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NEURODIVERGENT LEADERSHIP: BUILDING MULTIPLE POSSIBLE FUTURES THROUGH INTERSECTIONAL INTERDEPDENDENCE

A dissertation submitted in partial satisfaction
of the requirement for the degree of

DOCTOR OF PHILOSOPHY

in

SOCIOLOGY

by

Laura Harrison

December 2019

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Table of Contents

Chapter One:

an *INTRODUCTION* 1 - 16

Chapter Two:

The "*Rabbit Hole*" 17 - 60

Chapter Three:

Neurodivergent Leadership: The ACAT/ACT Case 61 - 113

Chapter Four:

"Nothing About Us Without Us":

A *Neurodivergent Education Model* (NEM) 114 - 167

Chapter Five:

Self-Determination Training: Trauma-Informed Practices, 168 - 242

Interdependent Transitions and *Multiple Possible Futures*

Chapter Six:

a *CONCLUSION* 243 – 250

Bibliography 251 – 272

List of Figures and Photographs:

Figure 1. HEW Occupation Map, p. 19

Figure 2. Photo of Ed Robert's Campus Mural, p. 21

Figure 3. Image from Disney's *Alice in Wonderland*, p. 25

Figure 4. Image of Judy Cunio, p. 65

Figure 5. Photo of ACAT/ACT Teaching Tool, p. 104

Figure 8. "Figure 1: Violent Victimization, by Disability Status, 2009-2015," p. 145

Figure 9. "Table 4: Rate of Violent Victimization Against Persons with Disabilities, by Disability Type and Type of Crime, 2011-2015," p. 147

Figure 10. "Victim Relationship to Offender," p. 148

Figure 11. "Sexual Assault Rates Among People with Intellectual Disabilities, 2011-2015," 149

Figure 12. Photo of ACAT/ACT Poster Presented at 2015 Day of Mourning Vigil at the Ed Roberts Campus to honor disabled murder victims, p. 164

Figure 13. Wehymeyer's (1999) "Figure 1: A Functional Model of Self-Determination," p. 176

Figure 14. "Figure 7: Cumulative pages published by the *Journal of the Experimental Analysis of Behavior* (JEAB) and by the *Journal of Applied Behavior Analysis* (JABA) between 1958-1996," p. 208

Figure 15. "Red Horn Woman" Quote, p. 227

Figure 16. "Son of Baldwin" Quote, p. 228

Figure 17. "10 Principles of Disability Justice," p. 236

List of Illustrations:

Illustration 1. “Prone, Basket and Supine ABAI-Advocated Restraint ‘Holds’,” p. 232

List of Charts & Tables:

Chart 1. Sex/Gender of ACAT/ACT CBTIs, p. 89

Chart 2. CBTI Age Ranges, p. 89

Chart 3. Race/Ethnicity of ACAT/ACT CBTIs, 90

Chart 4. Intersections of Race & Sex/Gender of CBTIs, p. 91

Chart 5. Divergent “Disability” Identities Among CBTIs, p.92

Chart 6. Neurotypical & TAD-Only CBTIs: Intersections of Race, Sex/Gender, & Disability, p. 94

Chart 7. ND-Only, N/A-Only & DNA CBTIs: Intersections of Race, Disability, Neurodiversity & Autism, p. 96

Chart 8. Intersections of Sex/Gender & Disability, Neurodiversity and Autism for CBTIs, p. 97

Chart 9. Intersections of Racial & Disability Identities Among CBTIs, p. 99

Table 1. Intersections of Race, Disability, Neurodiversity & Autism among CBTIs, p. 99

Table 2. Contrasting “Special/Medical” versus “Neurodivergent” Models of Education, p. 115

Abstract

Neurodivergent Leadership:

Building Multiple Possible Futures Through Intersectional Interdependence

Laura Harrison

Ala Costa Adult Transition (ACAT) and Adult Community Training (ACT) Programs' "neurodivergent leadership" and "Neurodivergent Education Model" (NEM) present a unique moment of opportunity for a neurodivergent and disabled ethnographer. In the findings from a case study of the ACAT/ACT programs, this project analyzes how "intersectional interdependence" is mobilized in transition-making and how "transition-making," grounded in self-determination skill training, can work as a model for social movement and change. Through the trope of a Carroll-ian "rabbit hole," this project travels through its Berkeley, CA field site to explore territories where self-determination skills are taught and shared among/between a majority-neurodivergent group of Community-Based Teachers/Instructors (CBTIs) and intergenerational cohorts of Intellectually and/or Developmentally Disabled (I/DD) adults immersed in their IDEA mandated "Transition Program." Under a disabled, neurodivergent, and autistic (DNA) leadership, ACAT/ACT CBTIs and I/DD students have, for just over a decade, been immersed in the intersectional work of designing interdependent and accessible methods of self-determination training that resist dominant and assimilationist methods of Applied Behavioral Analysis,

Normalization (be it behavioral or environmental), and/or Social Role Valorization. In working toward multiple possible futures for neurodivergent communities un-restrained by neurotypical disciplinary methods of compliance-making, the ACAT/ACT programs offer trauma-informed self-determination skill training for I/DD adults attempting to do the work of deinstitutionalization begun by past generations of neurodivergent leaders that is transition-making.

CHAPTER 1

an INTRODUCTION

Entre to the Field

If neurodivergent communities have a sort of "capitol," one such site is Facebook. Not surprisingly then, I first discovered *Ala Costa Adult Transition (ACAT) and Adult Community Training (ACT) Programs* by way of a job announcement for an open "Community-Based Teacher/Instructor" (CBTI) position shared on Facebook. The ACAT/ACT programs are unique because they are run under a disabled, neurodivergent and autistic design and direction. The job seemed as though it was tailored just for me. I was incredibly eager for part-time employment that would give me the opportunity to work with/for disabled people--ideally, disabled adults--while I worked toward completing my dissertation. After editing-out the many, enthusiastic exclamation marks present in my first drafts, I emailed my resume and cover letter to the director of ACAT/ACT, Brent White. Brent wrote back with an invitation to participate in an ACAT/ACT "meet and greet"—their preference in hiring processes "as opposed to traditional interviews"—and his email contained two exclamation marks (!!) which left me feeling that perhaps we were both excited to meet each other in equal measure. We scheduled my meet and greet for August 16th, 2016 at ACAT/ACT's office located at the *Ed Roberts Campus* (ERC) in Berkeley, CA. Suffice it to say, for now, I was not able to accept the job working as a CBTI with the ACAT/ACT programs. All the same, however, I began my journey through "the rabbit hole" that day.

But, before poking our heads too far into the rabbit hole, let's hop forward in time a bit so I can tell you about where the rabbit hole will go and how I learned to navigate it.

The Rabbit Hole: Neurodivergent Leadership, Self-Determination, & Transition-Making

Two years in the field with ACAT/ACT studying the concept and practice of "Neurodivergent Leadership" has given this project three primary foci:

1. What is "Neurodivergent Leadership"
    (a) Why practice Community-Based Teaching?
    (b) How does the practice of Neurodiversity affect Leadership?
2. How do people "make a move" from a position of intergenerational trauma?
    (a) What are Self-Determination Skills?
    (b) How can "transition-making" model "social movement"?
3. Is the future (of social movements) "accessible" to I/DD leaders?
    (a) What is *Intersectional Interdependence*?
    (b) How do we build transitions or make movements toward a more just future?

The history of neurodivergent communities in the United States of America is a largely institutionalized history—a story of discipline, almost exclusively told by institutionalists, through medical histories and/or educational reform models. Few historical accounts of the lived experiences of neurodivergent communities in the U.S. are written from a social perspective; and, even fewer personal accounts and testimonies have been documented[1]:

> **Ken Neuman:** You've seen what you've seen, and we've seen what we've seen, and the staff says, *"Hey, no one will believe you but they'll believe us."* OK, then from there you say what you say to the parents when you see something and you tell them nothing but the truth what happened out there, and soon as the parents leave, *then they'll put you in lockup*.
> **Shirley Neuman:** They treated us like dirt and they didn't treat us right. And we were scared and we didn't know what to do, and we just ran away and they caught us and we came back and *we were locked up*. (Neuman, 2019).

In this short excerpt, Ken Neuman and Shirley Neuman describe how presumptions of incompetence were mobilized to perpetuate the abuse and trauma of I/DD inmates[2] institutionalized at the Fairview Training Center[3] (1907-2000), a Salem, Oregon institution, in a short film called, "Fairview Survivors."[4] These are some of the leaders of past I/DD generations who were punished, abused, and "locked up" for over 100 years in U.S. history for their "community-based" leadership practices, self-

[1] For one example of personal accounts/testimony, listen to Karen Gorr (Gorr, 2019).
[2] Ken and Shirley Neuman's desciptions of being "locked up" also highlight the carceral situation of institutionalized I/DD children and adults and why it is more accurate to refer to institutionalized populations as "inmates" as opposed to "residents" or "students" (Neuman, 2019).
[3] "Voices of Fairview" is another film documenting Fairview inmate experiences of abuse, trauma, and "torture" with a "wet blanket," "scalding with hot water," "slapped/hit," "hung inside a laundry bag," "restraints/shackles," "inhumane treatment," and "forced sterilizations" (DD Coalition, 2014).
[4] Neuman, 2019.

advocacy skills, and self-determination to expose and/or escape a carceral institutionalization without possibility of "parole" for the "crime" of being intellectually and/or developmentally disabled.

Leadership is, put simply, a place to start. Today, in the ACAT/ACT program for I/DD adults attempting to "transition" out of special education and into independent adulthood in Berkeley, CA, the history of neurodivergent communities in the US has found new life, "turning history on its head" (so to speak of Marx). Under a "neurodivergent leadership"—as opposed to traditionally neurotypical, non-disabled, medical/educational superintendent "leaders"—this transition program is staffed by a majority of "neurodivergent-identifying" people. By applying the social model of disability to their community-based experiences of work, the neurodivergent staff understand their lived-experiences to be subject to far fewer disabling barriers than the I/DD student/clients whom they serve. To my knowledge, this program and leadership structure is the only one of its kind. At ACAT/ACT, neurodivergent "staff" and I/DD "inmates," in this historically revisionist experiment, train each other in neurodiverse, deinstitutionalized, trauma-informed, and community-based self-determination practices. The ACAT/ACT case works to highlight a necessary critique of disability and "neurodivergent leadership" as an impoverished U.S. tradition. To my knowledge, ACAT/ACT are the only autistic and neurodivergent led programs providing transition services to adults with intellectual and developmental disabilities in the history of the United States; including, the present. From their unique position within the history of special education services post-deinstitutionalization,

neurodivergent-led "transitional" priorities and strategies de-privilege "neurotypical competencies" as ableist measures of productivity, labor, value, and human worth.

The majority of community teachers and administrators at ACAT/ACT identify as neurodivergent. Students, however, do not tend to self-identify as "neurodivergent." This is also reflected in the language staff are most likely to use when describing students' disability statuses to community members--identifiers like "intellectual disability," "developmental disability," or "autistic" are the most common ascriptions and self-identifiers for students--especially in program literature and advertisements. While neurodiversity encompasses these terms, it is not synonymous with or reducible to them. In "**Neurodivergent Leadership**," instead of asking whether or not adult I/DD students are "capable" of self-identifying with a concept like "neurodiversity" (because that would be ridiculous), this chapter explores the relationship between terms like "neurodiversity" and "disability" as they impact the staff and administrators at ACAT/ACT who work under conditions of a "neurodivergent leadership." Through their experiences "working for" adult I/DD students in the community, the vast majority of teachers at ACAT/ACT have come to self-identify as "neurodivergent," but do not self-identify as disabled. In some ways, staff distance themselves from what they have come to recognize as a "disability experience" after witnessing the barriers to community life that I/DD student/clients experience on a daily basis.

With neurodivergent teachers' attempts to honor difference (degrees of access/privilege not shared with students) and unequal power relations, the term

"disability" is reserved for those whose bodyminds are most (or more) impacted by ableism and perceived in/by the community (on sight/site) as "disabled"--students cannot "pass" as nondisabled and do not self-identify as "only neurodivergent." The majority of community teachers trained in neurodivergent leadership at ACAT/ACT do not identify as "disabled" and can "pass." In order to respect and honor the lived experiences of the most impacted members of I/DD communities--i.e. people of color and/or women who may be identified as neurodivergent, but are near-universally identified as "disabled too" and/or "first"--the predominantly "neurodivergent-only" CBTIs, and "neurodivergent leaders" in-training, must ground their work in a self-determination-centered, pro-relational, anti-behaviorist practice of "intersectional interdependence" that spits in the face of Wolfensberger-ian[5], neurotypical normalization theories and a "PASS/ING-"trained leadership[6] in disability service provision or community organization. "Neurodivergent leaders" trained in ACAT/ACT programs ground their "work for" neurodivergent communities in what I call an "intersectional interdependence": "working for," "moving" or "transitioning" toward healing the on-going intergenerational trauma of institutionalization and the community disempowerment that inevitably results from over 100 years of dehumanization, violence, exclusion, and appropriation.

In an attempt to design a program that could embody and practice the slogan of the Disability Rights Movement—"*Nothing About Us, Without Us*"—ACAT/ACT

[5] Wolfensberg, 2017b
[6] Wolfensberg, 2017a

conduct community-based training with I/DD adults under a "Neurodivergent Education Model" (NEM) that encourages neurodiversity over/above normalization or "passing;" and, promotes community integration by way of interdependent commitments to diversity in self-determination, not cultural assimilation or acculturation. The chapter "***Nothing About Us, Without Us: A Neurodivergent Education Model (NEM)***" situates the historically radical, yet non-utopic, experiment in deinstitutionalized, neurodivergent-led education that ACAT/ACT represents today with its autistic, neurodivergent, and disabled design and leadership. NEM is broken into three major "movements" and this chapter explores the first two: legitimizing neurodivergent and trauma-informed practices. Following an analysis of these first two "movements" in "transition-making," the next chapter explores the program's third "movement": Community-Based Self-Determination Training.

Disability and neurodivergent leadership are long overdue in U.S. disability movement and "transition-making" after well over a century's long history of I/DD institutionalization[7]. Classically "pessimistic," neurotypically predetermined "transition goals" work for the foreclose of neurodivergent community organizing and leadership formation, particularly for those classified as most "severely disabled." It is long pastime for what I am calling an *intersectional interdependence* across disability communities and their leadership that works to make historically significant transitions toward multiple possible futures for the "most impacted" members of

[7] Classically "pessimistic," neurotypically predetermined and reified probabilities "working for" the foreclose of neurodivergent community organizing and leadership formation, particularly for those classified as most "severe."

disability communities. "**Self-Determination Training: Trauma-Informed Practices, Interdependent Transitions, and Multiple Possible Futures**" attempts to unpack this concept of "intersectional interdependence" in terms of what it "works for": a trauma-informed, self-determination-centered method of "social movement" (or, community-based transition) toward "multiple possible futures;" including, a neurodivergent leadership of "those most impacted" (Berne, 2015). One such possible future would include the material realization of "disability justice" in the form of an I/DD leadership that could (ideally abolish, but at least) "work for" de-privileging ableist hierarchies of "high/low" functioning, deconstructing neurotypical expectations of "social movement," and dismantling capitalist evaluations of productivity, labor, and value. "Transition-Making" will, throughout this work, be discussed as a model for Socio-Cultural "Movement-Making" as well and by the extension of self-determination theory from the individual (special education literatures) to the social (critical race and ethnic literatures) political scale.

A "Road Map": METHODOLOGY

When I was not able to take the job as a CBTI with ACAT/ACT in August of 2016, I didn't have the opportunity to work with them again until January 12th, 2017 when I began volunteering with the ACAT/ACT programs. Facebook served as my segue a second time. Around the new year (2017), I appealed to my Facebook community in a search for volunteer opportunities with disabled people in the Bay area of CA. In response to my post, Brent invited me to come by the ACAT/ACT

office. Brent was looking for some support in putting together a set of public and program-based presentations about "neurodiversity;" and, specifically, his work toward designing a "Neurodivergent Education Model" (NEM) built on a practice of "Neurodivergent Leadership." I was eager to take advantage of any opportunity to work with ACAT/ACT—a program designed by/for disabled adults—and enthusiastically accepted his invitation to volunteer.

Starting in January of 2017, I became a program volunteer specifically supporting Brent (Program Director), Tania Coffield (Program Supervisor) and "Joan" (pseudonym, Program Coordinator) in their efforts to design presentations about the ACAT/ACT program, NEM, neurodivergent leadership, and neurodiversity more generally. I would visit the ACAT/ACT office at least once a week (often more) on Thursdays and attend the voluntary (non-required) "Neurodivergent Leadership Training" sessions Brent and Tania would host for staff bi-weekly. During my office visits, Brent, Tania, Joan and I would have hours-long conversations about the ACAT/ACT program, its design, and the process behind the practice of that design.

