deepen that relationship by coming to know one another better and better as co-conversants.

In conversations between equals, each party comes to the conversation assuming the sincerity of the other, trusting their thinking to be directed towards arriving at shared truths, and trusting the other to take their own thoughts to bear the same truth and weight. Each trusts the other to develop their own thoughts – and their shared relationship – in sensitivity to the thoughts of the other. In sum: "Before we speak, we already understand this much each about the other. And we use this original mutual knowledge as the basis for deepening our understanding by way

of our each coming to know the other person's thought contents and her styles and procedures of thought in their full, contingent, gloriously idiosyncratic detail. Conversation marshals antecedent mutual understanding as the basis for taking it deeper" (Julius 2016, 198).

I've argued that communication need not occur via conversation. This much is clear from the richness of unspoken communication that can happen between two non-PID, language-using persons. Further, meaning-conveying communication can rely on non-language based RCMEs. Despite vast heterogeneity in form, the function of communication can be akin to conversation even when words are not the primary means by which that communication occurs.

#### III.i Difficulties communicating

But, the vast array of forms of communication make it the case that we often confront modes with which we are less comfortable or familiar. Communication can be hard: we often run into people with whom we are confronted by either their poor intentions or our inability to translate one another. But what remains the same for any type of communication is the sense in which, by attempting to communicate, two or more living beings enter into a shared activity in which those involved, when well-intentioned, have the goal of reaching some kind of shared understanding. This can be difficult – we might, for example, speak different languages, have trouble hearing one another, miss an implicature, or fail to reason with an upset toddler. Poorlyintentioned communicators differ from challenged ones: they might ignore one another, gaslight or silence others, or intentionally misinterpret a communicative act. Challenged communicators run into obstacles, but they are putting in the effort required to attempt to reach some kind of understanding. I will tackle both poorly-intentioned and what I am calling challenged pairs of communicators in turn.

Julius discusses poorly-intentioned communicators, though he does not delve into the asymmetries present in PID and non-PID pairs. His thoughts on poorly-intentioned communicators shed some light on what happens when non-PID participants behave dismissively towards PID persons, treating them as non-equals. When, for example, a male colleague behaves dismissively towards his female counterpart's work, his error is not merely epistemic and moral. It is also a curtailment of her freedom to act in ways she has reason to act – as opposed to conversing or presenting her work the way she might with respectful interlocutors, she must instead act in response to the ways his patterns of behavior force her to act (Julius 2016, 201-202). He presents this case as a way of getting at each of our personal stakes in egalitarian association – as opposed to thinking about personal stakes as an agent (that I act in recognition of equality in the other) and as a patient (the complaint I can raise should another fail to recognize my own equality), Julius illustrates how these are in fact inseparable aspects of equality, practically understood. When one person is a poorly-intentioned communicator, regardless of how that manifests, that person fails to "act from a conception of me as your fellow subject of mutually interpenetrating practical and epistemic responsibilities and capacities makes me unfree to engage you in that same way. My complaint, qua patient, against your failure to recognise me is that it makes me the agent unfree to act toward you in the recognising way" (Julius 2016, 202).

In the case of PID and non-PID pairs of interlocutors, the dismissal by the non-PID person of the PID individual as a potential communicator makes the PID person inherently unfree to engage the non-PID as a communicator, too. The increasing prevalence of non-speaking intellectually disabled persons in social media illustrates how this systemically occurs. Morgan, an Autistic writer and advocate (@NeuroDifferent on Instagram, @Neuro\_Different on

Twitter), shared a thread in honor of Augmentative and Alternative Communication (AAC)

Awareness Month. She writes:

I feel uneasy when parents of non-speaking Autistic kids say that they are 'their child's voice,' because their kid 'doesn't have one.' You cannot be 'A voice for the voiceless.' Nobody is voiceless. You're speaking over someone who's being silenced... Imagine everybody around you acting like you don't have anything significant to say, simply because you don't speak. Think of the despair, the frustration, the sheer \*helplessness\* you would feel. Ponder how that might manifest through your behavior as meltdowns, aggression, self-harm, eloping. This is the daily lived experience of so many non-speaking Autistic people. (@Neuro\_Different via Twitter, shared 10/24/2021)

The silencing that occurs doubles as a curtailment on the freedom of non-speaking Autistic people. They cannot communicate in the way they have cause to communicate because they are treated as non-communicators.

This can be fixed, when we recognize the heterogeneity of forms of communication that occur across the board in human life. If our intentions are improved – if we extend hermeneutic openness – it becomes apparent that even those with non-speaking intellectual disabilities or non-speaking Autism have the ability to form meaningful relationships and to communicate, particularly via the employment of RCMEs. But then we face a different practical problem: the challenge of translation. Even when we are well-intentioned, reaching our goal of shared understanding can be quite hard. Let's take the case of translation from one natural language to another. I, an English speaker, might be travelling in Paris and be stopped on the street by a Spanish-speaking tourist asking for directions in broken French. We are two non-experts in the lay of the land who also lack a common ground linguistically. When we realize that we are both non-natives, the challenge becomes clear, but if I have some geographical knowledge and translative skills, I may still be able to direct ther towards the Eiffel Tower.

A second sort of case might happen where friendly alien invaders who communicate solely via minute facial expressions land in Paris during my visit. Given their recent arrival on Earth and our very different natures, I might not recognize these small facial intricacies for what they are, acts of communication. Imagine an invader stops me on the street to try to get directions. Given her very different form of communication, I may not be sure whether she is asking me for directions at all, let alone where she wants to go. For all I know, she is merely stopped in front of me, not attempting communication at all. In order to recognize her attempting to make a connection, I would have to be very open to the possibility of communicating via very different modes of communication.

A lot of the cases of communication between PID persons and their non-PID interlocutors are more like this second case. When shared natural language is not available, things become complicated quickly. In both of my above cases, we are navigating unfamiliar terrain and need to communicate to better orient ourselves. This captures the sense in which, in many cases of interpretation, we need to figure out *how* to communicate in order to achieve our ends. This will of course be prior to figuring out what it is that we are attempting to communicate. The Spanish speaker and I are both tourists who do not speak French. Yet we both have the same set of tools to communicate at our command: natural language, gestures with similar meanings, facial expressions, direction of gaze, pointing. Communication will take some extra steps or some trial and error, but it could become effective fairly efficiently.