Sometimes four of us would be present for these conversations; whereas, other times fewer could participate--Tania and Joan regularly had to work as substitute-CBTIs, leaving the conversation to Brent and I on those days. When volunteering in the office, my job was to take notes and record our weekly conversations verbatim using a voice recorder so that we (especially Brent and I) could listen to our conversations again later, continue processing the conversation, and make any additions or changes felt necessary to the design notes. I also volunteered to ask

clarifying questions as the conversation proceeded. Praise was especially lobbed at me when I listened well enough to accurately translate or convert their complex ideas into accessible language that could be presented to an audience.

"Neurodivergent leadership trainings" were hosted by Brent and Tania bi-weekly from 2-3pm. More often than not, trainings were held in an ERC conference room, but sometimes we gathered together in the much closer-quarters of the office. During "neurodivergent leadership training" sessions, I would observe and take notes. Typically, I did not participate; however, I did participate when I was asked to do so by administrators or staff. These meetings were not like the staff meetings I started attending after April 1st, 2017 wherein weekly programmatic routines and/or changes were reviewed. Unlike Wednesday's weekly staff meetings (1-2p)[8] which were mandatory for all CBTIs as part of their work week; bi-weekly "neurodivergent leadership training" was entirely voluntary, technically not a part of any CBTI's job requirements, and thus exhibited much lower attendance rates of 4-10 CBTIs.

My work with ACAT/ACT from January 12th-April 1st, 2017 (approximately 2.5+ months) was purely voluntary with no connection to my own research or academic work; excepting the fact that I was volunteering my skills as a researcher and writer to their program. In late March 2017, however, Brent asked if he could talk to me about an idea he had been pondering for some time. I met Brent in the ACAT/ACT office for our usual volunteer work on Thursday, March 30th, 2017.

[8] Wednesdays are the only day of the week that ACAT/ACT closes before 2p and only for staff meetings.

After we had completed a good day's work toward drafting a description of neurodiversity, neurodivergent leadership and NEM--and after all student/clients had left program for the day—Brent proposed that I should conduct my dissertation research with ACAT/ACT. In his thinking, as he explained, I was already contributing a lot of valuable labor and support to the program as a regular volunteer; and, it would be to the benefit of the program if I could continue providing the support I had been providing thus far. Although there was not an accessible, paid position available for me at ACAT/ACT, Brent suggested a kind of "win-win" compromise for both of us: I could continue as a volunteer for the program while conducting ethnographic fieldwork and interviews with ACAT/ACT staff.

Brent essentially suggested that in exchange for my free, volunteer labor, he could--as the director of ACAT/ACT with vastly intersecting personal and professional expertise--volunteer the program as a field site for my doctoral research. I felt like Charlie Bucket the morning he celebrated finding a golden ticket to Willy Wonka's Chocolate Factory with Grandpa Joe--I had the opportunity to work with disabled adults with whom I had already formed a strong volunteer working relationship while conducting the necessary research for my dissertation in one golden package (1971).[9] From this conversation, Brent and I agreed to pursue a *co-participatory*[10] research project to study the concept and practice of "Neurodivergent Leadership" based on my ethnographic, participatory-observational field work at

[9] Wilder, G., Albertson, J., Stuart, M., Dahl, R. (1971). *Willy Wonka & The Chocolate Factory*.
[10] This research project was designed and implemented from the start with Brent White. Brent White is both co-researcher and research subject. The project grew as an "extension" of my original volunteer work and "transitioning" neurodivergent practices into academic discourses.

ACAT/ACT with Brent, Tania, and any CBTIs or program coordinators interested in participation. In order to avoid incredible institutional barriers, Brent and I agreed that while I would observe the program and all of its participants as a whole; I would limit my interviewing (and all "participatory" research) to ACAT/ACT staff only—ie. persons with the legal right to provide independent consent; not the case for most adult I/DD student/clients under the legal constraints of guardianships and conservatorships.

As of April 1st, 2017, I had my "researcher hat" on. However, I continued as an informal volunteer with ACAT/ACT from January 12th, 2017-November 30th, 2017, the date on which the UCSC review board (finally[11]) approved my research project protocol. It was not until December 1st, 2017 that I officially began my formal research with ACAT/ACT: a co-participatory ethnography involving subject dependent, non-/participatory-observation[12], one-on-one interviews, group interviews, and pseudo-/informal-focus group discussions in the context of staff trainings. After nearly one full year of informal volunteering, I began formally interviewing ACAT/ACT staff (administrators, coordinators, and CBTIs) and conducting participatory observational research for my dissertation project on "Neurodivergent Leadership."

[11] The process of IRB approval was significantly delayed because of the neurodivergent and/or I/D disability status of my research subjects and their automatic classification as "vulnerable" populations.
[12] No ACAT/ACT students were interviewed for this project. "Participatory" research involving students is strictly anonymous. ACAT/ACT student/clients are, regrettably, only non-participatory subjects in this research as a result of their legally compromised right to consent.

In addition to approximately 11 months of volunteer work (1/12/17-12/1/17), my formal research with ACAT/ACT took place from December 1st, 2017 - October 19th, 2018 (approx. 10 months). In total, I worked with ACAT/ACT as an informal volunteer and/or formal researcher from January 12th, 2017 - October, 19th, 2018. My project, therefore, is based on approximately 21 consecutive months, or nearly 2-full years, working in both in/formal capacities with ACAT/ACT; and, across two separate cohorts of ACAT/ACT student/clients "graduating" into "transition" services in the fall of 2017 and 2018.

My field site was the ACAT/ACT office; but, also generally included the ERC, its atrium, public and conference spaces. In my field site, I met and interacted with all ACAT/ACT student/clients (and some of their families) in-program from Winter, 2016 - Fall, 2018. I also met and worked with all CBTIs, program coordinators and administrators in-program during this same time period. While I did interact with students on a weekly basis throughout my fieldwork, I was not doing so for purposes of research. No in/formal interviews were conducted with any students/clients in this project. Only anonymous observational data was gathered during my interactions with students.

At the ERC, and especially in the ACAT/ACT office, I conducted participatory observational research for nearly two years. I quickly became a "regular" in the ACAT/ACT office, participating and/or observing IEP/ISP meetings, discussions with Ala Costa Center coordinators, prospective employee "meet and greets," Berkeley High School Special Education organizational meetings, and

interactions with the police among many other "regular" office procedures. Thursday's from 10a-4p, in particular, were schedule blocked-out as "Laura Research Days" because these were the days when I would shadow Brent and Tania (and sometimes coordinators as well) in the ACAT/ACT office. In addition to this subject-dependent participatory observational research, I also conducted weekly interviews with the programs' designer and director, Brent White. Sometimes these interviews would become group-based conversations and interviews involving the supervisor (Tania), coordinators, and CBTIs.

While shadowing Brent and Tania's daily work, I conducted informal interviews that consisted of asking Brent and Tania (unless Tania was in the community subbing) to explain--on a daily basis--more-or-less all of what they were doing, while they were doing it. Typically, this questioning required each of them respectively to explain: "how" they were doing things; "why" they were doing things in the specific ways that they were doing them; "how/why" one thing connected to another; and, what experience informed their understanding of the "hows" and "whys" involved in carrying out "transitional" work in this way. Quite often these questions revealed differences in Brent and Tania's experiences with, and interpretations of, "transition" work--some profoundly complimentary, others predictably divided, and still others surprisingly divergent—and gave each of them the opportunity to understand their officemate's perspective all the more than they seemed to already. For 4-6 hours each day, Brent (always) and Tania (most days)

taught me as much as they could within our openly-communicated professional[13], time[14], and "spoon"[15] constraints.

All CBTIs work part-time at ACAT/ACT Monday through Friday from 8a-2p for $15-$16/hr; that is, equal to or $1 greater than the city of Berkeley's minimum wage. They also frequently have to leave the ERC at 2p in order to make the commute to their second/third jobs--very few CBTIs work at ACAT/ACT exclusively. To put it lightly, ACAT/ACT CBTIs work really hard, and "on their feet," every day. It is understandable, for these reasons and many others, that most teacher/instructors were not in a position to offer me the free time and labor involved in any in/formal interviewing. All of the CBTIs I met between 2016-18 welcomed me to observe them and their interactions with student/clients as well as other staff while they were at work. These observations took place while they were working at the ERC, in moments between shifts, during staff meetings or trainings, and whenever CBTIs visited the ACAT/ACT office. The majority of the staff will, however, remain anonymous throughout this research; with five exceptions.

Five CBTIs were willing and able to participate in individual, formal interviews. These interview participants will be referred to by way of pseudonym so as to protect and respect their confidentiality outside of the program. Some CBTIs

[13] Strong efforts were always made to protect the privacy rights of all ACAT/ACT student/clients as a professional obligation both Brent and I observed independently and respectively as the program director and the program researcher.
[14] I was always taking up their work time. Their job was not my research, but the transition program and that was the main focus of their time--a focus I wanted to honor and respect. When time to talk or act was low (in short supply), it was time to do close observation and let staff carry out their work with students.
[15] Miserandino, 2003.

elected to conduct their interview at the ERC; while others preferred to be interviewed in their own homes. In addition to these five individual interviews with CBTIs, I also formally interviewed the programs' (now former-) supervisor, Tania Coffield. All six of these interviews were on the interviewee's personal time (not work time) and lasted between 1-3 hours each.

With this introduction to my project and methods, into the rabbit hole we go…

CHAPTER 2

The "*Rabbit Hole*"

In this chapter, I historically situate the space in which ACAT/ACT materialized into the programs they are today: Berkeley, CA. This brief historical review is accompanied by a discussion of how a disabled and neurodivergent graduate student like me came to design a co-participatory ethnographic research project with Brent White, the Disabled, Neurodivergent, and Autistic (DNA) Director of both programs. Woven together, these three threads—Disability Movements in Berkeley (1970s-1990s), Brent White's ACAT/ACT "vision" (2009-2019), and a disabled/neurodivergent ethnographer (2016-2018)—are like three acts in a historical play about deinstitutionalization movements, "transition-making" post-deinstitutionalization within the non-profit industrial complex, and the present moment where they intersect, even in this work.

The Ed Roberts Campus & Legacies of 504

Berkeley, CA—and the Bay Area of California, more generally—has been home to one of the most politically influential and powerful factions of the Disability Rights and Independent Living Movements in the US, especially since the 1970s. Perhaps the most historically recognized and publicly celebrated leader of these largely concurrent movements started his work in Berkeley: Ed Roberts (1939-1995) has gone down in U.S. Disability History as a "true pioneer":

> He was the first student with significant disabilities to attend UC Berkeley. He was a founder of UC's Physically Disabled Students Program, which became the model for Berkeley's Center for Independent Living (CIL) and over 400 independent living centers across the country. He was one of the early directors of CIL. He was the first California State Director of Rehabilitation with a disability; he was awarded a MacArthur fellowship; and he was co–founder and President of the World Institute on Disability ("About," edrobertscampus.org).

Roberts was one of several disabled leaders who participated in the "San Francisco Sit-In" or the "504 Sit-In" of 1977, for instance.[16] Importantly, however, and as is unique to the history of American Sit-Ins, the SF 504 Sit-In of 1977 was: 1) largely led by disabled women, with disabled queer women playing particularly powerful organizing roles; and 2) collaboratively led and largely sustained by members of the Black Panther Party (Cone, n.d.; O'Toole, 2015; Paul K. Longmore Institute, 2017; Schweik, 2011; NYT, 1977).

As perhaps the most politically prolific, former-504 leader and continuing disability civil rights advocate, Judy Heumann[17], put it:

> Through the sit-in, we turned ourselves from being ***oppressed individuals*** into being ***empowered people***. We demonstrated to the entire nation that ***disabled people could take control over our own lives and take leadership*** in the struggle for equality (Grim, 2015; emphasis added).

The San Francisco Sit-In was only one section of a nationally-organized, cross-disability protest demonstration meant to pressure the Carter administration into enforcing Section 504 of the *Rehabilitation Act of 1973*, an act recognized as the first disability civil rights law enacted in the history of the United States, the first law to prohibit discrimination on the basis of disability in the US, and the principle precursor to the Americans with Disabilities Act (ADA) of 1990. This national protest in 1977 sought to demand the enforcement of *Section 504*, to further define "disability-based discrimination" in view of the public--after several years of contradictory decisions handed down by courts post-1973--and to situate disability discrimination within U.S.

[16] Roberts, Ed. (1977).
[17] U.S. Department of State. (2010).

histories of racial and gender based anti-discrimination legislation. A group of approximately 120-150 disability rights activists and leaders of the disability rights and independent living movements from all over the Bay Area of California (Berkeley, San Francisco, Oakland, etc) occupied the Health, Education, and Welfare (HEW) building in San Francisco for 26 consecutive days in April, 1977--this sit-in is recognized as the longest occupation of a federal building in US history (Paul K. Longmore Institute on Disability, 2017).

Figure 1: Map of HEW Offices where Protests led by Disabled People Took Place in April 1977

Line Drawing of a US map showing the location of HEW offices where protests first took place: Washington D.C., Boston, Seattle, New York, Atlanta, Philadelphia, Chicago, Dallas, San Francisco, and Denver. (Paul K. Longmore Institute on Disability, 2017.

Victory for 504-occupants was signaled in two ways: 1) President Carter's Secretary of the HEW, Joseph Califano, signed regulations into effect on April 28th, 1977; and, 2) in the words of Kitty Cone--a queer and disabled leader and organizer of the SF 504 Sit-In--by "the public birth of the disability rights movement" because "for the first time, disability really was looked at as an issue of civil rights rather than an issue of charity and rehabilitation at best, pity at worst" (Grim, 2015; NYT, 1977). The Bay Area of California has a long, particularly "radical" history in the ongoing US Disability Rights and Independent Living Movements. Berkeley became a

particular hub of activity because of the Berkeley Center for Independent Living (CIL), the first CIL in the US which was largely organized by disabled UC Berkeley students, including (but far from limited to) Ed Roberts himself (Zukas, 1975; Kleinfield, 1992). This "radical" quality ascribed to Bay Area disability activists and the history of their disability activism, particularly as regards the rise of the Independent Living Movement, made the emergence of today's Disability Justice Movement in the same geographic spaces possible as well.

The *Ed Roberts Campus* (ERC)[18] was commissioned shortly after Ed Roberts' death in 1995 in order to memorialize and honor his lifetime of work in both Disability Rights and Independent Living Movements. The ERC is a nonprofit (501c3) corporation and center serving diverse groups of disabled Bay Area residents by housing a variety of organizations, including: *Toolworks*, *Lighthouse for the Blind*, *California Telephone Access Program* (CTAP), *Center for Independent Living* (CIL), *California Department of Rehabilitation*, *Alameda Alliance for Health*, and *Ala Costa Centers*, among others. Constructed collaboratively, the ERC is meant to be "a universally designed, transit-oriented campus located at the Ashby BART Station in South Berkeley".[19] However, one disabled elder--a disabled disability activist in the Bay Area since the 1970s who participated in the 504 Sit-In and who is currently still working, organizing and living in the Bay Area--describes the ERC as a

[18] Ed Roberts Campus, 2018; Wolfensberger, 1999: 54-55.
[19] Ed Roberts Campus. (2018).

"mausoleum" that resonates with the "death" or "dying" of the early-rights movement and serving as its pseudo-final resting place (Anonymous).

My scheduled "meet and greet" with Brent White in August of 2016 would not be my first visit to the ERC. The first time I ever visited the ERC was July 26th, 2015 (about one year earlier). I went to see the "Patient No More" exhibit hosted for a time at the ERC and organized by the *Paul K. Longmore Institute on Disability*. The "Patient No More" project is a uniquely accessible and interactive exhibit documenting the history of the 504-Sit In. In-person, it was like nothing I had ever encountered before or since. The only part of the exhibit that remains to this day at the ERC is a photographic mural depicting moments in the 504 Sit-In along a two-story wall that traces the perimeter of the building's first-to-second floor circular ramp.

Figure 2: Photograph taken by Laura Harrison, April 26th, 2015 at the *Patient No More* Exhibit located at the Ed Roberts Campus, Berkeley, CA. Also see: Paul K. Longmore Institute on Disability, 2018

I had never physically entered my own history as a disabled person in America in such a visceral way before viewing "Patient No More" (Paul K. Longmore Institute, 2018). I was absolutely awe struck by not only the access features of the exhibit itself (artistic and historical exhibits are often only minimally accessible to disabled communities and this project made it a mission to experiment with the possibilities of access in exhibition); but, also by the physical access features of the ERC building and how prominently these features were highlighted as proud architectural and design accomplishments. I can honestly say, I had never had the privilege of attending a disability history exhibit designed by/for disabled people and exhibited in a building designed with disabled peoples' access needs at the center. As a "neurodivergent[20]," "gimp[21]," "walkie[22]," and "blindie[23]," I noticed with relief and glee how: moving between the BART station and the ERC was as easy as an elevator ride; I was never forced to use stairs to get around with the presence of ramps and elevators between floors and open floor plans; there was a two-story wall of windows providing natural light to the building so my eye was under no strain to see; and, the

[20] I have a neurological disability called Charcot-Marie-Tooth (CMT) Disease which is progressive and effects my proprioception and causes neurological decay that "progresses" from my furthest extremities inward overtime eventually causing loss of sensation and muscle atrophy most commonly in the feet (legs) and hands (arms). In addition to CMT, my experiences with depression, anxiety, and trauma are three other reasons I identify as "Neurodivergent" and with neurodivergent communities (plural). Before I disclosed, Brent assumed I identified as neurodivergent because I am a blindie who can see the world only in two-dimensions.

[21] I move through the world using mobility devices (leg braces, currently) without which I would not be able to ambulate independently.

[22] I have the privilege of ambulation which limits access barriers for me, and distinguishes my lived experience from "wheelie" gimps who must contend with access barriers (ex. stairs) I do not experience on an everyday basis.

[23] I am completely blind in my left eye; however, I also wear a prosthesis that allows me to pass as a non-blind person more often than not. With vision in only one eye, I view the world in two-dimensions (do not experience three-dimensional vision) and thus must mentally calculate depths I cannot simply perceive with my eye (do not experience depth perception).

echoing sound of a water fountain was all I needed to find the back of the building (and an accessible bathroom).

It was not until I had been working with ACAT/ACT in their office at the ERC for several months that I became aware of how acutely inaccessible the building could be for my fellow neurodivergent community members. While the spatial design worked well for people like me, it could also be a nightmare for others; including many of the autistic adults with whom I conducted my ethnographic field work at the ERC from August 2016 through October 2018. For instance, the Autistic leaders of ACAT/ACT contended daily with the onslaught of fluorescent lights and permanently vetoed use of the installed fixtures in their office once they were able to construct their own lighting accommodations without ERC support. Not only were the overhead lights disconnected manually, but the wall switches were to be covered/hidden with office decor.

My "Meet & Greet" with ACAT/ACT: AUGUST 16th, 2016

My meet and greet at ACAT was only my second visit to the ERC. I found the *Ala Costa Adult Transition & Adult Community Training Programs* (ACAT/ACT) office on the second floor of the ERC, not far from the elevator that connects the ERC to the Ashby BART station. I rapped gently at the ACAT/ACT office door which was already partly propped-open by a small, black trash can. I immediately heard a dog barking from inside. Through the gap in the door, I could see that the overhead lights were all turned-off (but, I did not know why yet). I wondered if I had wandered from

my path. This was not the kind of office space I expected when preparing for my meet and greet in hopes of becoming a “CBTI” for a “transition program”--I was expecting something closer to your typical visit to any bureaucratic office space, more similar to the predictable experience I would later have while visiting the CIL just downstairs: a very quiet space with cubicle-like walls sparsely and neutrally decorated in a largely beige color-scheme and neatly arranged desks, chairs or other general office equipment.

The ACAT/ACT office consisted of a single room rather dimly lit by natural light coming through a wall of privacy-filmed windows, and a string of white Christmas lights hung along the wall opposite the door. I could hear several people talking inside as I was welcomed by a voice from inside to enter. I pushed the door open to find a beige-grey fold-out table--papers and writing utensils strewn over its surface--surrounded by five people and one white chihuahua seated on the lap of the man at the head of the table. This side of the room seemed designated as a meeting space complete with a table, chairs, and a futon-couch with its back to the wall of windows. The opposite, less-lighted and windowless side of the room held the more traditional office equipment, including: desks, computers, file cabinets, a mini-fridge, microwave and bookshelf filled with texts on neurodiversity, transition programming, and self-determination training. There was one empty seat at the table, closest to the door, toward which I was directed by multiple stimming hands. It was a scene that will forever recall to my mind Alice’s experience stumbling upon a tea party in her

own Wonderland. I had never before, in my life, been welcomed to the table by a group of stimming adults.

Figure 3: image taken from the Disney film "Alice in Wonderland" (1951) wherein a happy, curious, and intrigued Alice is seated at the head of a table surrounded by the Mad Hatter and the March Hare on one side and the Queen of Hearts and the White Rabbit on the other.[24]

As a PhD student, most of the meetings I attended were for academics who seemed to have unspoken rules against freedom of movement--just like in first grade. As a six-year-old girl, I was told repeatedly to sit with my knees closed and hands folded still in my lap, like a "lady." Nearly twenty years later and in order to present or pass as a universal (ie. nondisabled) scholar, I had to elaborate on those first-grade lessons with additional modifications to my behavior and bodily comportment: upon arrival you must find a seat, quietly sit, and hold your body still with "quiet hands" and movements so as to avoid interrupting or otherwise distracting speakers or facilitators; with the only real exception: pen moving across paper while maintaining

[24] Walt Disney Productions, Samuel Armstrong, and Lewis Carroll. (1951). *Walt Disney's Alice in Wonderland*. Racine, Wis: Whitman.

consistent eye-contact with whoever is speaking and only speaking when called upon (either when spoken to, or with hand raised to pose an appropriate question). In this way, stimming would be considered a violation of the behavioral milieu of the academy where minds (but never bodies) meet and where speakers (using their words, not bodies) presume to command the compliance of their audience. In learning to modify my own behavior by curbing my own stims--rocking my trunk and/or doodling in my notebook so as to focus on listening--I could avoid being policed by authorities, if I was willing to sacrifice my own needs in paying attention. Alternatively, when I failed to pass as a universal scholar--rocked in my seat, or dared to doodle when I was expected to be making eye-contact--I was sanctioned and threatened with the loss of my position.

I took a seat in the chair closest to the door with a mixture of wonder and comfort--I immediately (not coincidentally) found the company of stimming adults simultaneously "stimulating" and "soothing"--and settled in for a typical interview situation in which I would have to talk about myself a goodly amount. To my left sat two women. I knew the woman to my immediate left, S. (pseudonym), a fellow-graduate student attending a different university, also studying disability in the Bay Area. I came to learn that while S. had recently completed her fieldwork with ACAT/ACT, she regularly visited the office while writing her findings for her dissertation. We had never met in-person previously though, and so I didn't presume she would know who I was.

To S.'s left sat a white woman I had never met before named, Joan (pseudonym). Joan was one of the program's existing "community teachers/instructors" as well as a program coordinator--she worked in the community some days, and in the office other days. Both S. and Joan appeared to be young women in their 30s, glowing in their femme-expressions of beauty. Together, they stimmed with their hands and fingers, rocking back and forth occasionally yet rhythmically humming a bit, and smiling from ear to ear between what I perceived to be comradery-inspired giggles. Seated next to Joan at the far-head of the table was Brent--a white man in his 50s--with Nora (the Chihuahua) seated in his lap. In his left hand, Brent lightly but tightly whipped the clasping, metal-end of Nora's red leash back and forth, enjoying the sound of it clacking as near as possible to his left ear without ever touching. With his right hand, Brent stimmed with finger/wrist motions in a complementary rhythm to the sound of the metal leash clacking, nearly producing a snap with his fingers to echo the clack of the metal.

Seated to Brent's left, going around the table, was a woman named, Tania. Tania sat on an ergonomic ball-chair bouncing up and down, sometimes stopping abruptly to rock back-and-forth from her core and with poster-posture as her golden-blonde curls swayed in the directions of her movement. All the while, Tania kept herself seated; however, I couldn't help thinking she did not want to be and would prefer to be climbing a mountain or (as would turn out to be more consistent with Tania's past times) navigating a small raft against rushing river rapids. Like Joan and S., Tania appeared to be a white woman in her 30s and presented (to me, upon first

impression) as a strong, potentially fierce, femme who had a firm penchant for physical exercise. Seated next to Tania, and to my immediate right, was Stanley (pseudonym). He stood out to me as perhaps the youngest person in the room--I perceived him as a white man in his late-20s. I came to learn that both Joan and Stanley were working as "community teacher/instructors" and "programs coordinators." Stanley sat relatively still, in contrast to his colleagues, but kept his focus tightly and intently on the space his body occupied, especially the space on the table where his hands were and on the writing utensil he was holding.

The meet and greet began with each person in attendance offering a spoken introduction going around the table, beginning with S. I learned quite a bit about their individual roles at/with ACAT/ACT, but I noticed one other, very significant unifying characteristic across all of their unique introductions: these were all, self-identifying autistic, disabled, and/or neurodivergent adults. After completing the go-round of introductions at the table, this was the point Brent wanted to reiterate: S., Joan, Brent, Tania, and Stanley all identified as disabled, neurodivergent and/or autistic. While S., Joan and Tania all identified similarly with all three identifiers, I noticed a contrast between the two white men in the room. Whereas 50+ year old Brent very strongly identified with all three community identifiers (disabled, neurodivergent, and autistic); 20-30 years-old Stanley was most comfortable with one identifier in particular: neurodivergent. The three women at the table seemed to privilege autism, but only in the company (not to the exclusion) of neurodivergence and disability;

thus, identifying strongly with the intersections of all three, but with their experiences as autistic women holding a central position.

When it was my turn to introduce myself, I was not afraid to identify as both disabled and neurodivergent. This was the very first (and only) time I have ever been unafraid to disclose my disability status in an interview. In any other job interview, I would have been afraid because I knew, for instance, that the employment-population ratio for disabled people in the U.S. in 2016 was a meagre (and terrifyingly dismal) 17.9%; and, this only for those of us in the disability community who are not currently institutionalized, who qualify as part of the "civilian noninstitutional population" (BLS, 2018). It was clear to me by their introductions that my relationship to disability was important to the workplace and to my prospective employment with ACAT/ACT overall; as was my capacity for listening. One of the best things about this neurodivergent "meet and greet"--as opposed to a traditional, neurotypical interview--was that I was not forced to do very much talking at all. My role in the room seemed clear to me: I was there to listen, process, and self-reflect, first and foremost. Post-introductions, it was time for us to review the "little spiel" ACAT/ACT uses to introduce the public and new/prospective employees to their methods and practices of "transition" programming.

What is a "Transition Program"?

Under Section 504 of the *Rehabilitation Act of 1973*[25] and the *Education of All Handicapped Children Act of 1975* (PL 94-142), all disabled children in the U.S. have the right to access a "free appropriate public education" (FAPE). Section B of the *Individuals with Disabilities Education Act* (IDEA)--which, in 1990, amended and replaced the *Education for All Handicapped Children Act of 1975*--continues to mandate that all disabled children in the US have access to a "free and appropriate public education" in the "least restrictive environment" (LRE). Degrees of "restrictiveness" are determined on an individual, case-by-case basis through (typically) annual "Individualized Education Plans" (IEPs) or "Individualized Service Programs" (ISPs)--these are meant to provide individualized guides for disabled students (and their IEP/ISP teams) in their efforts to achieve socially-normative rites of passage (ex. High School Diplomas or GEDs) that mark the student's cultural "transition" from "child" to "adult" (IDEA, 2004; PL 108-446).

Prior to 1975, the vast majority of disabled children in the U.S. could be, and most often were, denied access to education--especially "severely" *intellectually and/or developmentally disabled* (I/DD) children formerly medically diagnosed as

[25] Replacing the Vocational Rehabilitation Act, and amended in 2015 through PL 114-95, the Rehabilitation Act of 1973: "Sets forth requirements for eligibility including the following which a State must demonstrate to the Commissioner: (1) the State has in effect a policy that assures all handicapped children the right to a free appropriate public education; and (2) the State has developed a plan which requires it to assure that a free appropriate public education will be available for all handicapped children between the ages of three and eighteen within the State not later than September 1, 1978, and for all handicapped children between the ages of three and twenty-four within the State not later than September 1, 1980; and (3) each local educational agency in the State will maintain records of the individualized education program for each handicapped child and such program shall be established, reviewed, and revised" (Conference Report Filed in the Senate, S. Rept. 94-455, Education of All Handicapped Children Act, 11/14/1975). See: Library of Congress Congressional Research Service, 1975.

"idiots," "morons," "feebleminded," "mental deficients," and/or "mental retards"[26] (among many others):

> Before the date of enactment of the Education for All Handicapped Children Act of 1975 (Public Law 94-142), the educational needs of millions of children with disabilities were not being fully met because:
> (A) The children did not receive educational services;
> (B) The children were excluded entirely from the public school system and from being educated with their peers;
> (C) Undiagnosed disabilities prevented the children from having a successful educational experience; or
> (D) A lack of adequate resources within the public school system forced families to find services outside the public school system. [27]

This means that, in the history of the United States, disabled children have only been granted a diagnostically-predetermined right to access public education for 44 years so far.[28] I/DD children raised within the public special education system today, especially members of the post-ADA (1990) generation, are less than two generations separated from this world of blanket disability exclusion and discrimination as structured upon a century's-long, national, politico-scientific commitment to "custodialism" and a "common sense"[29] of "pessimism" with regards to educating disabled people (Trent, 1994).

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[26] In 2010, President Barack Obama signed "Rosa's Law" in an effort to end use of the term "Mental Retardation" (MR) and replace it with "Intellectual Disability" (ID) or "A Person with an Intellectual Disability" (person-first language). The DSM replaced "mental retardation" with "intellectual disability" in 2013. MR is still very much part of common language used as both a medical diagnosis and an overt insult. See: United States. Congress. Senate. Committee on Health, Education, Labor, and Pensions. (2010)

[27] Cornell Law School, Legal Information Institute, "20 US Code, Section 1400 - Short Title, Findings, Purposes," 2019

[28] Or, since the enactment of Section 504 of the *Rehabilitation Act of 1973* (PL 93-112), which mandated the *Education for All Handicapped Children Act of 1975* (EHA, PL 94-142)

[29] Gramsci, 2000

In comparison, non-disabled (particularly white) U.S. children--depending on their state of residence--have been subject to compulsory education laws for anywhere between 102-167 consecutive years now: Massachusetts was the first U.S. state to mandate compulsory education in 1852 and Mississippi was the last U.S. state to do so in 1917. Additionally, states' public schools were not racially de-segregated until 1954--*Brown v. Board of Education of Topeka*--and, often only under threat of federal occupation.

> Throughout the 1800s, states claimed more and more supervisory responsibility over not just the schools themselves but also the children who were expected to attend them… Because of the diversification of the nation's population and the mass concentration of immigrant populations in cities, [by the early-1900s] ***schools were charged to assume a greater role as social service and acculturation agencies***. The nation's schoolhouses, many argued, had ***to take the lead in guiding children from all kinds of backgrounds down paths that ensured public safety, economic stability, and cultural integrity*** (Osgood, 2008: 6).

The push for the first "common schools" and compulsory education laws in Massachusetts coincided with the push for the first public institutions for people medically diagnosed as "idiots," "imbeciles," and/or "feebleminded" during the late 1840s and early 1850s--people who would today be diagnosed with "intellectual" and/or "developmental" disabilities (I/DD). The first public[30] institution established exclusively for this population, the "Syracuse State Institution for Feeble-Minded Children," also known as the "New York State Asylum for Idiots," was established in

[30] Smaller, private schools and classrooms were being organized by Howe and Wilbur at the same time in Massachusetts.

1851 near Albany, NY: "the state of New York thus became the first in the United States to make ***separate and special provision*** for the feeble-minded" (Stuhler, 2011).

From the 1850s through 1975--for well over a century--the closest approximation to a "school" or "compulsory schooling" experience that disabled people shared were segregated "special" classrooms[31] and/or mass custodial institutions:

> In 1853, Samuel Gridley Howe, noted social reformer in Massachusetts and pioneer in American special education, identified ***'***_institutions for the blind, deaf, and dumb, and for the feeble minded… [as] links in the chain of common schools_***--the last indeed, but still a necessary link*** in order to embrace all the children in the State.'" (Osgood, 2008: 8; italics added).

Contemporary "Special Education" programs are supposed to de-legislate historical policies of segregation, exclusion, and custodialism--the dominant practices in the education of disabled children since at least the mid-1800s--historical policies that routinely institutionalized I/DD children and adults. After a century, or four consecutive generations of I/DD citizens' institutionalization, the Deinstitutionalization Movement (post-1960s) demanded a "transition" away from "custodialism" and toward what came to be known as "independent living" as the Disability Rights Movement demanded the codification of anti-discrimination and civil rights legislation protecting disabled Americans. Healing from over a century of intergenerational trauma--routine dehumanization (denial of self-

[31] Often shared with immigrant and other racialized children categorized with "incorrigible behaviors" and sentenced to "special classrooms" for moral training, acculturation purposes, and/or as an alternative to the criminalizing aspects of emergent juvenile courts.

determination/consent), abuse (neglect/violence), and segregation (isolation/exclusion) as documented by institutional reformers and abolitionists alike--is something deinstitutionalization and disability rights activists recognized could not happen overnight and would require a "transitional" process.[32]

Key to contemporary Deinstitutionalization Movements and the Special Education paradigm since the Americans with Disabilities Act of 1990 are "transition services." All three—deinstitutionalization, special education, and transition services—share links with the proto-deinstitutionalization movement of the early 1900s, built upon colony structures and institutional parole systems. The precursors to the contemporary U.S. Deinstitutionalization Movement were a proto-deinstitutionalization movement that took the form of an institutional colony/parole system and "special classes" that initiated a movement toward "special education" (Trent, 1994; Ferguson, 1994). are "transition services" (ADA, 1990, 2004; Trent, 1994; Ferguson, 1994). The responsibility to provide transition services is shared between individual school districts, state vocational rehabilitation agencies, and state/federal Departments of Education as well as Health and Human Services (King, Swenson, LaBreck & Ryder, 2017: 8). All I/DD "special education" students ages 16 and older who are "transitioning" out of high school and into the normative expectations of "adulthood" have the right to a "transition program" as an IDEA-mandated portion of their IEP or ISP. According to the IDEA:

[32] How do you train a people for over a hundred years that they are not human enough to participate in society only to flip your script overnight (you are human, you should be in community, leave the institution now) and expect a people to survive in a society with which they have no experience and/or sense of belonging, without supports and/or making reparations?