This is not as difficult as the communicative challenges that arise between pairs of individuals who do and do not use natural language.<sup>32</sup> Assuming we do share the goal of

<sup>&</sup>lt;sup>32</sup> For what it's worth, I include sign languages as a form of natural language and do not mean to include them as fodder for the distinction I'm making between natural language and the atypical means of communication employed by non-speaking intellectually disabled persons.

communicating with one another, and that we are well-intentioned communicators in the sense sketched above, our problem is clear: that one of us is a human being who, like most human beings, uses natural language as her primary mode of communication, whereas the other is a human being who, unlike most human beings, is unable to access natural language. A PID person has different tools at her disposal than I do. She may have unfamiliar bodily comportment or very different vocalizations and intonations than the ones I know; something like direction of gaze may have a different meaning for her than it does for me. This is why this case can look more like the interaction between the alien invader and me. Ian Hacking addresses a similar phenomenon in "Humans, Aliens, and Autism," where he discusses how some autistic individuals perceive their experiences with neurotypicals as so unfamiliar that it feels like one side is alien, the other human (Hacking 2009). This sense of differentness operates in both directions.

There is one significant respect in which my alien invader case differs from the alien comparison pertaining to autistic individuals: an actual alien is of a different, novel species and would be completely foreign to us. Hacking's point is deep but merely metaphorical. Our equality of moral standing – which may wind up extending to alien invaders, for all we know – coupled with the familiarity that comes from preexisting relationships with intellectually disabled persons provides a starting point. When we perceive those with PID as our equals, with whom we might engage in the shared endeavor of communicating to establish and deepen relationships, recognizing attempts at communication and beginning to engage in the work of interpretation becomes easier. We are not, so to speak, starting from scratch.

So, the communicative challenges that arise between pairs of non-PID and PID persons turn out to be less of a dead-stop than they often appear to be. Like many other interpretive

challenges, workarounds – in this case, our equality of moral status, hermeneutic openness, interpretive work, and some knowledge about the other – make communication possible. The knowledge derived from previous interactions and a relationship's shared history aid in the ability to recognize communicative acts and begin to interpret them. But more significantly, our equality, which both derives from our ability to use RCMEs and serves to motivate the development of RCMEs, provides the grounds to overcome our challenges. The reason our challenges are not a dead-stop has to do with the deep symmetry between what each person is doing. By developing and deploying RCMEs, both are using the relationship to deepen the relationship.

### III.ii Virtues of the relational egalitarian view

A truly relational basis for basic equality of moral status like the one I am proposing does not ultimately locate the status-conferring attribute at the level of the individual, in isolation of other. Moral status is a product of one possessing a capacity, but the very presence of the capacity presupposes its presence in others. Rationality, for example, does not operate this way: one could be the sole rational agent in existence. Dependency does not necessarily presuppose that others are also dependent, because although dependency shifts over time, it operates in one direction between the person caring and the person cared for. Although couples, for example, care for one another, the presence of my dependence or my caregiving does not presuppose its presence in a partner. The capacity to communicate to establish and deepen relationships, however, does presuppose that the other can do the same. Because of this, even though the capacity to communicate is in a certain sense a status-conferring attribute, locating the grounds for moral standing in this capacity is unique in communication relying upon a deep symmetry between the capacities of even very differently-abled persons.

Further, my relational view is based on possibility, not actuality. The relational capacity I rely upon – the shared capacity for the shared activity of establishing and deepening relationships via communication – does not require that we all establish and deepen relationships with one another. This would be impossible and impractical. However, it does presuppose the possibility of establishing and deepening a relationship with anyone who possesses that same capacity. Our equals are thus all of the people with whom we *could* be friends – even pairs of people who will never actually become friends or even meet one another.

Beyond this, my relational view does not locate value in the means to an end or the end itself, but rather in the possible and actual relationships themselves. Any given episode of communication is not merely a means to the distinguishable outcome of a valuable relationship, but rather blurs this line. Insofar as it makes sense to speak of the relationship as an outcome of communicating, my view insists that the relationship is what we use to produce the outcome of the relationship. This is precisely what RCMEs are: idiosyncratic yet ubiquitous forms of communication that use a relationship to deepen a relationship. The capacity to develop and deploy RCMEs just is what gives us moral standing, and that moral standing is the wholly relational capacity to use communication to establish and deepen relationships.

This means that there are two ways that the means-ends distinction is surpassed: the relationship does not just figure as a product, but figures in as the thing that is used to add to the relationship, and communication, the means, adds to and draws upon the relationship. A relationship is a process that consists in the things people do together (like communicating). Every conversation not only transforms and adds to the relationship, but uses its past as the means to successfully do so. Here, each party is doing the same thing in using this history and

this capacity to engage together in order to work towards the outcome of coming to know one another better and better.

To summarize, locating the grounds for moral status in the capacity to communicate to establish and deepen relationships – a capacity which presupposes its own existence in others – is not merely a case of distinct individuals, each independently having capacities that grant them moral standing, that standing giving answers with regards to the reasons they owe it to one another to treat each other as equals. The egalitarian insight that they are equals is present in the very attempt at communication and in the relationship itself. To return to Singer's assumptions about cognitive capacities, the very thing I am doing in refusing to make a guess about the capacities of another and in instead relating to that person as someone with whom I can and perhaps should get closer means that *I am proceeding on the presumption that we share the capacity to get closer*. In attempting to communicate, I am proceeding on the presumption that we share the capacity to communicate. In establishing and deepening a relationship, I am assuming that you can do the same and that, as such, we are in a deep sense on another's equals.

#### IV. Distinctive equality and non-human animal lives

I want to briefly discuss the implications of my view for non-human animal lives. Kittay clearly means to include only human beings and has always been justifiably disturbed by comparisons between the cognitive attributes of non-human animals and intellectually disabled human beings. In their paper, Jaworska and Tannenbaum address worries about the claim that perhaps some owners do intend to turn their animals into self-standing persons, in which case their picture of moral standing would extend to those non-human animals.