> The term "transition services" means a coordinated set of activities for a child with a disability that—
>
> (A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability ***to facilitate the child's movement from school to post-school activities***, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
>
> (B) is ***based on the individual*** child's needs, taking into account the child's strengths, preferences, and interests; and
>
> (C) includes instruction, related services, community experiences, the development of employment and other ***post-school adult living objectives***, and, when appropriate, acquisition of daily living skills and functional vocational evaluation. (ADA, Part A, 20 U.S. Code Subchapter 1, Section 1401, 34;[33] bold emphasis added)

Transition programs--as federally reinforced by the IDEAAA, the DD Act, the ADA, and Section 504 of the Rehabilitation Act of 1973--exist to address the well-known barriers between I/DD people and most culturally normative "post-school objectives," with a general emphasis on work, or "Employment First" policies (California State Council on Disability, 2018; U.S. Department of Labor, Office of Disability Employment Policy; California Department of Education; APSE)

While graduation rates for disabled students (including I/DD students) have climbed over the last four decades (from a point of zero), educational access and achievements are only a fraction of non-disabled peers'. Even a decade after the passage of the *Developmental Disabilities Assistance and Bill of Rights Act* (DD

[33] US Department of Education's IDEA Website (2019)

Act)[34] of 2000, Sharon Lewis—Commissioner of the Administration on Developmental Disabilities—testified in 2010:

> Currently [2010] there are approximately ***one million*** ***American students with*** disabilities age 3-21 eligible for services under the Individuals with Disabilities Education Act (IDEA) ***categories of intellectual disability, multiple disabilities, autism, traumatic brain injury, and developmental delay***.[35] Only ***34 percent*** of students with intellectual disabilities, ***40 percent*** of students with multiple disabilities, and ***56 percent*** of students with autism graduated from high school with a regular diploma during the 2007-2008 school year. Among all students, those with the most significant cognitive disabilities are the least likely to graduate with a regular high school diploma.[36] And, even with a diploma, youth with intellectual disabilities demonstrate the lowest rate of paid employment among students with disabilities (***29.8 percent***), one to four years after exiting high school. (Lewis, 2011; emphasis added).

A high school diploma, as a form of cultural currency in the U.S. and a "rite of passage" into independent "adulthood," functions as a ticket to employment or a mark of employ-ability.[37] However, employment rates for I/DD adults have either been stagnant or on the decline since 1990—the same year the *Americans with Disabilities Act* was passed, in part to prevent employment discrimination.[38] One of the main

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[34] The culmination of decades of amendments to the "mental retardation laws" that came out of the Kennedy administration and the recommendations of the President's Panel on Mental Retardation beginning during the early 1960s. (Administration for Community Living, 2017).

[35] "The current definition under the DD Act (adopted in 2000) defines 'developmental disability' as a severe, chronic disability of an individual that: '(i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated'." (Administration for Community Living, 2017).

[36] These three classifications are some of the most commonly shared among ACAT/ACT student/clients.

[37] Compulsory Education and Child Labor Laws emerged in U.S. legislation contemporaneously.

[38] ARC, 2019; Barnow, 2008; National Council on Disability, 2008.

purposes of transition programs then is to address the very broad loss of support services experienced by I/DD citizens as they transition from the legal status of "child" to "adult" often without a traditional high school diploma and/or statistically-viable prospects for employment.

Transition service planning is critical to structuring a free and appropriate public education in the least restrictive environment possible and to building a scaffold to disabled adult life outside the protective institutions of special education and laws pertaining to school-aged children or other legal "dependents." The particular push for effective transition services in attaining normative employment and educational outcomes was reinforced with the 2004 amendments to IDEA: "As the graduation rates for children with disabilities continue to climb, providing effective transition services to promote successful post-school employment or education is an important measure of accountability for children with disabilities."[39]

What are the ACAT/ACT Programs?

Brent White designed *Ala Costa's Adult Transition* (ACAT) *Program* for *Ala Costa Centers* in late 2008, but the program was not officially established until the start of the 2009 academic-year. ACAT is now celebrating its 10th Anniversary as a transition service provider located in Berkeley, CA. In 2017, after directing ACAT

[39] IDEA. (2004). "20 US Code, Section 1400 - Short Title, Findings, Purposes." *Cornell Law School, Legal Information Institute: Open Access to Law*. Retrieved November 17, 2019 (https://www.law.cornell.edu/uscode/text/20/1400).

for eight years, Ala Costa Centers requested that Brent take-over, redesign, implement and direct the *Adult Community Training* (ACT) *Program* as well. Thus, the two programs were brought together under the same roof and "transitional" methodology.

ACAT: Ala Costa Adult Transitions

As a non-profit "transition program," The *Ala Costa Adult Transition Program* (**ACAT**) serves I/DD adults ages 18-22 in the Berkeley Unified School District and North Region SELPA (Alameda, Albany, Berkeley, Emery and Piedmont Unified) of California.. ACAT follows the school district's academic calendar; thus, ACAT student-clients do not attend during their designated school vacations: summer, winter, and spring breaks are observed. The student-client population of ACAT is reduced to zero during these breaks (especially during the long summer months), as are the school district funding resources these 18-22 year old I/DD student/clients supply for Ala Costa's programming. Unlike ACT clients, ACAT students are still eligible for school districts' special education resources which fund their transition programming as a crucial part of their "free and appropriate public education;" but, only until they turn 22 years of age (IDEAAA). As 18-22 year old adults still affiliated with the special education system, Ala Costa pays for ACAT students' transportation throughout program every day, whether via BART, AC Transit, or Paratransit.

ACAT is then designed to support I/DD adults between ages 18-22 in their transition away from the support systems set-up for school-aged children and towards the normative expectations of independent adulthood. All ACAT students have annual IEPs (individualized education plans). These IEP meetings are often hosted in the ACAT/ACT office or other private spaces at the ERC, and ACAT staff members (teachers/instructors and administrators) contribute to their annual revision typically with the goal of reinforcing students/clients' self-advocacy using program observations and interactions:

> ACAT is a person-centered, community-based program which focuses on self-determination skills, vocational skills, and community integration. (ACAT Website, 2009/2019).

ACAT student/clients are the youngest adult program members; thus, they are also typically the least practiced in independent living and self-determination skills for lack of experience outside the special education system. I/DD student-clients "graduate" from ACAT when they "age-out" of special education services at 22 years of age. Many ACAT student/clients then "transition" directly into ACT.

ACT: Adult Community Training

For clients making the transition away from special education services and the legal status of disabled "student" and/or "child," the *Adult Community Training* (**ACT**) *Program* offers an "Adult Day Program" that functions non-traditionally as an

"extended" and year-round transition program with no vacations.[40] As a non-after-school program for non-students, ACT clients supply the ACT program with year-round funding for year-round services via the Regional Center of the East Bay. Summer programming is then particularly geared toward the ACT population (22 years of age and older) as ACAT students are on vacation.

ACT serves I/DD adults ages 22 and over in their post-high school efforts to avoid coercive situations of dependence or social isolation, and to self-advocate for their self-determined support needs by learning independent living skills, building sustainable community connections, and participating in social activities where involvement is or can be made accessible. At 22 years of age, I/DD adults "graduate" from services designed to serve disabled "child students," including after-school programs (also offered by Ala Costa Centers), and must transition into the legal responsibilities and obligations of "adulthood" whether independently; or, more often than not, from within the legal constraints of guardianships[41] or conservatorships[42]:

> Once students graduate from the Ala Costa after-school program at age 22 their venue for socialization and activity comes to a halt. Most of the time individuals remain at home for the duration of their day with no one to challenge them or socialize with. ACT focuses on engaging participants in activities ranging from attending college, employment, volunteering, internships, and exercise programs at local gyms. (ACT Website, 2009/2019).

[40] Attendance is not mandatory for ACT clients unless mandated by a criminal or other court of justice as an alternative to more punitive sentencing.
[41] National Council on Disability, 2018.
[42] Alameda County Social Services Agency, 2012.
Superior Court of California, 2019.

With the addition of ACT to the original ACAT design, the program's population (students and staff) and budgetary needs grew by approximately 40%--nearly doubled--in 2017 alone.

Brent White's "Little Spiel" on "Ala Costa Adult Programming Methodologies"

At the time of my "meet and greet" in August of 2016, new and prospective ACAT/ACT employees (like myself) were trained in three primary methods of teaching and instruction for I/DD adults: Community-Based Instruction, Self-Determination Skills, and Presumptions of Competence. These three commitments comprise the "[Brent] White method" of adult "transition-making"[43]:

1) **Community-Based Instruction** prepares students in the *least restrictive environment*[44] for a successful transition to adulthood, helps students to live independently, and enhance their quality of life (White, 2016[45]).
2) **Self-Determination** promotes student independence and empowerment by incorporating components of self-determination across all learning environments... [because] these skills are not properly learned in sheltered settings such as classrooms or sheltered workshops. Individuals need real world, real-time, hands on experiences and, just as importantly, they need space to try things for themselves[46] (White, 2016).
    a) Components of Self-Determination:
        i) Choice-Making
        ii) Problem-Solving
        iii) Decision-Making
        iv) Goal-Setting and Attainment

[43] "Transition-Making" will, throughout this work, be discussed as a model for Socio-Cultural "Movement-Making" as well and by the extension of self-determination theory from the individual (special education literatures) to the social (critical race and ethnic literatures) political scale.
[44] Reflecting a commitment to the IDEA, deinstitutionalization, and unsheltered, relational, interactive, and interdependent adult transition-making.
[45] "Little Spiel" by Brent White, 2016
[46] Note how space for risk taking marks the intersection of the community-basis and focus on self-determination skill building. Community and Self-Determination are thus cumulative in effecting the possibility for risk-taking.

v) Self-Regulation
vi) Self-Advocacy
vii) Self-Awareness
viii) Personal Responsibility
ix) Self-Efficacy

3) **Presumptions of Competence**[47] give individuals the space, the trust, the respect and the responsibility to work out problems themselves. This is how all of us learn and the same is true for intellectually/developmentally disabled individuals. (Brent White's "Little Spiel", 2016)

These methods are introduced, however, with a cautionary note: "we understand that this might look very different from the way the education of intellectually/developmentally disabled individuals is traditionally done and people often have questions about our methods and the reasons behind them" (White, 2016). As the administrators at ACAT/ACT anticipate after a decade of training, to practice community-based instruction, self-determination, and presumptions of competence typically requires new/prospective employees to reorient themselves in relation to the I/DD student/clients they will work to serve; and, in admittedly historically unprecedented ways.

In introducing their methodology to new and/or prospective employees, these methods are presented as neither traditionally "proven" nor historically "common" discursive practices:

> Historically, those who provide services to intellectually/developmentally disabled adults ***create and perpetuate systems of dependence*** for the very disabled adults they are meant to serve. ***The roots of our current provider systems are found in a long history of institutionalization and isolation, which created the***

[47] With the necessary access to space and skills/supports, everyone should have a *right to try*. The right to try (presumed competence), to determine what you would like to try (self-determination), and to advocate for the space to try (relational community-basis), are key to adult learning processes. While Douglas Biklen (1992) is credited with coining "Presumptions of Competence," my work engages primarily with Jenkins (1998) cross-cultural analysis.

> ***narratives that continue to pathologize, stigmatize and infantilize disabled lives today. The ACAT and ACT programs are working to change systems of dependence***… Our participants are all adults learning how to adapt and be in the community to [the] best of each individual's ability. We give participants respect; we do not hover, restrict, constrain, shame, or in any way coerce participants. We support through mindfulness, acceptance, empathy and presuming competence. (White, 2016; emphasis added)

This is a brief but rather indicting summary of the historical and cultural context--the past-in-present re/production of institutionalized systems of dependence designed for I/DD people--in which the ACAT/ACT methods are situated in resistance. Following on the heels of this critique, however, is the evocation of a historically unprecedented claim to the productive potential of a disabled lived experience and of disabled leadership: "Established in 2009, these programs are ***designed and directed by autistics*** with the goal of creating a better model for decreasing dependence while learning independent living, life and vocational skills" (White, 2016).

The productive potential of a disabled lived experience is evoked repeatedly throughout the "little spiel" presented to prospective/new employees in the form of "we" statements referring to program administrators (director and supervisor) and program participants (adult student/clients) simultaneously. The "reasons behind" their methods are grounded in a combination of "we," "our," and "us" statements (of political and lived, experiential solidarity) and "they" statements (in recognition of the material realities of differential positions of power):

- **We slow down, listen, and are patient**. The guideline **we** use in **our** program is: when you ask someone a question or make a request, wait as long as you possibly can for a response. Then wait a little longer. Intellectually/developmentally disabled individuals process information differently and it may take **us** a little longer to respond.

- **We treat our participants as adults.** They deserve the same respect as any other adult. Intellectually/developmentally disabled individuals have been historically infantilized--framed as children no matter their age.
- **We ask questioning directly to our participants. We** don't ask their others to answer for them. It is disrespectful to the participants and the staff is just going to refer you back to the participants anyway.
- **We presume competence.** Presume that each individual has strengths and the capacity to learn and grow.
- **We believe its OK to be different.** Remember just because someone doesn't do something in the manner or the order in which **we** do it, doesn't mean that they are doing something wrong.
- **We believe communication isn't just the use of words.** Communication is deep and complex. Words are limiting, but watch someone communicate with their environment by using their body, or flapping their hands or arms. Listen to the language of stimming: it is often more beautiful than words.
- **We believe in the right to fail.** This is how **we** all learn! One of the biggest burdens the special education system places on **our** backs is that everyone is afraid to let **us** fail. Failure, dealing with failure, overcoming failure makes **us** stronger. It makes **us** adults.
- **We believe in the right to take risks. We** learn by doing, by making mistakes, by struggling and finally figuring it out in **our** own way.
- **We believe in the right to struggle**. The world for intellectually/developmentally disabled individuals is more often than not, chaotic. **We** learn to adapt and the ways in which **we** adapt are pretty amazing. The way **we** measure success is by how well someone adapts as opposed to how well they can pass for neurotypical.
- **Self-determined, empowered individuals need spaces to try and succeed.** This cannot be accomplished by being shuttered away in some classroom or some other incarnation of an institution. **We** need to be in the community, working on skills hands-on, and in real-time. And just to note, this is not accomplished by herding large groups of disabled people around in vans under the ever watchful eyes of hovering staff. (White, 2016).

"We/our/us" statements of disabled solidarity work to ***abolish*** the historically traditional division of labor between "staff" and "inmate"/"patient" in disregard of institutionally situated hierarchies of "laborers" (citizens) versus "dependents" (deviants) (Goffman, 1961; Carey, 2010). This abolitionist work is situated, at the same time, in "they" statements that do the critical work of acknowledging how I/DD people within the broader neurodivergent community experience widely divergent

degrees of power and privilege in relation to "special" institutions and civil rights, more generally: "It is fairly obvious that treating different things the same can create as much inequality as treating the same things differently" (Crenshaw, 1997; Collins & Bilge, 2016). Both of these kinds of "divergence" are made all the more evident in the context of ACAT/ACT's everyday work in presuming the competence of adult I/DD student/clients learning self-determination skills through peer-based community immersion.

As a prospective "CBTI" who identifies as disabled and neurodivergent, I did not experience the typical disassociation with I/DD adult student/clients anticipated by autistic program leaders in their "little spiel"—I am often the neurodivergent and disabled person from whom others attempt to disassociate or condescendingly encourage to work harder at "passing;" especially when it came to academic professionalization training. Over the next two years (2016-2018) conducting interviews and ethnographic field work with ACAT/ACT, I would observe and participate in nearly a dozen "meet and greets" for other new and/or prospective employees. In these participatory observations, I came to understand why ACAT/ACT leaders anticipated some measure of disassociation from most new/prospective employees in their neurodivergent interview processes. While observing non-disabled prospective employees[48], or those previously trained in the

[48] The majority of job applicants identified as non-disabled; however, on some occasions job applicants would identify with aspects of a lived disability experience without identifying as "disabled." These two groups of non-disabled-identifying job applicants experienced the greatest degrees of dissonance when trained in the "White Method" of adult transition making; especially if their previous qualifications included past employment in special education and/or programs employing Applied Behavioral Therapy.

methods of behavioral modification common to more traditional special education settings, I witnessed this anticipated disassociation in the form of a bewildered confusion at best (the "wait, you do what?" responses) and a condescending phobia at worst (overtly questioning the director's competence and the competence of his staff).

I had no questions about the programs' methods or the reasons behind them. I was eager to better understand how the "White Method" worked in-practice; and so, my only question was when I could start working with them. The next step in the hiring process for me, then, was to shadow Joan in the community-based program for a day. Joan--I was excited to learn--worked with a group of adult I/DD student/clients who were all neurodivergent women (including Joan, herself). All ACAT/ACT student/clients are divided into small groups never exceeding six student/clients per group. Community-based teachers/instructors work in co-teaching pairs with the rare exception of a teacher who works independently with a maximum of three student/clients. This means that groups never exceed a teacher to student ratio of 1:3.