At this point, I take myself to be set up to claim that there does not need to be a question of non-human animal versus human equality or inequality insofar as I am no longer in the

business of establishing ontological hierarchies based upon presumed capacities. Instead, I am asking what things two or more people are capable of doing *together* and how we might take these shared activities as foundational to shared moral standing. So, we might insist that I do the same thing with my dog that I do with my PID brother or with my non-PID friends. We might alternatively ask what it is that we share with our non-human animal companions when we share our lives with them. Is it using communication to establish and deepen relationships? Is it an impoverished version of what non-PID pairs do when they communicate using language?

We might also be interested in relationships between non-human animal parents and their own companions and offspring. Evidence from studies in animal cognition shows that many nonhuman animals engage in activities directed towards developing their young in what looks like morally meaningful ways. Communities of female elephants care for their young together. Their rearing includes things like learning by practice so that their young can become members of their same community in time. The grooming practices of many chimpanzees and great apes, particularly between mothers and female offspring, evidence similar transformative actions directed towards ends which include the creation of the next generation of rearers. While we may not know how non-human animals conceive of intentions, the relationships between actions and ends resemble those of humans. Minimally, we have insufficient grounds to dismiss these practices as insignificant to the process of using communication to establish and deepen relationships.

If non-human animals can participate in meaningful relationships or shared activities, or if their lives are shaped by their interactions with others, or if they can develop and deploy RCMEs, then it seems that according to my account, they should be granted the same basic

equality of moral standing as all human beings. It is likely the case that my relational capacitybased view of moral standing would likely not preserve humans' distinctive moral standing.

Humanist positions on human moral standing have long attempted to simultaneously defend human distinctiveness and basic human equality of moral status. However, more and more data from animal studies have begun to debunk distinctiveness claims to many of the status-conferring attributes that have been favored. Simultaneously, those attributes that remain on the table as means for defending distinctive human equality exclude significant portions of human life, most often the intellectually disabled. So, it may well be the case that we have arrived at an impasse where a concession must be made. Either we abandon the idea of basic human equality of moral standing (as Peter Singer does) or we abandon the idea of our distinctiveness over other forms of life.

I do think it is the case that, if we had to make a choice, distinctive equality ought to be the criterion we jettison in thinking about moral standing. A commitment to basic equality of moral status grounds the parts of equal moral standing that are the most significant to normative questions about how we are to live together. The abstract ideal of there being no significant moral distinctions between human individuals or groups of individuals replaces that of our superiority over other animals. This is because basic equality of moral standing ensures that the most basic rights – whatever these may be – of all individuals are respected. The mere thought that we are superior to other living creatures forces us to ask why that is the case, and if the answer to that question has to do with certain capacities humans possess that non-human animals lack, then we continue to come up against the fact that certain humans may resemble certain non-human animals more than they resemble other humans beings. Why should it be the case that we continue to seek metrics that set us apart as opposed to ones that draw us together?

Rather than backtrack and bootstrap to attempt to defend an extension that does not capture some non-human animal life, I suggest that the way forward is a more thorough defense of basic equality of moral standing that is unconcerned with claims to human distinctiveness. Perhaps the horrific realities of factory farming and animal abuse will be cast in a different light if it turns out to be the case that certain non-human animal exclusions from basic equality of moral standing are indefensible.

And yet, we want to be sure that we are not following the same old order of explanation that has led to exclusions in the past. With my account of the egalitarian insight that we are all, after all, doing the same thing in relating to one another – that in attempting to become friends, we are presupposing that the other person has the capacity and standing to do the same - we are refusing to make assumptions about higher order capacities of mind, what the other person is like, and what they might bring to the table. We are not asking "do you have the relational capacity? Do I have the relational capacity?" and concluding from each of our individual possessions of that relational capacity that we are equals. Likewise, in asking whether a nonhuman animal can do this thing or that in order to establish whether they have status comparable to our own, we are just getting back to the traditional explanation of the relationship between capacity, equality, and treatment, where the possession of a capacity (individual or relational) explains who is equal with whom, and how we should treat our equals and unequals. I suggest instead that we think about what it is that we do with our non-human animal companions and what they do with one another. The capacities that matter are not the individually possessed capacities to relate to other beings, but instead the capacities to communicate in order to develop and deepen relationships - capacities that presuppose their existence in others. With our nonhuman animal friends, some agnosticism may be necessary, but that agnosticism might translate

to openness to the possibility of their shared moral status to our own. Our treatment of nonhuman animals should reflect this agnosticism and a commitment to working to come to know our potential friends.

# **Conclusion**

I began my dissertation with a question about moral status and profound intellectual disability (PID). Having spent the past decade first as an undergraduate philosophy major, then working on my master's degree in philosophy, and finally completing doctoral studies in the same field, I noticed time and time again that traditional philosophical perspectives on the grounds for moral status excluded people with PIDs – people like my brother. Accounts that did manage to capture those with severe- to profound intellectual disabilities erred in other ways. So, with the help of two very supportive supervisors, I began my own very circuitous route to answering this question, the product of which has been these past three chapters.

In order to put forward a positive argument for an egalitarian grounds for the moral status of human beings, I began with an argument for characterizing PID as a communicative as opposed to cognitive deficit. When we think about PID solely in terms of cognitive incapacity, and when we track the connection between cognitive capacity and philosophical accounts of moral status that are based upon the possession of certain cognitive capacities, we land in a very bad place where those with PID are perceived as unworthy or incapable interlocutors with diminished moral status as compared to other human beings. I gave the example of Peter Singer's graduated view of human moral standing, where possession of particular attributes (in his case, sentience and rationality) provided the grounds for moral status, and where equality of moral status implied particular answers to the question of what we owe to whom. On this view, the lack of possession of particular attributes implies different treatment, and, in the case of sentient but ostensibly non-rational PID human beings, moral status and hence treatment are on par with certain higher-order non-human animals. I argued instead for a view where PID is characterized by the impossibility of successful, mutual linguistic communication. While the *cause* for the communicative difficulties of PID persons may ultimately be a cognitive one, thinking about PID in terms of communicative difficulties yields preferable practical outcomes in several ways. First, it respects all that we do not know about the inner lives of these people. Second, it encourages non-PID persons to approach PID ones as potential communicators as opposed to individuals incapable of much of anything. This leads to the potential to form relationships worth emulating, like the one between Susan Brison and Sesha Kittay, or between David Goode and Christina. What is special about these relationships is their depth despite apparent asymmetries between the two parties, a depth that emerged from the development and harnessing of atypical forms of communication that allowed the pairs to come to know one another.