We scheduled my shadowing date for Friday, September 2nd, 2016, from 8:30am to 2:00pm so that I could experience a typical working day in the life of the program (Monday through Friday, 8am-2pm). Because it was the Friday after the first day back to school for Berkeley Unified School Districts, ACAT and ACT student/clients were both in the program (summer vacation had just ended); however, Friday's group was expected to be small and comprised of mostly ACT students making it a very manageable task to add me to the group for a day. Fridays are also traditionally "travel training" days for student/clients; meaning, Fridays are typically

less structured in-advance so as to give students the opportunity to work on building their daily schedules, budgeting, and travel plans for themselves, with a group, through peer-negotiations, and in community.

A Shadow Following A Group of Women: September 2nd, 2016

Pretty much nothing went according to plan during my shadow-date—September 2nd, 2016—but, that was kind of perfect. After check-in at the ACAT/ACT office at 8:30a, Brent and Tania guided me to a cafe about five blocks from the ERC to meet-up with Joan and a small group of three adult I/DD student/clients I'd be shadowing for the day: E., J., and A. (pseudonyms). Only 1-2 groups meet at the ERC every day. The vast majority of groups—like the one I shadowed—meet each morning at 8a at a designated location in the community (ex. a cafe, the YMCA, etc.).

E., J., and A. are multiply disabled women in their twenties, all diagnosed with I/D disabilities in addition to multiple other disabilities. J. and A. are women of color and E. is white. Representative of the larger ACAT/ACT student population, the group I shadowed was a majority people of color with multiple disabilities, including I/DD. In October 2018,[49] less than 15% of student/clients were identified as "white." In addition to "mild" to "severe" intellectual and/or developmental disabilities, several other medical diagnoses were relatively commonly shared, lived-experiences for many student/clients; including: autism (ASD), visual/auditory/speech

[49] When I was finishing my work with ACAT/ACT, over two years after shadowing.

impairments, cerebral palsy, seizures, dyslexia, ADD/ADHD, depression and anxiety. Unlike other ACAT/ACT groups, however, this was an all-women's group. Most other groups are not gender/sex specific, and the program's student/client population as a whole typically has a relatively equal sex/gender ratio from year to year.

From 8a-9a, the group spent time in the cafe making group "travel plans" for their day: sometimes writing/drawing ideas in their notebooks, sometimes talking with group-mates, and sometimes just drinking coffee or eating breakfast in an attempt to wake-up fully. Everyone agreed on a plan to go to a local worksite where the group of I/DD student/clients would spend the day providing volunteer labor to a local community organization, learning different vocational skills along the way, and interacting with community members both independently and as a group. This is one of the most common activities in which student/clients participate while in program at a series of community organizations with whom ACAT/ACT has established working relationships and accessible expectations for adult I/DD student/client volunteerism.

One group member, E. (pseudonym), offered to call the worksite on her cellphone as a courtesy to let them know when we would be coming as a volunteer group for the day. After repeatedly calling the organization with no answer, group members agreed that a new plan might be best. After some debate among familiar peers, the new plan was to go to the library where some student/clients could practice

computer skills, some could read books, and others could continue working on their "Self-Advocacy Zines."[50]

With a group-made plan in-hand, the next step was to decide on a route, to make literal "travel plans" for moving between the cafe and the library without access to private transportation and as a group of five: Joan, E., J., A. (three adult women I/DD student/clients), and myself. Student/client E., who had already learned how to use google maps, suggested that we take the BART and showed everyone in the group the mapped route she had procured on her phone for all to see. It was close to 9:30a when we began our walk to the Ashby BART station together (about five blocks away, just below the ERC) in order to catch the next Fremont-bound BART that would take us to the Lake Merritt BART station. It was while waiting as a group at the Ashby BART platform that I was taught my first real lesson in self-determination skills by adult I/DD student/client, E.

Without warning, E. shouted, "personal space!"

I was standing within approximately 2-3 feet of E. on the BART platform where we were both facing the tracks when she shouted. I was startled at first by the volume of E.'s voice as it also echoed a bit through the underground platform. I looked down to our feet to see that, unbeknownst to me, I was in fact standing unnecessarily close to E. and took a few steps back.

[50] A "zine" is a small, typically handmade/copied maga-"zine" that usually focuses on a specific topic of interest to its author that may combine personal insights with previously published ideas and privileges images as much as words

Feeling that I should apologize and that I had wronged E. unintentionally, I said, “I’m sorry, I didn’t realize I was standing so close.”

E. reiterated her point: “I need personal space,” she said in a slightly lower volume in recognition of my apology but with equal seriousness.

The tension began and ended in that short exchange, but I continued thinking about this interaction for the rest of the day. When I returned to the ACAT/ACT office around 2p that afternoon, I wanted to process my interaction with E. with both Brent and Joan. Joan was with us on the platform and had witnessed the interaction between E. and I, but had not made any comment.

Even though I was startled at first by E.’s volume, I found myself admiring the sheer force behind E.’s sense of spatial vigilance and self-advocacy throughout the day. I couldn’t count the number of times I have wanted to ask strangers on public transportation to give me a little more personal space but failed to self-advocate out of fear or a perceived lack of right--sometimes exposing myself to violence as a result of my own failures to self-advocate. I wanted to learn from E.’s skill and discuss what I had learned with Brent and Joan.

When I finished recounting my interaction with E., Brent and Joan explained that the first two lessons ACAT/ACT teachers/instructors offer adult I/DD student/clients--who are often learning and practicing these skills at 18 years of age for the first time in their lives--were:

1. You have a right to say “No” or Refuse--including with us.

2. You have a right to Personal Space--others have no right to invade your personal space without your express permission and permission is yours to give or refuse.

I was struck by the intersectionality of ACAT/ACT's feminist approach to an I/DD body-centered education—the staff's understanding of how disability interacts or "intersects" with race, sex, gender, age, and other aspects of student/clients' personal/political identities in social settings to produce unique amalgamations of privilege and oppression—but, that was my bias as someone who had only ever been taught such lessons in the company of avowed feminists. These two lessons, Brent and Joan explained, were not intentionally feminist; although, they were unopposed to, and altogether enthusiastic about the descriptor. ACAT/ACT's methodical principles, Brent explained, were designed for I/D disabled adults and need to work for both male and female presenting student/clients, the vast majority of whom are also people of color. These methodological commitments "keep us safe" when navigating public spaces (community-based), "assumes that we know our own needs" whether they are apparent to others or not (presumes competence), and "promotes a sense of personal agency," a wealth of autonomy or intrinsic sovereignty (self-determination). These two lessons, they also explained, can take adult I/DD student/clients years (sometimes decades, if ever) to learn for lack of early socialization; and, specifically as a consequence of the more-or-less exclusive socialization of I/DD citizens in "sheltered" environment--like "special" classrooms and/or "sheltered workshops"--where cultures of compliance are cultivated over and

above community-based strategies for presuming I/DD adults' competence to determine and communicate their own, interdependent access needs.

The primacy of these lessons, Brent explained, is also illustrated in one of the first rules staff are trained to observe: no hugging allowed. Only fist bumps or hand shakes are allowed as signs of physical affection and recognition between staff and student/clients. This is a radical departure from most "special" and/or "sheltered" programs serving I/DD adults or children; and, it is often a point of harsh criticism leveled at ACAT/ACT staff by outsiders to the program.

The neurodivergent and "trauma-informed" rule against hugging is meant to symbolically and physically hold the space between staff and "inmate" so as to teach student/clients how to recognize potential abusers and how to protect themselves from abuse. This is an overt and intentional acknowledgement of differential positions of power between staff and student/clients--many of whom are I/DD adults confined within legal guardianships/conservatorships--in terms of how these different positions result in differential exposure to violence/abuse. According to the *U.S. Department of Justice's* Bureau of Justice Statistics for the years 2009-2015, for instance:

- A higher percentage of **violence against persons with disabilitie**s (40%) was **committed by persons the victims knew well or who were casual acquaintances** than against persons without disabilities (32%).
    - Other **relatives** (including parents, children, and other relatives) accounted for a higher percentage of violence against persons with disabilities (10%) than persons without disabilities (6%).
- The **rate of violent victimization** against persons with disabilities (32.3 per 1,000 age 12 or older) was 2.5 times the rate for persons without disabilities (12.7 per 1,000) during 2011-15

    - Among those with disabilities, persons **ages 12 to 15** (144.1 per 1,000 age 12 or older) had the highest rate of violent victimization among all age groups measured.
    - **One in 5** violent crime victims with disabilities believed they were targeted due to their disability
    - For both **males and females** during 2011-15, the rate of violent victimization was higher for persons with disabilities than for those without disabilities.
        - The rate of violent victimization against **males** with disabilities was 31.8 per 1,000, compared to 14.1 per 1,000 males without disabilities.
        - For **females** with disabilities, the rate of violent victimization was 32.8 per 1,000, compared to 11.4 per 1,000 females without disabilities.
    - For each **racial and ethnic group** measured, persons with disabilities had higher violent victimization rates than persons without disabilities during 2011-15.
        - Among the racial groups examined, **persons of two or more races had the highest rates of violent victimization among persons with disabilities** (128.5 per 1,000) and without disabilities (33.6 per 1,000).
- The **rate of serious violent crime** (rape or sexual assault, robbery, and aggravated assault) for persons with disabilities (12.7 per 1,000) was more than three times the rate for persons without disabilities (4.0 per 1,000).
    - Serious violent crime accounted for a greater percentage of violence against persons with disabilities (39%) than violence against persons without disabilities (32%)
    - Sixty-five percent of rapes or sexual assaults against persons with disabilities were committed against those with multiple disability types, the highest percentage among the crime types examined.
- The **rate of simple assault** against persons with disabilities (19.6 per 1,000) was more than twice the rate for persons without disabilities (8.7 per 1,000).
- During 2011-15, **persons with cognitive disabilities**[51] had the highest rates of total violent crime (57.9 per 1,000), serious violent crime (22.3 per 1,000), and simple assault (35.6 per 1,000) among the disability types measured

[51] BJS defines a "Cognitive disability" as causing the following "limitations": "serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition." However, most ACAT/ACT students have multiple disabilities. For instance, many ACAT/ACT students could also be said to have "Independent Living Limitations" including "physical, mental, or emotional condition that impedes doing errands alone, such as visiting a doctor or shopping." How I/DD adults, especially multiply disabled adults (like most ACAT/ACT students, and myself for that matter), do not "fit" well into the Justice Bureau's *National Crime Victimization Survey* classifications of "disability" or associated categories of "limitation": "The NCVS defines disability as the product of interactions among individuals' bodies; their physical, emotional, and mental health; and the physical and social environment in which they live, work, or play. A disability exists where

    - Among both males (55.4 per 1,000) and females (60.3 per 1,000), those with cognitive disabilities had **the highest rate of total violent victimization** among the disability types measured
    - During 2011-15, persons with a single disability type (29.6 per 1,000) were less likely than **persons with multiple disability types** (35.2 per 1,000) to be violently victimized (90% confidence level)
    - Violence against persons with ambulatory disabilities (55%) was more likely to be reported to police than violence against persons with vision (42%) and cognitive (47%) disabilities.
- Twenty-one percent [of unreported violence] was not reported because the victim did not think the police would help.
    - **Forty percent [nearly half!] of unreported violence against persons with disabilities was dealt with in another way.**
    - During 2011-15, a greater percentage of violence against persons with disabilities (12%) involved receipt of assistance from a nonpolice victim service agency than violence against persons without disabilities (8%).[52]

Given the reality of these statistical likelihoods as they represent part of the everyday lived-experiences of disabled (especially I/DD) citizens, the goal of ACAT/ACT's staff-to-student "no hugging rule" is to help students understand the difference between their "chosen" friends and family versus "assigned" support staff workers; the kinds of physical and emotional affectations that are/not appropriate to each group of people in their lives; and, student/clients' "rights" to communicate their boundaries in the most accessible way to them, to say "no" or refuse, and to demand "personal space" from others.

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this interaction results in limitations of activities and restrictions to full participation at school, work, home, or in the community. Disabilities are classified according to six limitations: hearing (deafness or serious difficulty hearing), vision (blindness or serious difficulty seeing, even when wearing glasses), cognitive (serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition), ambulatory (difficulty walking or climbing stairs), self-care (a condition that causes difficulty dressing or bathing), and independent living (physical, mental, or emotional condition that impedes doing errands alone, such as visiting a doctor or shopping)." (Bureau of Justice Statistics, 2017).

[52] Bureau of Justice Statistics, 2019.

Students--and staff, for that matter--are first trained in these lessons of self-determination: to know that their bodyminds are their own, that they deserve to protect themselves, that they have a right to demand safety and security from others as much as they have a right to refuse invasion, uninvited and/or violent encroachment. These are the sovereign lessons of self-determination and the first "transitional" lessons learned by adult I/DD student/clients transitioning out of "special" and "sheltered" institutions that foster the idea that "special/sheltered" bodies are also "public" bodies--free to touch, free to control, free to manipulate, free to access, appropriate, and even abuse--public "charges" and/or public "property." "Special" institutions function to "shelter" (or "protect") inmates from the risks/rights of self-determination. High school "graduation" (a rite of passage) is then earned by way of learned compliance and a disciplined demonstration of docility (Foucault, 1995). To "pass" or "graduate" into adulthood, the student either internalizes the presumption of their own incompetence; or, must learn to act upon the assumption that, as a subject of "special" powers, they will be "sheltered" from (denied) rights of self-determination--a kind of presumed dehumanization. I just so happened to be trained in this first lesson of self-determination by E., an adult I/DD woman; and, while in the company of a group of neurodivergent women--highlighting for me the radically feminist outcomes of such skill training.

After a short BART ride, we emerged from the underground concourse and climbed the stairs up to the street at Lake Merritt where we began a four-block walk to the Downtown Branch of the Oakland Public Library together. J. (pseudonym) and

I took up the rear as the slower walkers; while, Joan, E. and A. (pseudonyms) walked at a somewhat brisker pace a short ways ahead, but always in clear and direct view and never out of ear-shot. Our plans were again foiled. Upon arriving at the library's doors, we discovered that the library would not open until 11a--budget cuts to the Oakland public library system had reduced hours of operation significantly in 2016. With a little over an hour before we could enter the library, some group members were frustrated and needed time to process yet another change of plans because "transitions"--even seemingly "small," "normal" or "everyday" transitions--"are often the hardest moments of the day for students and teachers" (ACAT/ACT: "New Hire Training Checklist").

Student/client E. was especially frustrated and took a hard seat on the cement stairs leading to the library in a sort of protest; or, as a way of announcing to the group "I am staying put" without words. In short time, E. began expressing her anger with a somewhat raised voice, repeating her desire to get inside the library and to go on with her day as she had planned--a plan she was committed to, and did not want to see thwarted, even temporarily. The other two group members were disappointed as well, but were not expressing the same kinds of frustration as E.

After giving E. some time to process and vent her frustrations, Joan encouraged the two students who were less frustrated--A. and J.--to talk with E. about what they would like to do as a group for the next hour before we could come back to the library and resume our plans. A few minutes later, I turned to see all three I/DD women--E., A., and J.--sitting together on the stairs, two attempting to console one,

and all three processing the present circumstances with the goal of agreeing on a new short-term plan independent of Joan and I. E. was feeling "stuck" (or, unable to process next steps right away), though; and J. was starting to feel anxious to get up and do something. Student/client J. waited as long as she could for E. to process; but, then got serious and began advocating for herself by telling E. directly that she did not want to sit and wait. J. wanted to take a walk around near-by Lake Merritt until 12 and advocated strongly for this plan as best for everyone. Slowly but surely, that is what we did and J.'s new plan was the one we all agreed to follow.

It was a shorter, two block walk from the library to Lake Merritt on a very sunny and warm but breezy day in Oakland. We walked along a cement path that encircles the lake itself for a little over an hour, sometimes taking short breaks along the way; especially when the opportunity arose to engage with dogs and their owners on walks in the park. We returned to the library just as its doors were opening at 11a and went inside. After a brief check-in about our individual goals while at the library and our stop-time--we all needed to return to the ERC by 2p which meant we needed to leave no later than 1:30p--everyone went their separate ways: some to use computers, others to read books, and others to tables where they could draw/write. If a student needed Joan, she would be in the main hall of the library with me; but Joan--as J., E., and A. already understood--had no intention of following them around, hovering over their shoulders, or otherwise impeding E., A., or J.'s ability to access the library's resources independently. E., A., and J. could always ask Joan for support anytime they desired support; or they could ask a librarian; or they could ask a fellow

community member at the library that day. This was not a "special" classroom, a "sheltered" workshop, or a field trip "privilege," but a community space where student/clients were learning how to be a part of their community with the support of a CBTI whose role was to "step-back" until asked by a student/client (not a community member) to "step-in."