This brought me to my second chapter, where I conceptualized a ubiquitous form of communication I called *relationship-constituted and constituting meaningful expressions* (RCMEs). RCMEs are unique in the way they are contextualized within the fabric of a particular relationship and the way that they serve to develop and deepen that relationship. To use a language-based example, inside jokes are particular to pairs or small groups of users. An inside joke is only meaningful in the way it was developed to bear meaning to that group ("you just had to be there!"), and referring back to it or riffing off of it deepens the relationship. In a sense, by employing an inside joke we use a relationship to deepen that relationship. Language-based RCMEs that allow pairs to use the history and context of a relationship to deepen the relationship in a manner unique to the pair. I cited Goode's work with Christina and my own experiences with my brother and our use of "becket" or "ay-yo." Plenty of non-utterances can serve as RCMEs too, so long as they serve to develop or deepen a particular relationship.

RCMEs have special moral weight because of their situatedness within particular relationships. The use of RCMEs centers on the trust between a pair and the fabric of their unique relationship. RCMEs can also bear particular salience between pairs of PID and non-PID persons where the relationship faces the communication challenges I pointed out in Chapter I. Insofar as the primary practical problem faced by pairs of PID and non-PID persons is overcoming the communicative barrier posed by the inability of one person to communicate via natural language, RCMEs serve as a means to communicate effectively. An added bonus is that, once RCMEs get going, like an inside joke they can "snowball": establishing initial RCMEs can lead to the development of more, as the pair continues to garner additional communicative tools and greater depth to their relationship.

The existence and use of RCMEs, especially non-language-based ones, illustrates two communicative virtues: hermeneutic openness and willingness to translate. Hermeneutic openness refers to a stance of communicative humility: one party, the observer, must first view the other as attempting to communicate. This will involve a certain degree of epistemic humility in terms of what types of persons may be capable of communication, and what types of acts might count as communicative ones. This is important, as non-speaking intellectually disabled people are so often perceived as non-communicators. Then, both parties must be willing to engage in the often very trying work of attempting to translate one another. This is less difficult when both parties use language as their primary means of communication. However, in PID and non-PID pairings, atypical and creative means will need to be employed, and this may require significant effort on both sides.

I finally returned to the question of moral status in Chapter III. Having rehearsed an alternative approach to defending the grounds for moral status and the implications of those

grounds in Chapter I, I revisited the traditional tack taken by many philosophers including Singer. I noted that for Singer, the order of explanation went from abstract philosophical questions regarding moral standing down to implications regarding treatment, whereas for me, my principal concern was the practical interactions between PID and non-PID persons. This is why I began with an alternative conception of PID and focused on the moral significance of nonlanguage-based forms of communication for developing relationships between PID and non-PID pairs. Hence, I worked from the ground up: from the question of what we owe to its implications for the grounds for moral standing. In Chapter III I argued for an alternative view of equality of basic moral standing where what matters is not individualized capacities of mind assessed in isolation from others, but instead capacities to use communication to form and deepen relationships whose very possession presupposes their existence in others. As illustrated in Chapters I and II, all human beings have that potential, whether or not they engage it with all possible interlocutors. I left open the question of where and how this applies to non-human animals, but I am open to expanding the scope of basic equality of moral standing to some nonhuman animals.

I want to close my dissertation with two reflections: first, some thoughts on the implications of my work that pertain to the question of advocacy for non-speaking intellectually disabled persons, and second, with a final take on the interaction between Eva Kittay and Peter Singer at the Stony Brook conference, which I cited in my introduction.

#### I. Intellectual disability and advocacy

As expressed in Chapter I, non-speaking intellectual disability does not necessarily entail that the individual lacks desires, needs, or opinions. As argued in Chapter II, there may be means to develop the communicative tools necessary to determine what these are. However, when we

are dealing with non-speaking intellectually disabled persons, we sometimes need an advocate – whether in the private sphere or in the more public spaces of education, political rights and obligations, or within clinical contexts. So we may wonder, given the disability rights commitment to the slogan, "nothing about us without us," who has the right to speak for whom when the group spoken for quite literally cannot speak?

The broader question of advocacy boils down to a question about who ought to speak for whom, for what reasons – on what grounds, in which contexts, and in which ways. Should black women, and only black women, speak on ending black women's oppression? What should the goal of gay rights advocacy be? Are non-marginalized allies in the workplace good advocates for marginalized co-workers? Why are disability rights self-advocates insisting on their slogan, "nothing about us, without us," and does that refrain have limits? Who *should* advocate for those human beings without the capacity to speak for themselves – namely, the non-speaking intellectually disabled? When we advocate, we speak for someone, on behalf of their interests, which are ordinarily discerned by the entity that is the object of the advocacy. One might advocate for women's rights by fighting for suffrage, for fairer college admissions by supporting diversification efforts, for one's own advancement in the workplace by illustrating one's accomplishments to one's superior, or for the just treatment of animals by being vocally vegan.

There are many types of advocacy, which include self-advocacy, in-group advocacy, intimate advocacy,<sup>33</sup> institutional advocacy,<sup>34</sup> and ally advocacy. Sometimes different forms of

<sup>&</sup>lt;sup>33</sup> Intimate advocacy occurs when a person close to another advocates on the other's behalf: this may be a friend for a friend, a parent for a child, or a sibling for a sibling. Eva Kittay's work on behalf of her daughter Sesha is a good example: Kittay works professionally as a philosopher to argue for the personhood and value of those with PID.