We began our walk back to the Lake Merritt BART station shortly after 1pm where we caught a Richmond-bound BART toward the Ashby BART station in Berkeley. Our group returned to the ERC with a few minutes to spare before 2p when program ends for the day. This meant that A., J., and E. would have some time to hang out with their ACAT/ACT peers from other groups before 2p. Exiting the underground Ashby BART station, the elevator doors opened on the first floor of the ERC where we found all of the ACAT/ACT student/clients in attendance that Friday gathered together with their teachers in the ERC's main atrium, just below the remnants of the "Patient No More" exhibit's 504 photographic mural. We merged into a sea of actual and photographed disabled people gathered together, and I couldn't help but smile in gratitude for the experience--such a rare opportunity. J., A., and E. wasted no time finding their friends in the atrium and striking up conversations about the day's events, sharing experiences across groups, looking forward to weekend plans, exchanging hugs, smiles, and stimming comfortably in the company of peers, or fist-bumping other teacher/instructors they know and like.

Student/clients spend their days in the community and often do not see each other when they belong to different groups; however, students end program each day

together with all of their peers and many form lasting friendships with group members and other program participants independent of the program in this way—a rare opportunity in the lives of adult I/DD peers. Monday through Friday, at 2p, all students and teachers return to the ERC to coordinate transportation as students leave program for the day. Many students travel via paratransit, requiring them to wait often long periods of time for "scheduled" rides that rarely arrive on-time (if ever). Other students who have extensive "travel training" and/or a "legal guardian's permission" leave program independently via public transit, taxi, or other form of private transportation (ex. Lyft, Uber, etc.) after checking-in. Still, other students receive rides from family.

After debriefing with Brent, Joan and Tania in the ACAT/ACT office, I left with a stack of new hire papers, a deep sense of optimism, and a strong sense of my own exhaustion. I made it home before my hip "went out" and I spent the next week attempting to recuperate from the physical demands of my one magical day as a "CBTI." I emailed Brent from my bed on September 8th, 2016 to inform him that I could not take the position I had been offered due to my own disability. The ability to walk and stand for long hours had not been listed in the job description, but I could have read between the lines if I hadn't been wearing such rose-tinted glasses of unrealistic and impractical optimism. Walking, standing and even the ability to run when necessary are critical aspects of all "CBTI's" day-to-day work and Brent and I agreed that the position could not be modified to "reasonably accommodate" my physical disabilities without radically altering the position itself. I simply wasn't a

good fit for the "CBTI" position working with I/DD student/clients (the vast majority of whom are fully ambulatory) as a physically disabled person. My near-PhD replete with six-plus years teaching experience would not help me "overcome" the requirements of the job. We were forced to go our separate ways--the program and I--until I started searching for volunteer opportunities in January of 2017 when my relationship with the program was sparked anew. And, now that we know where the rabbit hole starts, we are in a good place to begin exploring where it leads…

This chapter offered a recent history of "the field" wherein the rabbit hole emerged, from the ground. The next chapter follows the lead of "Neurodivergent Leadership" as we explore the rabbit hole's depths through the ACAT/ACT Case. In this case study, the history of "neurodiversity" and "disability" in the U.S. will help illuminate the particular ways in which ACAT/ACT staff practice neurodivergent leadership.

CHAPTER 3

Neurodivergent Leadership: The ACAT/ACT Case

In this chapter, situate the ACAT/ACT Programs within the formation of a "neurodivergent leadership" that only became possible as a practice in the U.S. around the turn of the 21st century and at the intersection of decades of movements toward the deinstitutionalization of divergent, intergenerational traumas unevenly experienced across marginalized communities of the US; and, particularly intersecting in the lived experiences of Mad, Intellectually and/or Developmentally Disabled Women of Color. In the case of the ACAT/ACT programs, I argue that the majority neurodivergent staff are more likely to identify as "neurodivergent" than "disabled" as a way to acknowledge their ableist (and other forms of) privilege over their I/DD student/clients. In witnessing the everyday ableism (often intersecting with racism, sexism and classism) that I/DD students/clients experience in their community-based program, CBTIs interdependently learn to "check their privilege" and literally "follow the lead" of their I/DD student/clients. In so doing, CBTIs respect the self-determination of their I/DD student/clients and honor their leadership as "those most impacted" by their shared, community-based environments. I also consider the ways that Community-Based Teacher/Instructors (CBTIs) at ACAT/ACT represent a cross-section of larger populations. Many CBTIs openly identified with lived experiences of trauma, anxiety, and depression but did not identify as "disabled" or "neurodivergent"—they were "TAD-Only." This was most common among POC CBTIs. In light of these findings, I will consider how traumas passed between generations of BIPOC are not necessarily self-identified as forms of neurodivergence and/or disability; but/and, why intersectionally lived experiences of/with intergenerational trauma could make multiple de-medicalized and decolonized futures of cross-movement and cross-disability organizing possible.

An Intersectional Congress of Intergenerational Traumas

I would argue that *the most commonly shared lived experience among and between all neurodivergent communities is trauma*, and accompanying trauma responses. This trauma is most often caused by the structural denial of *neurodivergent self-determination*; or, a lack of divergent access to what I call "multiple possible

futures." One Community-Based Teacher/Instructor (CBTI) described this as a staff-to-student kinship of "total confusion" that affects "knowing how to move through the world or like knowing the rules and understanding them":

> ...that total confusion and not having a place in the world felt really, really familiar. I think ACAT just collects those people. For sure, yeah...I think there's like different levels or degrees of like knowing how to move through the world or like knowing the rules and understanding them. That may be the difference sometimes between students and teachers, it's like: I know the rules and they may seem arbitrary or terrible to me, but like I know how to follow them well enough; [whereas] these people [I/DD student/clients] like are having a hard time knowing the rules. And you can just show them the rules and then they can do whatever the fuck they want with them. As long as they have the choice to engage them the way that they are. That they [I/DD student/clients] have agency and they are making decisions, that's the thing! That's what teaching is for me. And that's what makes a teacher I think too… like I know those things and I can show you those things (anonymous CBTI).

I would also argue that trauma—like many other medical diagnoses—is *a term to describe one of a multitude of ways people practice neurodiversity*.

This chapter offers a brief history of the concept of "neurodiversity" by situating its emergence within what we have come to know as the Self-Advocacy and Autism Movements of the United States. From this discourse, a new form of "leadership" came into formation with the practice of neurodiversity. The discursive practice of "neurodivergent leadership" became a historical and material possibility only as a result of the intersection of social movements within the United States between 1960-1990—Civil Rights, American Indian, Black Power, Black Nationalist, Gay Rights, Disability Rights, Independent Living, and Deinstitutionalization Movements, just to name a few—*an intersectional congress of movements united*

through intergenerational experiences of divergent traumas and past-in-present struggles to deinstitutionalize those traumas[53]. These movements were formed and thrived under community-based leaders who not only understood but shared lived experiences with these traumas, and responses to those traumas in the form of "visions" toward decolonizing and desegregating US institutions.

Because "anyone can become disabled," members of all of these movements included disabled people; and, because marginalized communities experience structural inequality everyday in the US, they are also more likely to have lived experiences with trauma. The neurodivergent community—when united against divergent experiences of intergenerational trauma—come to "represent a new addition to the familiar political categories of class/gender/race" at the same time that their divergent practices of resistance and resilience work to decolonize, desegregate, and "augment the insights of the social model of disability" in profound ways (Singer, 1999). I situate the ACAT/ACT Programs within the formation of a "neurodivergent leadership" that only became possible as a practice around the turn of the 21st century and at the intersection of decades of movements toward the deinstitutionalization of divergent, intergenerational traumas unevenly experienced across marginalized communities of the US, particularly intersecting in the experiences of Intellectually and/or Developmentally Disabled Women of Color. In recognition of these intersecting forms of oppression, the majority neurodivergent staff at ACAT/ACT are

[53] Whether in law, in schools, on reservations, through direct community-based action/intervention, etc.; and whether rooted in racial/ethnic, sexual, gendered, class-based, disability or other intersecting experiences of historically structured inequality

more likely to identify as "neurodivergent" than "disabled" as a way to acknowledge their ableist (and other forms of) privilege in comparison to their intellectually and/or developmentally "disabled" clients; and, as a consequence of witnessing the everyday ableism (often intersecting with racism, sexism and classism) clients experience in their community-based program. However, staff's lived experiences with other forms of marginalization and/or privilege also impact how they identify with "neurodiversity" in their community-based work; staff who experience everyday white-privilege are more likely to identify as "neurodivergent" while in the community "working for" their "disabled" clients than their POC-colleagues.

Historical Context: An Uneasy Wedding

International "People First" and "Self-Advocacy" organizations have been in formation since 1968 (Sweden), and made their way into US organizing via collaboration with Canadian organizations by 1974 when 560 people attended the first US Self-Advocacy Convention in Oregon[54]. The name, "People First," was elected at this convention as proposed by Judy Cunio, a white woman in attendance who was born and raised in Salem, OR and who had been institutionalized as a teen after being denied access to education because she was born with Cerebral Palsy[55]. As Sharyn Kaplan, another attendee at the 1974 Convention, recalls in memory of Judy Cunio (1952-2011):

[54] People First of West Virginia: "History of People First."
[55] Note the neurodivergent origins of the People First Movement. Northwest Independence. (2011).

> Judy made a profound impact on history. I was a witness to that incredible moment and it changed my life forever. In 1974 at a very large gathering of people with developmental challenges in a very crowded room filled with people who already left the Institution and people who had not, there was an exciting conversation happening. Everyone in the room was searching for a way to be recognized for their individual talents and abilities. Everyone present wanted some kind of group to belong to so that they could help one another feel good about themselves. The decision was made to unite together, form a group and create a group identity. There were lots of rather silly names that were proposed for the new group. Names like "The Sunshine Kids" or "The Happy Acres Group" were proposed but quickly dismissed. After a very long time, Judy raised her hand. As she began to slowly rise to her feet, the room got completely quiet. You could hear a pin drop when Judy opened her mouth to speak. Everyone wanted to hear what Judy had to say and they all respected her individual struggle to be understood. Judy calmly looked around and acknowledged her peers with a smile. ***Slowly and clearly she said ..."Our name should say who we are. We are PEOPLE FIRST and our handicaps are secondary." Immediately there was a resounding round of applause by everyone and "PEOPLE FIRST" was born.*** That was the moment that Judy changed the world and changed me forever (bold and italics added).[56]
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The name, "People First," was a call to abolish the dehumanizing practice of referring to developmentally disabled people exclusively by their medical diagnoses--ex. prior to this convention, references were most commonly made to "retards" as opposed to

[56] People First of Oregon (n.d.); Kaplan, 2011. Figure 4: Image of Judy Cunio.

people with "mental retardation"[57] and/or "mongoloids" as opposed to *people with* "Down's Syndrome."[58]

Unlike any rose, this group could not be called by any other name and still be recognized as "people"[59] on the verge of forming international ties of solidarity in a movement for disabled self-advocacy. "People First" as a name "mattered" in the form of a political socio-linguistic demand for "personhood," particularly in the form of "person-first language." After decades of organizing, this originally I/DD-led self-advocacy initiative came to "matter" on a national scale when the US Government mandated the adoption of "Person-First Language" in reference to disabled Americans; for example: "*Individuals with* Disabilities Education Act" (IDEA, 1990) "*People with* Intellectual Disabilities" and/or "*Individuals with* Developmental Disabilities" (Rosa's Law, 2010; Federal Register, 2013).

By the mid-1990s, however, in addition to People First, "over 600 self-advocacy organizations existed in the United States, including the national organization Self-Advocates Becoming Empowered (SABE, 1991)".[60] People First leaders who began organizing in the US during the 1970s--many of whom were

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[57] The term "mental retardation" was replaced in the Federal Register with the term "intellectual disability" in 2013, following on the heels of 2010's "Rosa's Law": "The term "intellectual disability" is gradually replacing the term "mental retardation" nationwide. Advocates for individuals with intellectual disability have rightfully asserted that the term "mental retardation" has negative connotations, has become offensive to many people, and often results in misunderstandings about the nature of the disorder and those who have it." (Federal Register, 2013).

[58] National Association for Down Syndrome: "In 1866 British physician, John Langdon Down, for whom the syndrome is now named, first described Down syndrome, as "Mongolism." The term Down syndrome didn't become the accepted term until the early 1970s." (National Association for Down Syndrome, 2018).

[59] Literal *human beings* struggling for liberation while still confined within a long history of total institutionalization and medico-politically sanctioned dehumanization

[60] The Minnesota Governor's Council on Developmental Disabilities. (2019). "We Are People First."

intellectually and/or developmentally disabled people organizing from within institutional confines like Cunio--can, in many ways, be said to represent a critical point of origin for the US Self-Advocacy, Autism and Neurodiversity Movements that emerged during the 1990s. The US Autistic Self-Advocacy Movement of the 1990s, however, took a very different stance on the "political correctness" of person-first language (Brown, 2011).

Although the 1974 People First Convention was largely an initiative led by eight then-current/-former residents of the Fairview Institution in Salem, OR, the resulting People First organization and movement has, since its beginning, been burdened by two major constraints:

> 1) Links to "normalization" and "applied behaviorist" (ABA) theories and therapies as defined by Lovaas's (195, 1969, 1973) work on ABA in the US during the 1960s, as well as Nirje's (1969) work in Sweden and Wolfensberger's (1972, 1983) work in the US during the 1960s-1980s on principles of normalization and social role valorization (SRV); and,
>
> 2) Parents and other non-disabled people ready to take hold of the rapidly growing organizations' leadership.

In effect, many people involved in neurodivergent movements today perceive People First organizations in the same historical vein as the ARC[61] wherein parents are

[61] Originally formed in 1950 as NARC, The National Association for Retarded Children

positioned to advocate for their own interests for their disabled children more often than disabled people are in a position to "self" advocate.

After decades of movement struggle and litigation during the 1970s-1980s (technically on-going today), deinstitutionalization finally achieved federal enforcement. Community transitions out of mass institutions were placed into effect—a perfect platform for for-/non-profit industrial development—and the push for the disability desegregation of public schools was mediated further by "inclusion" and other "advocacy" initiatives instituting broad "special" education and community "services."[62] After two decades of contiguous social movement toward deinstitutionalization, disability rights, independent-living, and self-advocacy between the 1960s-1980s, the Autism Movement emerged during the 1990s. Unlike leaders of the People First Movement (including people like Cunio), leaders of the Autism Movement refused political constraints on the future possibilities of the International Self-Advocacy Movement; especially when it came to the formation of political identity by way of an autistic community-based leadership.

Movement Across/Between People-First and Identity-First

Self-Advocates invested in the Autism Movement emerging during the 1990s would not accept a "politically correct"/(ed) and/or politically mediated version of "personhood" as a political identity. In their demands for political rights, authority,

[62] "Special education" has its origins in mass institutions and "Community-Services" in the pseudo-deinstitutionalization movement of the early 20th Century (Trent, 1994; Ferguson, 1994).

autonomy and liberation from the constraints instituted by non-disabled "guardians"/"conservators" (especially parents) during the autism "advocacy epidemic" of the 1990s, Autistic Self-Advocacy Movements came to demand political "Identity-First" (McGuire, 2016). The Autistic Self-Advocacy Network (ASAN, 2009), for instance, advocates against person-first language and for the use of "identity first language," for example terms like disabled people, autistic people, and/or autists as opposed to terms like people with disabilities, people with Autism and/or people on the (Autism) Spectrum. ASAN, in contrast to People First, is also politically dedicated to operating under an Autistic leadership[63] and, to organizing leadership training[64] for future generations of autistic people. Critical to the emergence of an autistic identity, for the Autistic Self-Advocacy Movement, is a politically-mobilized autistic (ie. community-based) leadership.

These two positionalities—"Person" versus "Identity" First—have since formed a sort of discursive schism as explained by Lydia Brown, an Asian American, Autistic, Disability Rights activist and writer, in "The Significance of Semantics: Person-First Language: Why It Matters" (2011)[65]:

> ***When we say "person with autism,"*** we say that it is unfortunate and an accident that a person is Autistic. We affirm that the person has value and worth, and that autism is entirely separate from what gives him or her value and worth. In fact, we are saying that autism is detrimental to value and worth as a person, which is why we separate the condition with the word "with" or "has." Ultimately, what we are saying when we say "person with autism" is that the person would be better off if not Autistic, and that it would have been better if

[63] Autistic Self Advocacy Network, 2019: "Leadership"
[64] Autistic Self Advocacy Network, 2019: "Empowering Leadership"
[65] Brown, Lydia. (2011).

> he or she had been born typical. We suppress the individual's identity as an Autistic person because we are saying that autism is something inherently bad like a disease.
>
> ***Yet, when we say "Autistic person,"*** we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life as an Autistic. Ultimately, we are accepting that the individual is different from non-Autistic people–and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference. (Brown, 2011).

In contrast to "person-first language" (PFL), "identity-first language" refuses any diminution of disability in so that disability cannot be made "secondary" to personhood (Cunio as quoted by Kaplan, 2011).