<sup>&</sup>lt;sup>34</sup> Institutional advocacy happens when experts or professionals advocate for a person or group for whose well-being they are to some degree responsible. For example, a board of experts consisting of clinicians, researchers, and organizations come together to form a task force every

advocacy can conflict with one another: the self-advocacy of a rebellious teenager may differ from the intimate advocacy of her mother. Advocacy also crosses many institutional and private spaces, including the political realm and the clinical sphere. The tension between different advocates' perspectives can be tricky to balance, as I will illustrate momentarily. Further, orienting advocacy efforts towards the right goal requires both epistemic and moral considerations. Epistemic considerations involve things like discerning the concrete needs, desires, and interests of the lives of those at stake, weighing these against social, economic, and political resources, communicating effectively with interested parties, and assessing the practicality and efficacy of various programs or efforts. Moral considerations include things like proper levels of care, the question of who is responsible for whom, the solicitude particular marginalizations and conditions require, fairness, justice, and so on. Advocates need to get right the interests that matter most for the groups for whom they advocate, know what living well looks like for different sorts of people, and perceive the most important issues at stake.

A basic assumption I work with in my present discussion is that individuals know their own desires, needs, and interests in a way that positions them well as advocates for themselves. I know and orient my actions towards my projects because they are my projects; I know what roadblocks I face because I experience those roadblocks; I can often identify remedies for issues in my life, even if I cannot alone achieve them. I can communicate these things to others in a way which renders them capable of aiding me. Others typically become aware of my projects, problems, and potential solutions second-personally because I tell them. Of course, there are cases of weakness of will, lack of self-awareness, self-sabotage, etc., but I will bracket these for

decade or so to edit the diagnostic criteria and conditions covered by the DSM. In 1971, the task force reacted to social change, homophobia, and scientific data in order to de-classify homosexuality as a mental disorder.

the purposes of imagining what ideal advocacy might look like. In general, (adult) people or groups of similar people can discern their own interests for themselves better than others can discern their interests for them (see, for example, Collins 1990 for a thorough defense of this claim). Working with this assumption, self-advocacy looks like the ideal form of advocacy in terms of proximity and access to considerations of what would be best for the individual or group at stake. Because self-advocacy more often than not has more solid grounds than other-advocacy, if we wonder whose thoughts should supply the content of arguments about things that affect her life, the person whose life is at stake is our answer.

Yet, in the case of non-speaking intellectual disabilities, the impairment is precisely an impairment that makes speaking or advocating for oneself impossible. So, who is best positioned to discern what matters to those with PID and who ought to speak on behalf of these types of persons? We might think, the closer the advocate to the person in question, whether in terms of relationship, nature of disability, knowledge of disability, or knowledge of particulars, the better the advocate will be. One might think that the next-best case would be quasi-in-group advocacy from less severely disabled or more verbal intellectually disabled persons. Those with intellectual disabilities who do have the ability to speak for themselves look like good in-group advocates because of their similarities. Respecting their perspectives would encompass at least to some degree the ideals of the "nothing about us, without us" campaign.

Then again, the right *kind* of attention toward the individual must be present. Care for the person advocated for must be sufficient. Instead of other intellectually disabled folks, perhaps intimates would make the best advocates for non-speaking intellectually disabled persons. However, care may not be like knowledge in that the greatest degree of care leads to better advocacy. Sometimes our judgement can be clouded by too much investment in the case at stake.

But, in most cases, it seems like something ranging between the care of a typical parent and the care of a good friend might be ideal.

To think through the various factors at play in advocacy efforts for non-speaking intellectually disabled persons, I will consider autism spectrum disorders.<sup>35</sup> Autism spectrum disorders (ASD/ASDs) cover a lot of territory. Some autists speak using natural language, and others have very little language-based communication and may be classified as profoundly intellectually disabled. (My brother belongs to this latter category.) This leads me to a complex example of how different types of advocacy may yield totally different results emerges in the politics of clinical practice and research surrounding autism. Some in-group advocates for autism view autism as a valuable component of human diversity, whereas some self-advocates wish for a cure. Intimate advocates have complex perspectives depending on the nature of the autists they know: some may advocate for inclusive public education and job opportunities while some may want institutionalization or a care. An institutional advocate, Autism Speaks, a nation-wide nonprofit organized around the needs of individuals with autism spectrum disorders and their families, received significant critique in 2009 when they published a press release about an "autism epidemic" in which they called for immediate action oriented towards seeking a cure. The organization, purportedly aimed at autism advocacy, medicalized ASD and urged its immediate eradication. Self-advocates and ally advocates claimed that this marginalized the lives

<sup>&</sup>lt;sup>35</sup> There is much debate regarding the terminology for autism and autism spectrum disorder (ASD). I will use ASD here to capture the range of neuro-differences that have been called "autism" in the past thirty or so years, though I do not personally take autism to be a disorder. Rather, like many autists and autism advocates, I take autism to be a mere-difference or a form of neurodiversity.

of those with ASD and particularly those who do not see their autism as something needing to be weeded out from forms of human diversity.<sup>36</sup>

One critic of the medicalized verbiage in their press release was the Autistic Self

Advocacy Network (ASAN), an online self-advocacy group. ASAN criticized Autism Speaks'

methods of fear-mongering, evoking pity, using dubious statistical data, and representing of

autism as a debilitating disease rather than as a valuable component of human diversity.<sup>37</sup>

Because many of the members of ASAN are themselves autistic, they claim greater authority on

the reality of life with autism.<sup>38</sup>

ASAN's goals and position statements are oriented by motivating principles of

autonomy. Their mission statement reads:

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us! (ibid.)

And their position statement:

ASAN advocates specific policy positions on issues of importance to autistic people and others with disabilities. In so doing, we seek to ensure the meaningful involvement of autistic individuals in making policy at all levels, to promote a culture of inclusion and respect for all, to enforce the rights of autistic people to equal opportunity at school and at work, and to improve funding for community services and supports along with research into how they can best be provided. (ibid.)

<sup>38</sup> See <u>https://autisticadvocacy.org/about-asan/</u>. Another self-advocate network, Self Advocates Becoming Empowered, endorses similar positions, as documented in Carey 2009.

<sup>&</sup>lt;sup>36</sup> Autism Speaks has since restructured the goals of their research and funding.

<sup>&</sup>lt;sup>37</sup> See <u>https://autisticadvocacy.org/2009/10/disability-community-condemns-autism-speaks/</u>.

Here it seems that autonomy comes prior to any (perhaps paternalistic) discussions of well-being that would be about, or in their words, without them. Autism Speaks' mistake lay in speaking about autistic individuals in a way that was far removed from the actual experiences of individuals living with ASD. Their mistake was both epistemic, in ignoring the facts about autistic lived experience, and moral, both in facilitating falsely founded fear and pity and in the marginalization of actual autistic lives. ASAN claims greater authority on the lived experience of autism, which they believe better positions them as advocates for autistic lives, needs, and interests.

However, we can imagine the limits of this case. Some autistic individuals are severely intellectually disabled in such a way that renders them incapable of self-advocacy. Further, there are individuals with less severe forms of ASD that do advocate for cures. Jonathan Mitchell, a highly articulate writer and self-advocate with autism, argues that his life has gone much worse because of his autism. He cannot hold down a job, has never had a girlfriend, and constantly suffers because of sensory overload. The tagline on his website is "We don't need no stinkin' neurodiversity."<sup>39</sup> He is highly critical of anti-cure measures and wrote in 2011:

I will write a third post about this, because I suffer everyday from the isolation of autism, the not being able to make a living and the inability to get things done during the day. The fine motor coordination problems that impair my handwriting as well as the irrational fear of birds. I had to attend special education schools for 8 years, as well as an after school tutoring program for a few years. I had to spend recess time at one school to receive tutoring for my handwriting. I was also a chronic bedwetter up until age 13. However, compared to some persons on the spectrum, I have it really good. There are others who engage in self-injurious behaviors, who cannot speak a word, can't dress themselves or take the bus anywhere and will require 24/7 care for the rest of their lives if no way is found to cure them. I hope that we can get a consensus of pro-cure people in the blogosphere to write posts how much they want a cure for this horrific disability and have more than three.<sup>40</sup>

<sup>&</sup>lt;sup>39</sup> See <u>http://autismgadfly.blogspot.com/</u>.

<sup>&</sup>lt;sup>40</sup> See <u>https://autismgadfly.blogspot.com/2011/07/yes-lets-find-cure.html</u>.

There is a dramatic asymmetry between the advocacy goals of those with negative and positive lived experiences. Given the disparities in the experiences of some people as compared to others and the vast heterogeneity of forms of intellectual disabilities, it may be that case by case consideration is required when we think about how to best advocate for non-speaking individuals.

We should also weigh in the perspectives of families, caretakers, friends, and intimates. Because more severe forms of intellectual disabilities, autism included, often involve life-long care, advocacy considerations need to take seriously the caretakers of dependent intellectually disabled persons. When thinking about the goals of research, care, and clinical practices, proximity considerations need to play a role. Parents, caregivers, and other intimates have historically played crucial roles in advocating for intellectually disabled persons: they know them well, love them, and have pushed for better education, resources, and services. However, they have been criticized for sometimes paternalistic practices and their own personal interests often compete with those of the groups for whom they advocate. Caregivers need respite and this may influence their advocacy efforts. They may selfishly advance interests that serve themselves more so than the non-speaking intellectually disabled persons whose own interests are at stake.

Caring for an adult dependent with a PID can be draining. Given my own experiences, I cannot overemphasize how years upon years of care for a person like my 6'4", 240 pound brother who needs help with everything from feeding himself to wiping after using the bathroom to avoiding self-injury when he aggressively bites his radial artery can exhaust a person. But admitting this comes at a cost. As an ally to disabled people and their needs, rights, and interests, emphasizing the needs of caregivers or acknowledging their competing interests can remind people of histories of marginalization, degradation, and abuse. This is largely due to past

caregivers who neglected or institutionalized their charges because they found caregiving to be too much to handle. In the case of an infant, equally dependent, we would not say, with no limitations, to always do what is best for the baby, ignoring the needs of the caregiver. Why is it then taboo to say that about an intellectually disabled adult dependent a caregiver must care for? This aside, I do think that the special knowledge of the intimates of those with non-speaking intellectual disabilities places them in a good position to advocate for their friends, children, charges and/or siblings.

Advocacy for non-speaking intellectually disabled persons is clearly a complex issue with many competing interests to weigh. Insofar as the goal of advocacy involves remaining true to the interests of those we advocate for, it is unclear whether epistemic priority goes to those with similar disabilities or the intimates of those with PIDs. It seems that in order to advocate for someone or something else, an advocate should have a degree of both knowledge and care for them. The knowledge and care qualifications on advocacy point to the different moral shapes advocacy can take: there are ideal and insufficient forms of advocacy, there are better and worse ways to advocate and better and worse types of people to advocate for others, there is epistemically and morally problematic advocacy and non-problematic advocacy. Without the knowledge condition, one may be targeting insufficient or incorrect interests. Without the care condition, one may be more swayed by institutional interests or self-promoting goals than is appropriate for the advancement of the interests at stake. But this must be balanced with the needs of those doing much of the heavy lifting: the lifelong caretakers of those with PIDs.

To that end, we can make a distinction in the different sorts of reasons the intimates of those with PID might make good advocates for PID persons. One way to think about advocacy is sponsored by a kind of welfarism. Thinking about those with severe- to profound intellectual

disabilities, the welfarist advocate might think, "these people are suffering, need help, and need good non-intellectually disabled advocates who can use special knowledge about the interests at stake to make sure these people get the help that they need." This is quite compelling. However, there is something else we can see advocacy as doing. Perhaps the practical problem is not "how do *we* help *them*," but rather "how do *we get to know each other*?" This is a problem for all kinds of pairs of people, with special salience for pairs of PID and non-PID persons, as I've flagged from my outset. Insofar as friends are an intrinsic good (let's assume this point) and insofar all of the people surrounding me, near and far, are potential friends, there is a deficiency in my life in my inability not to befriend them. Further, there is a systematic barrier preventing PID and non-PID friendships due to the inability of these pairs to communicate with the same ease as pairs of non-PID persons. How do we overcome this barrier?

Non-PID intimate-advocates are in a position, as people who have intimates with PID, to be *friends in common* between PID persons and everyone else.<sup>41</sup> As a sibling of a person with PID, my expertise is not merely about his interests; rather, my priority as an advocate for my brother rests in the fact that we have a close relationship. I'm not an intermediary but rather a person with a relationship who can serve as a bridge to those lacking relationships with PID persons. The RCMEs, tools, hermeneutic openness, and so on, that I have developed can help me help others develop similar tools so that they too can come to know one another *with* individuals with PIDs.