During the 1990s, and with the federal shift from the "Education for All Handicapped Children Act" to the "Individuals with Disabilities Education Act" (PFL) came a platform for Autistic Self-Advocacy leaders who sought to demand more than a "special" notion of "personhood" and, specifically, to demand the rights that accompany political identity as a minority population within the US--not just "special" language, but actual structural change led by actual disabled people. As with other Americans, there is no place for a "with" or "has" separating personhood from politically marginalized identities. Socio-linguistically, it would not make sense to refer to a "Person who has Blackness" or "People with Gayness." Minority communities in the US are recognized by their politically marginalized identities "first": Black (African American) people or Gay (LGBTQIA) people. As this political socio-linguistic logic pertains, it does not make sense to refer to "people with

Autism" or a "person who has Autism," nor "people with disabilities" or a "person who has disabilities"—people are "autistic," people are "disabled." Identity-first language proponents demand political identity as marginalized "Autists" or "Autistic people," "Disabled" or "Disabled people" (Brown, 2011). This discursive practice was coming into formation within the Autistic-led Self-Advocacy Movement as the concept of "neurodivergence" emerged during the late-1990s and the "neurodiversity paradigm" quickly came to "ground" the Autism Movement (McGuire, 2016: 60). Not so surprising, considering the rich diversity of disability movements that form the roots of the Autism Movement--the Deinstitutionalization, Self-Advocacy, Disability Rights, Independent-Living, and People-First Movements, all of which co-organized with other diverse social movements taking place in the US between 1960-1990--that "Neurodiversity" would work to "Unite!"[66] them all as they watched their commonly institutionalized histories seemingly "melt into air" during the last decade of the 20th century (Singer, 1999).

Judy Singer's Concept of "Neurodiversity" (1999)

Some credit Judy Singer, an Austrialian, autistic, white woman and sociologist, with coining the term "neurodiversity" between 1996-1999, and many consider her to be a "Neurodiversity Pioneer."[67] As an autistic sociology student during the late 1990s, Singer's perspective was radically shifted in the direction of the

[66] Marx, 1848
[67] Singer (1998); (1999).

"social model of disability"[68] after meeting her academic mentor, a polio survivor and wheelchair user. As the Autistic Movement emerged during the 1990s,

> He [Singer's mentor] introduced her [Singer] to what's called the "social model of disability" — that is, seeing disability as a relationship between the individual and society. She noticed that terms that include "disorder" were inherently pathologizing. Singer wanted to come up with a term that would be judgment-neutral, or even positive, to indicate that these conditions can also convey gifts and advantages. She decided on "neurodiversity," to draw a comparison with how biodiversity — having a variety of species — contributes to the overall resilience of the environment. (Silberman & Leviton, 2017)[69]

In her attempt to apply the social model of disability, canonical sociological theory, and ecological concepts of biodiversity to her intergenerationally lived experiences as an autistic woman--an autistic mother, and the daughter of an autistic mother--Singer published "*Why can't you be normal for once in your life?*: From a 'Problem with No Name' to a New Category of Disability" in 1999:

> For me, the key significance of the Autism Spectrum lies in its call for and anticipation of ***a politics of neurological diversity, or 'neurodiversity.'*** The neurologically different represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability. The rise of neurodiversity takes postmodern fragmentation one step further. Just as the postmodern era sees every once too solid belief melt into air, even our most taken-for granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) – are being dissolved. (Singer, 1999)[70]

[68] Oliver. (1981).
[69] Silberman & Leviton (2017).
[70] Singer. (1999).

Neurodiversity--as a concept and later a movement then--links Marx's critique of capitalism and call to action[71] in the "Communist Manifesto" (1848) to contemporary critiques prominent in emerging fields of "Deep Ecology" and "Third and Fourth World" Studies[72] of Marx's classically liberal anthropocentrism.

Singer's concept of "neurodiversity" simultaneously breathes new life and "diversity" into Marx's early philosophical reflections on "species-being"[73] at the

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[71] "All that is solid melts into air, all that is holy is profaned, and man is at last compelled to face with sober senses his real conditions of life, and his relations with his kind...Workers of the World, Unite! You have nothing to lose but your chains" (Marx, 1848).

[72] "Haraway faults Deep Ecologists and biologists for attempting to speak for the indigenous peoples and endangered species of the Amazonian rainforest. The central concern for this "collective entity," claims Haraway, is social justice, and that they be allowed to speak for themselves (Zimmerman, pp. 365-66). For Jerry Mander, who has spent considerable time studying the political problems of, and being with, Fourth World tribal peoples, they are appreciated not only for their multicultural diversity, but also for their ecocentric philosophies and cultures which respect the wild world and plants and animals. As Mander points out (*In The Absence of the Sacred*), Fourth World tribal peoples have already spoken out. They want nothing to do with the monocultural megatechnological/consumer society (and its satellite television) that is destroying their cultures and exploiting their wild lands. Other books which also discuss the resistance of Third and Fourth World peoples to the invasion of megatechnological society are Vandana Shiva, *Staying Alive: Women, Ecology and Development*, 1992) and Helena Norberg-Hodge, *Ancient Futures: Learning from Ladakh* (1991). While explicitly concerned with social justice, Haraway's Cyborg Manifesto hardly sets an appropriate example for, or shows solidarity with, these tribal peoples worldwide who are fighting for their lives, cultures, and homelands." (Sessions, 1995).

[73]**Here is how Marx defined species being in the 1844 Manuscripts**: "To say that man is a species being, is, therefore, to say that man raises himself above his own subjective individuality, that he recognizes in himself the objective universal, and thereby transcends himself as a finite being. Put another way, he is individually the representative of mankind." "Man is a species-being, not only because he practically and theoretically makes the species – both his own and those of other things – his object, but also – and this is simply another way of saying the same thing – because he looks upon himself as the present, living species, because he looks upon himself as a universal and therefore free being." "The animal is immediately one with its life activity; it is that activity. Man makes his life activity itself an object of his will and consciousness. He has conscious life activity. It is not a determination with which he directly merges. Conscious life activity directly distinguishes man from animal life activity. Only because of that is he a species-being." "It is therefore in his fashioning of the objective that man really proves himself to be a species-being. Such production is his active species-life. Through it nature appears as his work and his reality. The object of labour is therefore the objectification of the species-life of man: for man reproduces himself not only intellectually, in his consciousness, but actively and actually, and he can therefore contemplate himself in a world he himself has created. In tearing away the object of his production from man, estranged labour therefore tears away from him his species-life, his true species-objectivity, and transforms his advantage over animals into the disadvantage that his inorganic body, nature, is taken from him."

same time that it condemns classical idealist and broadly Western theories of an ableist "human nature" to "dissolution" (Marx, 1844; Marx, 1845): "The selfish misconception that induces you to transform into eternal laws of nature and of reason, the social forms springing from your present mode of production and form of property – historical relations that rise and disappear in the progress of production – this misconception you share with every ruling class that has preceded you" (Marx, 1848). I argue that Singer's concept of "neurodiversity" is part of a broadly disciplinary "Eco-Paradigm Shift" with deep structural sociological, yet eco-centric roots in the vein of many social ecologists, eco-Marxists, and ecofeminists doing the

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Rose: "To speak of species being and social being means at the outset placing oneself on two different levels. When one speaks of ***species being***, the reference is to a concept of human nature, and a concept is an abstraction. That abstraction only exists concretely when it assumes a form – a social form. If species being represents human nature, human needs, in a large and abstract sense, ***social being*** would be the way in which those general tendencies and those needs find a concrete form and expression; a form that is constantly changing and evolving in a dynamic interaction between the historical conditions and the praxis of the human collectivity that lives it. Social being, thus, reflects ***every aspect of the transformation that this praxis has on the objective conditions that make up the social environment, as well as the effect on the consciousness that the collectivity develops through its own practice.*** In that sense, it is mistaken to oppose species being to social being: one cannot exist without the other. But can one speak of a "human nature" or is it created by the very activity of social being? In a sense, one must answer both questions in the affirmative. In effect it seems clear to me that the human species is marked by certain broad features, and that these are essentially the same in all epochs, in all cultures. At the same time, the forms in which these features express themselves depend on the social context within which they are placed. The life force and death force [pulsion], the drive to understand [pulsion épistémophilique] (the need to understand the world), the need to belong to a collectivity and to bond with other members of that collectivity, the need to give and to receive love, creative activity, the aesthetic quest, are all elements that mark our species from the cave paintings of Lascaux to its most formidable technological developments. ***What puts the human being perpetually in motion, what makes her never stop, what makes him never satisfied, is the quest for, and expression of, his species being through the mediation of her praxis. In that respect, one cannot speak of species being without inscribing it in history, that is to say, in the movement of continual transformation that man effects on his environment in the effort to satisfy his needs***...Marx defined a human nature, a human essence of man, which is situated beyond modes of production or features of the environment. ***One of the characteristics of alienation or estrangement, for him, is precisely the loss of this species being.*** The capitalist mode of production renders the product of production alien to the person who has produced it, thus making man alien to himself – and, therefore, to his human essence; ***that is to say, alien to the universal, collective, character of the human being, to his need for bonding, for creative activity, for knowledge, for self-consciousness and consciousness of his environment, as well as alien from his capacity to project himself into the future."*** (Rose, 2005).

work to "position" and/or "situate" the context of their "thinking/process" toward social change; or, toward the divergent possibilities inherent in what I call "multiple possible futures."

Harvey Blume's Concept of "Neurodiversity" (1998)

Harvey Blume--a white, American (NYC) man and journalist--was in regular correspondence with Singer during the mid-late 1990s about their shared interest in Autism. Not surprisingly then, Blume similarly attempted to link disability and biodiversity in his 1998 article published in *The Atlantic*, "Neurodiversity: On the Neurological Underpinnings of Geekdom"[74]:

> The common assumption in cognitive studies these days is that the human brain is the most complicated two-and-a-half pounds of matter in the known universe. With so much going on in a brain, the argument goes, the occasional bug is inevitable: hence autism and other departures from the neurological norm. ISNT [Institute for the Study of the Neurologically Typical] suggests another way of looking at this. ***Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general.*** Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favor a somewhat autistic cast of mind. (Blume, 1999).

While his work was technically published a year prior to Singer's in a more popular and accessible format, Blume's *Atlantic* article "trades on the stereotype of the mildly autistic person as being talented with technology and computers, suggesting that Asperger syndrome may be beneficial for the development of future technologies and thus" argues that neurodiversity is a form of biodiversity critical to the advancement

[74] Blume. (1998)

of human societies; and specifically, existing and future modes of "mega-technological" production (Garen, 2011; Sessions, 1995)[75]. In this way, Blume's "biodiversity" argument promotes "neurodiversity" as "productive" for Western and techno-cratic capitalism, or as a uniquely "natural" and renewable but predominantly untapped source of "biopower."

In tracing the post-1800 emergence of "disciplinary power," which centers the human mind as the locus of subjugation, Foucault defines "biopower" as the "developmental" twin of disciplinary power relations:

> The second [biopower], formed somewhat later, ***focused on the species body***[76], the body imbued with the mechanics of life and serving as the basis of the biological processes: **propagation, births and mortality, the level of health, life expectancy and longevity, *with all the conditions that can cause these to vary* [ex. disability].** Their supervision was effected through an entire series of interventions and *regulatory controls:* ***a biopolitics of the [disabled] population*.**
> (Foucault, 1978: 139; original italics, bold added).

Where disciplinary techniques subjugate disabled minds via "presumptions of incompetence," biopolitical techniques control disabled populations. Discipline becomes the technology by which populations are formed, affording biopolitics the bio-disciplinary power to unevenly distribute disciplinary technologies (for instance, institutionalization). The shift into disciplinary and biopolitical relations of power became "without question, an indispensable element in the development of capitalism" by making possible "the controlled insertion of bodies into the machinery

[75] Garen, Josef. (2011).
[76] Consider inserting Marx's "species being" in place of Foucault's "species body" as the locus of biopolitics and human "biodiversity."

of production and the adjustment of the phenomena of population to economic processes" (Foucault, 1978: 140-1; Adams, 2017). Thus, by the late 20th Century, the emergence of prison and non-profit industrial complexes is seemingly "naturalized" as a consequence of bio-political shifts in population sorting and dis/placements (for instance, deinstitutionalization). In Blume's conception, neurodivergent (and/or disabled) people, as a population, can be inserted into dominant modes of production precisely through their subjugation as (un/paid) docile laborers and as a "natural" consequence of their "cast of mind" or "form of wiring." This subjugation is accompanied by a classically ableist form of dehumanization that literally turns neurodivergent "humans" into the "machines" (technologies) for which they work. This transformation is unmistakably akin to Marx's critique of alienation and call to protect species being from what Foucault would later coin as the "disciplinary power" of "biopolitics."

Mobilizing Biopolitics in Developmental Models of Human Society: "What is it Good For?"[77]

In alliance with emerging Self-Advocacy and Autism Movements of the 1990s, and on the eve of the 21st Century, both Singer and Blume had the intention of shifting commonly moralized attitudes toward people on the autism spectrum in the direction of something "positive," good, or at least "judgement-neutral": "Perhaps the greatest barrier was the attitude of many people, including parents, who thought that

[77] Edwin Starr, "War" (1970).

individuals with developmental disabilities [ex. Autistics] were not capable of living and growing in the community" ("We Are People First," 2019)[78]. However, I would argue that both Singer and Blume mobilize the concept of "biodiversity" in a way that works to promote "neurodiversity" as "inherently productive" for the advancement of human society—as in, "naturally *good"* for any national or global measure of political-economy—and that this biopolitical qualification is far from "judgement-neutral."

To propose that neurodivergent people are "good" for society because they increase bio-political-diversity[79] serves as a mobilization of "value-laden" Western ideals that promote the production of docile laborers within neoliberal, capitalist modes of production[80]. In their attempt to promote Autistic inclusion, these bio-/diversity-based concepts of neurodiversity work to reify capitalist relations of production that valorize those who are (or can be made to be) "able" to work within seemingly naturalized capitalist labor relations only in order to mask their simultaneous subjugation[81] once "included" within those same labor relations. Blume, in particular, accomplishes this by mobilizing biopolitical logics that valorize bodies that "work for" national and global capitalist development, like globalized "cybernetics and computer cultures" and their respective industrial development.

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[78] Minnesota Governor's Council on Developmental Disabilities. (2019) "We Are People First"
[79] If the social model of disability, Foucauldian theory, and/or especially feminist disability studies teaches anything, it is that "biology" is always political.
[80] "Inclusion" is often measured by un/employment rates and educational access is often promoted and justified as a gateway to employment. National organizations--including ASAN, SABE, the ARC, and the US government--share in organizational efforts to promote access to employment as a key marker of social "inclusion."
[81] Not to mention, disablement or debility: Puar, 2009; 2011.

This is how the concept of neurodiversity can be so easily appropriated and linked to neo-Darwinian notions of social evolution, for instance, in the practice of what Walker coined "neurocosmopolitanism": "To embrace the neurodiversity paradigm is to refuse to pathologize neurocognitive styles and experiences that differ from our own, and to accept ***neurodiversity as a natural, healthy, and important form of human biodiversity – a fundamental and vital characteristic of the human species, a crucial source of evolutionary and creative potential***" (Walker, 2013)[82]. In this example, "neurocosmopolitanism"—in its claims for neurodiversity's "naturalness" and "evolutionary" advantageousness in keeping with Singer's original conceptualization--comes to resemble a neoliberal, bio-politically-situated form of positive eugenics that seems to miss Marx's critique of capitalist labor relations (alienation of species being via "inclusion") and/or Foucault's genealogy of biopower (population/production control via the sorted "inclusion" of bodies). In this way, "neurodiversity" as a concept, when mobilized, may fail to "augment the insights of the social model of disability" and/or "represent a new addition to the familiar political categories of class/gender/race" in its reliance on a developmental model of human societies.

Taken out of the context of developmental models of human society and positioned within the "War on Autism", however, the concept of "neurodiversity" may be "good"—unlike "War"—for more than "absolutely nothing" (Starr, 1970; McGuire, 2016). McGuire (2016) contextualizes the emergence of "neurodiversity"

[82] Walker, Nick. (2013b). Also See Walker, 2013a; 2014a; 2014b.

as a concept within the "War on Autism" and particularly the "advocacy epidemic" of the 1990s:

> "Recall that, at this historical moment, countless professional/parent-led advocacy organizations were emerging and there was a proliferation of discourses of autism as an undesirable disorder/disease in need of management and/or cure. Vis-a-vis such overwhelmingly dominant cultural understandings of autism, notions of neurodiversity offer a creative, alternative, and liberatory narrative. ***They reclaim autism from the vice-grip of pathology and reassert the autistic subject as autonomous, agentive, and uniquely invested participant in the work of social advocacy. Thus, the neurodiversity paradigm has and continues to ground the autistic self-advocacy movement***" (59-60).