# II. Greenfeld, Singer and Kittay, and my brother: final takeaways

At my outset, I discussed how three things motivated this project. We are now in a position to shed some light on the significance of these three sources of inspiration. What was it

<sup>&</sup>lt;sup>41</sup> I am indebted here, again, to AJ Julius for this point.

that Greenfeld missed in his relationship with his brother? Why was it the case that Singer and Kittay seemed to talk past one another at the Stonybrook conference? Why do I feel that my relationship with my brother is not impoverished in the way others seem to think it must be?

Karl Taro Greenfeld's memoir recounting his experiences growing up with a PID brother is not to be taken lightly. It reflects the experiences of many families with intellectually disabled children who do in fact require much more care from parents, often to the detriment of other siblings. And yet his insistence that his brother, Noah, is "unknowable" seems to me to deny an element of humanity to Noah. Without passing judgment on Greenfeld himself, who undoubtedly had a difficult and (in the case of families with PID children) sadly not uncommon childhood, I do think that his experiences may have been less tragic had his family lived in a world where PID was not characterized solely as an extreme cognitive deficit. Were societal focus instead on the communicative difficulties, perhaps more resources and education would be aimed at developing technologies, therapies, and tools to communicate with our PID intimates. Were that the case, perhaps Greenfeld and his family could have come to know Noah better.

Regarding Singer and Kittay, Singer's vehement refusal to meet Sesha unless Kittay explained to him precisely what that interaction might reveal seems to me to be a result of his particular commitments to the order of explanation grounding human moral status and questions about what we owe one another. In his view, the characterization of PID as an extreme cognitive deficit is taken for granted. Because obligations regarding treatment rest upon answers about what sorts of people or non-human animals are our equals and inequals, that question itself being answered by the possession of capacities of mind assessed in isolation of other individuals, those with PID are owed less due to their not possessing the salient status-conferring attributes that would grant them full human moral standing. Kittay's relational view rests on the salience of

being some mother's child and the ubiquity of dependency, so renders her daughter and those like her as having full moral standing. Nonetheless, her order of explanation parallels Singer's, inserting an alternative status-conferring attribute and noting its relationality but nonetheless pinning questions of what we owe one another solely on the possession of that attribute. So while the extension of full moral status for human beings increases in scope, it is still hard to say what it is Singer is missing by refusing to meet Sesha, as it seems like he and Kittay merely disagree about the status-conferring attribute at stake.

By my view, full moral standing is a product of the possession of a more robustly relational capacity. Here, the capacity at stake is the capacity to use communication (specifically, RCMEs) to develop and deepen relationships. This is a capacity whose possession presupposes its existence in others. Unlike rationality, sentience, or even dependence, using communication to forge relationships requires that there be others like you with whom you can communicate and form relationships. This sheds some light on what went wrong between Singer and Kittay. By changing our order of explanation: by not assuming things about the inner workings of others, and by instead approaching potential communicative partners with openness about the things that you can do together, we simply cannot do the computation of equals and unequals based upon what we presume they can or cannot do *without* accepting our symmetric abilities to figure out those things about one another, together.

Finally, my brother. I suppose what my view implies is simply that, if you'd like to know more, you'll need to meet him (or someone like him) yourself. You may just have a new friend if you do.

### Works Cited

- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington: American Psychiatric Association, 2013.
- Adeli, H., Rahimian, P., and Tabrizi, N. "Communicating with People with Profound Intellectual Disabilities Using Brain Computer Interface." California State University, Northridge, The Journal on Technology and Persons with Disabilities, 2016, 133-145.
- Armstrong, Joshua. "The Evolution of Minded Communication," forthcoming.
- Bar-On, Dorit. Origins of Meaning: Must We 'Go Gricean'?. Mind Lang, 28: 342-375, 2013.
- Barnes, Elizabeth. *Minority Body: A Theory of Disability*. Oxford: Oxford University Press, 2016.
- Baron-Cohen, Simon. *Mindblindness: An Essay on Autism and Theory of Mind*. Cambridge: MIT Press, 1997.
- Baron-Cohen, Simon, Leslie, Alan, and Frith, Uta. "Does the autistic child have a theory of mind?" Cognition 21 (1985): 37-46.
- Berube, Michael. "Equality, Freedom, and/or Justice for All: A Response to Martha Nussbaum." Rpt. in "Cognitive Disability and its Challenge to Moral Philosophy," eds. Eva Feder Kitty and Licia Carlson. Wiley-Blackwell, 2010. 97-109.
- Brison, Susan. Foreword to *Learning from My Daughter: The Value and Care of Disabled Minds* by Eva Feder Kittay. Oxford: Oxford University Press, 2019.
- Carey, Allison C. 2009. On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America. Philadelphia: Temple University Press.
- Carlson, Licia. 2010. *The Faces of Intellectual Disability: Philosophical Reflections*. Bloomington: Indiana University Press.
- Carlson, Licia, and Kittay, Eva Feder (eds.). Cognitive Disability and its Challenge to Moral Philosophy. Wiley-Blackwell, 2010.
- Cascella, "Receptive Communication Abilities among Adults with Significant Intellectual Disability." Journal of Intellectual & Developmental Disability Vol. 29, Issue 1, 2004.

- Charlton, James. *Nothing About Us Without Us*. Berkeley and Los Angeles: University of California Press, 2000.
- Cheney, Robert and Seyfarth, Dorothy L. "Monkey responses to three different alarm calls: evidence for predator classification and semantic communication." Science. 210:801-803.
- Crary, Alice. "The Horrific History of Comparisons between Cognitive Disability and Animality (and How to Move Past It)." *Animalidies*. Ed. Gruen, L. and Probyn-Rapsey, F. New York: Bloomsbury, 2018.
- Crary, Alice. "Animals, Cognitive Disability and Getting the World in Focus in Ethics and Social Thought: A Reply to Eva Feder Kittay and Peter Singer." ZEMO 2, 139–146 (2019).
- Davy, L. (2015), Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory. Hypatia, 30: 132-148.
- De Klerk, Carina C.J.M., Hamilton, Antonia F.de C., and Southgate, Victoria, "Eye contact modulates facial mimicry in 4-month-old infants: An EMG and fNIRS study," Cortex, Volume 106, 2018, Pages 93-103, ISSN 0010-9452.
- Dover, Daniela. "The Conversational Self." Forthcoming.
- Dunbar, Robin. *Grooming, Gossip, and the Evolution of Language*. Cambridge: Harvard University Press, 1997.
- Engber, Daniel. "The Strange Case of Anna Stubblefield." The New York Times Magazine, Oct. 20. 2015. Accessed at: <u>https://www.nytimes.com/2015/10/25/magazine/the-strange-case-of-anna-stubblefield.html</u>.
- Engber, Daniel. "The Strange Case of Anna Stubblefield, Revisited." The New York Times Magazine, April 5, 2018. Accessed at: <u>https://www.nytimes.com/2018/04/05/magazine/the-strange-case-of-anna-stubblefield-revisited.html</u>.
- Fleishmann, Arthur and Carly. *Carly's Voice: Breaking Through Autism*. New York: Touchstone, 2012.
- Foot, Philippa. Natural Goodness. Oxford: Oxford University Press, 2001.

Goode, David. A World Without Words: The Social Construction of Children Born Deaf and Blind. Philadelphia: Temple University Press, 1994.

Greenfeld, Karl Taro. Boy Alone: A Brother's Memoir. Harper: New York, 2009.

- Hacking, Ian. "Humans, Aliens & Autism." Daedalus, Vol. 138, No. 3, On Being Human (Summer, 2009), pp. 44-59.
- Jaworska, Agnieszka and Tannenbaum, Julie. "Person-Rearing Relationships as a Key to Higher Moral Status." Ethics , Vol. 124, No. 2 (January 2014), pp. 242-271.
- Julius, AJ. The Jurisprudence Annual Lecture 2016, "Mutual Recognition." Jurisprudence, 7:2, 193-209, 2016.
- Kittay, Eva Feder. Love's Labor. New York: Routledge, 1999.
- Kittay, Eva Feder. "Comments on Alice Crary's The Horrific History of Comparisons between Cognitive Disability and Animality (and How to Move Past It) and Peter Singer's Response to Crary." Presented at the Center for Human Values, Princeton University, November 28th, 2017.
- Kittay, Eva Feder. Learning from My Daughter. Oxford: Oxford University Press, 2019.
- Kittay, Eva Feder. "The Personal is Philosophical is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield." Metaphilosophy, 40: 606-627. 2009.
- Kittay, Eva Feder. "The Ethics of Care, Dependence, and Disability." Ratio Juris, 24: 49-58. 2011.
- Kittay, Eva Feder and Feder, Ellen. *Theoretical Perspectives on Dependency and Women*. Rowman and Littlefield, 2002.
- Leslie, Sarah-Jane. "Expectations of brilliance underlie gender distributions across academic disciplines." *Science*, Vol 347, Issue 6219, pp. 262-265. 2015.
- Light, Janice, and McNaughton, David. "Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication?" Augmentative and Alternative Communication, Vol 30. 2014

- McMahan, Jeff. "Cognitive Disability, Misfortune, and Justice," *Philosophy and Public Affairs*, 25:3–31, 1996.
- McMahan, Jeff. The Ethics of Killing. Oxford: Oxford University Press, 2002.
- McMahan, Jeff. "Radical Cognitive Limitation," in *Disability and Disadvantage*, K. Brownlee and A. Cureton (eds.), New York: Oxford University Press, 240–259, 2009.
- Patel, D., Apple, R., Kanungo, S., & Akkal, A. (2018). Intellectual disability: definitions, evaluation and principles of treatment. *Pediatric Medicine*, *1*. doi:10.21037/pm.2018.12.02
- Porter R., Wright D. *The Confinement of the Insane: International Perspectives*, *1800–1965*. Cambridge University Press, 2003.
- Simpson, E. A., Murray, L., Paukner, A., & Ferrari, P. F. (2014). The mirror neuron system as revealed through neonatal imitation: presence from birth, predictive power and evidence of plasticity. *Philosophical transactions of the Royal Society of London. Series B, Biological sciences*, 369(1644), 20130289.
- Singer, Peter. Animal Liberation: A New Ethics for Our Treatment of Animals. Harper Collins, 1975.
- Singer, Peter. "All Animals are Equal." In Tom Regan & Peter Singer (eds.), *Animal Rights and Human Obligations*. Oxford: Oxford University Press. pp. 215--226 (1989).
- Singer, Peter. *Practical Ethics*, Second Edition. Cambridge: Cambridge University Press, 1993.
- Singer, Peter. The Life You Can Save. New York: Random House, 2009.
- Singer, Peter. "Speciesism and Moral Status." *Cognitive Disability and its Challenge to Moral Philosophy*. Maldon: Wiley- Blackwell, 2010.
- Singer, Peter. "Comments on Alice Crary's The Horrific History of Comparisons between Cognitive Disability and Animality (and How to Move Past It)." 2017.
- Stubblefield, Anna. 2007. "'Beyond the Pale:' Tainted Whiteness, Cognitive Disability, and Eugenic Sterilization." *Hypatia: A Journal of Feminist Philosophy* 22 (2): 162-181.
- Taylor, Ashley. "'Lives Worth Living:' Theorizing Moral Status and Expressions of Human Life." Disabilities Studies Quarterly, Vol 33, No 4 (2013).

- Trent, James. *Inventing the Feeble Mind: A History of Intellectual Disability in the United States*. Oxford: Oxford University Press, 2016.
- Waldron, Jeremy, "Basic Equality "(December 5, 2008). NYU School of Law, Public Law Research Paper No. 08-61.
- Wehmeyer, Michael L., ed. The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception. Baltimore: Paul H. Brookes Publishing Company, 2013.
- Williams, Bernard. *Philosophy as a Humanistic Discipline*. Princeton: Princeton University Press, 2006.
- Wolfensberger, W. "The Origin and Nature of Our Institutional Models". Changing Patterns in Residential Services for the Mentally Retarded. President's Committee on Mental Retardation, Washington, D.C. 1969.
- Wong, Sophia. 2010. "Duties of Justice to Citizens with Cognitive Disabilities." In Cognitive Disability and its Challenge to Moral Philosophy, edited by Eva Feder Kittay and Licia Carlson, 127-146. Malden, MA: Wiley-Blackwell.