The historical emergence of "neurodiversity" was couched in a proliferation of for-/non-profit organizational developments matched by the rapid professionalization of "the work of autism advocacy." I refer here to McGuire's (2016) definition: "distinct from the autistic self/advocacy and activist work being done by autistic people, ***autism advocacy*** denotes the advocacy work of parents, family members, professionals, politicians (and their groups and organizations) who do not identify as autistic and who understand themselves as speaking on behalf of autistic people." In her analysis of the cultural war on Autism, McGuire argues that "instead of disrupting the dominant cultural orientation *'against' autism* by advocating *'for' autism*, mainstream autism advocacy work, most often, supports and sustains it" (2016: 20). "Neurodiversity," as it emerged in the context of a national surge in the professionalization of autism advocacy, represents a unifying call to neurodivergent communities to disrupt the biopolitical population sorting affected by such for-/non-profit industrial developments that transform community-based activism into "work."

Once community leaders become situated within the for-/non-profit industrial complex's "buffer-zone" they become alienated from the "species being" cultivated by such community activism as it is transubstantiated into wage labor (Marx, 1848; Thunder Hawk, 2007: 101-6; Kivel, 2007).

The "neurodiversity paradigm" shift, as part of a larger "eco-paradigm" shift--situated within the rise of the non-/for-profit industrial complexes since at least the 1970s and particularly post-deinstitutionalization--challenges the way in which biopolitical logics sort disabled populations into research subjects and/or funding sources. It works to desegregate and re/unite groups of disabled people who are past-in-present "cellmates" in two senses of the term:

1. Carceral (institutional/geographic discipline):

   The shared history of "special" institutionalization for the "idiot" and the "insane," their eventual forced segregation, followed by the segregation of the "low" from the "high" functioning within and between each respective institution (inmate cell sorting).

2. Biopolitical (industrial complexes of biopower):

   The distribution of biomedical research and community service funding to identify, sort, manage/cure people with "developmental disabilities" and "neurological disorders": the umbrella diagnostic roofs under which neurodivergent people--the historic "idiot" and "insane"—are housed in bio-politically mediated groups as research subjects (genomic sorting).

Native and indigenous populations of North America have a long history of struggling against such bio-politically orchestrated disciplinary sorting--racial/ancestral, genetic, institutional, and geographic--that continues to this day. The effects of environmental racism on the bodies and minds of native and indigenous populations, for instance, makes a neurodiversity augmented social model of disability all the more critically important to the resilience and unification of diversely intersecting resistance movements. Third and Fourth World scholars document and demonstrate historically situated modalities of community-based self-determination, resilience, and resistance that resonate with the growing neurodiversity movement and the broader "eco-paradigm" shift.

Counterintuitively, it is because Singer revives Marx's early philosophical work on "species-being, "in her attempt to "Unite!" neurodivergence (a neurological spectrum characteristic of the human species) with biodiversity (a sustainable spectrum of living beings or varieties of cohabitating life), that her concept of "neurodiversity" has the potential to bring the social model of disability into communion with ecological perspectives that directly critique Marx's anthropocentrism. I argue that the social model of disability, as augmented by the concept of neurodiversity, and anti-anthropocentric, ecological—especially Third and Fourth World—perspectives share three foci[83]:

[83] Where Ward Churchill (2004), Michel Foucault (2004, 1998), Mike Oliver (1981), Vandana Shiva (1993, 2005), Sylvia Wynter (2015) & Saidiya Hartman (1997; 2008) Meet to Challenge Adam Smith (1776/2014) and Karl Marx (1848/1969).

1) Relationality: a focus on the relationship between living beings and their (structured/situated) environments both local and global (Interdependence).

2) Decolonial: human beings are not, by nature, the center, the cause, or the "proper/ty owners" of such global[84] relations--nor the central "problem" in need of fixing/curing—because it is not in "human nature" to conquer "nature"[85] and ableist, white supremacist, patriarchal, capitalist notions of "human development"[86] are not the ideal/apex of "nature," or human society (Biodiversity).

3) Sovereignty: exacting a fundamental alteration in our understanding of what "human/nature" mean, particularly when it comes to situating "human nature" and/or human societies within both local/global relations between all living beings[87] (Self-Determination).

Put simply, these perspectives—a neurodiversity augmented social model of disability in the company of Third and Fourth World studies—share a "vision" of "chang[ing] human relations to nature;" or, a "re-vision" of "relationality" and "self-determination" that does not revolve around a classically Western ideal of white,

[84] I could substitute the word "spiritual" here to denote not only the knowledge of Third and Fourth World perspectives, but also to denote the "inconceivability" of such "global" relationality between beings in shared environments.
[85] This was Adam Smith's (1776/2014) mistaken perception of human nature--"propensity to truck, barter and trade"--leading him to advocate for free market capitalism and an understanding of the body and its labor as property.
[86] Historically considered ideal when able-bodied, white, male, and property owning.
[87] Think Indigenous resistance to environmental racism--Madonna Thunder Hawk, 2007.

property-owning, able-bodied/minded masculinity. It is in these ways that neurodiversity as a concept has the capacity--as originally intended by Singer--to critically "augment" the social model of disability and "represent a new addition to the familiar political categories of class/gender/race" (Singer, 1999). In combining these perspectives, "neurodivergent leadership" becomes a means of liberation for all neurodivergent communities seeking to transition from generations of trauma induced by centuries (500+ years on this continent) of conquest, capitalism, and confinement.

This too, is the work of "Disability Justice," as it "augments"[88] the Disability Rights and Independent-Living Movements of the 20th Century and "represents a new addition to the familiar political categories of class/gender/race"-based social movements:

> There was phenomenal and historic work to develop the disability rights movement in the U.S., and it had many successes in advancing a philosophy of independent living and opening possibilities for people with disabilities through the establishment of civil rights for people with disabilities. Like other movements, the current disability rights movement includes advocacy organizations, service provision agencies, constituency led centers, membership based national organizations, as well as cultural and academic spaces. And, like many movements, it is contextualized within its era of emergence and left us with "cliff-hangers": it is single issue identity based; its leadership has historically centered white experiences; its framework leaves out other forms of oppression and the ways in which privilege is leveraged at differing times and for various purposes; it centers people with mobility impairments, marginalizing other forms of impairment; and centers people who can achieve rights and access through a legal or rights-based framework. The political strategy of the disability rights movement relied on litigation and the establishment of a disability bureaucratic sector at the expense of developing a broad-based popular movement. While a concrete and radical move forward toward justice, the disability rights movement simultaneously invisibilized the lives of

[88] Singer, 1999.

> peoples who lived at intersecting junctures of oppression – disabled people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others… (Berne, 2015).[89]

This community-based critique of the Disability Rights Movement in the US is more than critique, as I witnessed when Leroy Moore first presented the "10 Principles of Disability Justice" at the *Disability Justice Summit* held in Atlanta, GA on June 10th, 2015--one day prior to the Society for Disability Studies (SDS) Conference in the same location.

These principles, as organized since 2005 under a POC, queer, and/or gender non-conforming, diversely disabled leadership, offers an intersectional "vision":

> What has been consistent [in the Disability Justice Movement, by contrast to the Disability Rights Movement] is the leadership of disabled people of color and of queer and gender non-conforming disabled people. **Disability Justice activists, organizers, cultural workers understand that able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation. The histories of white supremacy and ableism are inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination. We cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated "other" from whom profits and status are extracted.** 500+ years of violence against black and brown communities includes 500+ years of bodies and minds deemed dangerous by being non-normative – again, not simply within able-bodied normativity, but within the violence of heteronormativity, white supremacy, gender normativity, within which our various bodies and multiple communities have been deemed *"deviant"*, *"unproductive"*, *"invalid."* A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that

[89] Berne, Patty. (2015). "Disability Justice--A Working Draft By Patty Berne."

> must be met. We know that we are powerful not despite the complexities of our bodies, but because of them**. We understand that all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and that we cannot separate them. These are the positions from where we struggle. *We are in a global system that is incompatible with life.*[90]** There is no way [to] stop a single gear in motion — we must dismantle this machine. **Disability Justice holds *a vision* born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life.** Disabled people of the global majority -- black and brown people -- share common ground confronting and subverting colonial powers in our struggle for life and justice. There has always been resistance to all forms of oppression, as we know through our bones that there have simultaneously been disabled people visioning a world where we flourish, that values and celebrates us in all our myriad beauty. (Berne, 2015; emphasis added)

In these early stages of the Disability Justice Movement, a transition in disability leadership is taking place. Moving away from Disability Rights frameworks includes decentering: rights-based claims, single-issue platforms, physical/mobility impairments, and whiteness. Decolonizing existing frameworks, however, is a process. This process of "transition" between "rights-based" and "justice-based" social movements can be witnessed in the ACAT/ACT staff as a direct consequence of its "neurodivergent leadership." The ACAT/ACT programs demonstrate what I consider to be a radical, yet non-utopic transition program toward justice situated within the non-profit industrial complex and "special" education system.

The neurodivergent practice of reorganizing and reuniting communities of intergenerationally traumatized people who share historically divergent experiences

[90] Where "Neurodiversity" and "Biodiversity" meet in a critique of colonial mentalities, capitalism, and ableist supremacy.

of medicalization and total institutionalization, followed by segregation and displacement, can be seen in the ACAT/ACT programs. The staff's relationship to the term "neurodiversity" as an identity is significantly impacted by two major factors: 1) staff witnessing the everyday ableism (combined with sexism, racism and classism) experienced by I/DD student/clients during program; and, 2) staff's lived experiences with racial/ethnic, class-situated, and/or sex/gender marginalization and/or intersecting "courtesy stigma"[91] while working in a community-based program (Goffman, 1963). "Neurodiversity" is often perceived by ACAT/ACT staff as a term of staff-to-student "unity," while "disability" becomes reserved for those who should be acknowledged as the "most impacted" by ableism[92]. In this way, the term "neurodiversity" works to reorganize disability community at the same time that it seems to reproduce hierarchies of disability between neurodivergent "staff" (able to work/pass) and disabled "student/clients" (situated within "special" systems of forced dependence).

Who Are the ACAT/ACT Staff?

In my time working with ACAT/ACT from 2016-2018, I met a total of twenty-one (21) staff members, or "community-based teacher/instructors" (CBTIs). Two of the twenty-one CBTIs—"Joan" and "Stanley"—also held titles as "program coordinators." These twenty-one CBTIs worked under Tania Coffield, the programs'

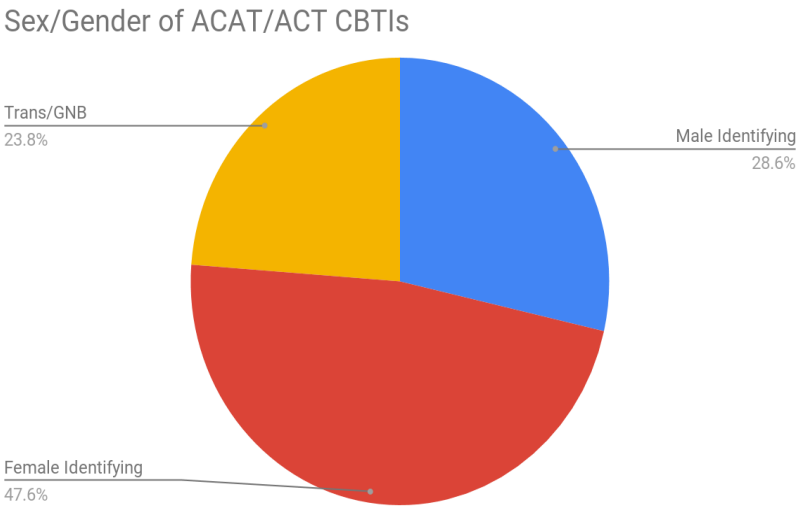
[91] Stigma by association.
[92] Berne, 2015

(now former-) supervisor; and, Brent White, the programs' director[93]. Tania and Brent--the programs' primary leadership training CBTI's in neurodivergent leaders--both identify as disabled, neurodivergent and autistic (DNA[94]).

Sex and Gender:

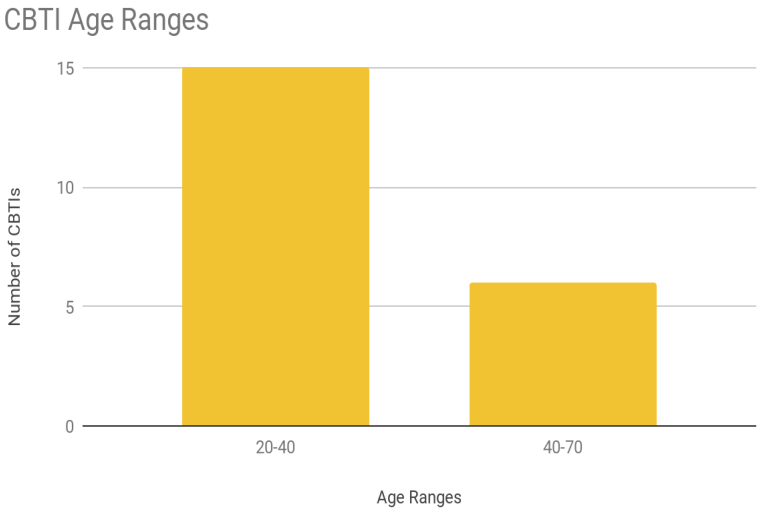
Approximately half of the ACAT/ACT CBTIs--10 out of 21--identified as women. Five CBTIs, almost ¼ of the staff between 2016-2018, identified as trans and/or gender non-binary (Trans/GNB)[95]. The remaining six staff members--just over ¼ of the staff--identified as men. I did not survey employees about their sexual orientations while they were working; however, a significant proportion of CBTIs identify as LGBTQIA. What is more important is this: fifteen of the twenty-one CBTIs--over 2/3rds--I met identified as sexual/gender minorities: women and/or Trans/GNB.

[93] Not included in the 21 total staff. "Staff" refers to "community-based teacher/instructors" (CBTIs).
[94] The acronym "DNA" here describes people who identify openly as with all three lived experiences: Disability, Neurodivergence, and Autism (D.N.A.). Some staff only identify with one or two aspects of DNA, or none. Only those staff who identify as all three without excluding any one because they understand them to be inter-connected lived-experiences, identify with "DNA." So, for instance, staff who only identify as "autistic and neurodivergent" are not identified with "DNA" because they exclude "disability" from their experiences of autism and neurodiversity; similarly, staff who only identify with "neurodiversity" are not identified with "DNA" because they exclude autism and disability from that experience. Similarly, staff who identify exclusively with TAD (trauma, anxiety, and/or depression) are not identified with "DNA" because they do not connect their experiences with TAD to disability, neurodiversity or autism; however, most who are identified with DNA also experience TAD.
[95] These gross divisions are admittedly reductive. However, they are not meant to negate differences between differently identifying groups within trans communities and they are not meant to present any assumptions about trans people who also identify as women/men. These divisions are primarily designed to prevent identification within any cluster and to make relevant distinctions between heteronormative and queer CBTIs. Sidenote: the vast majority of trans CBTIs at ACAT/ACT between 2016-2018 also identified as Gender Non-Binary.



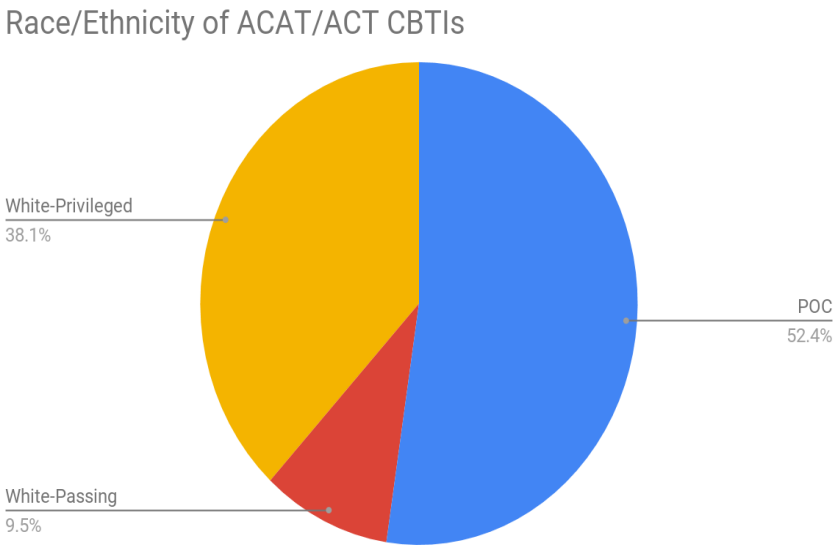
Race & Age:

Eleven CBTIs identified as people of color (POC)--that is approximately half of all CBTIs. Of the eleven POC CBTIs at ACAT/ACT between 2016-2018, five (almost half) were over the age of 40 and were thus born prior to 1980.[96]



[96] The year 1980 is significant because it is a full decade prior to the passage of the ADA. Meaning that the typically older, POC CBTIs are more likely to remember or have personal experiences with pre-ADA U.S. education systems and the deinstitutionalization movement.

A small number of CBTIs identified as non-white, but universally white-passing; or, as people who identify with POC-ancestry even if they experience white privilege on a daily basis[97]--both also identified as trans and were under the age of 40. The remaining eight CBTIs--38% of staff--identified as white. This means that of the twenty-one CBTIs I met at ACAT/ACT, ten (approximately half) recognized white-privilege as part of their daily experience in doing community-based work [See Chart: "Race/Ethnicity of ACAT/ACT CBTIs"]. In addition to this, the majority of white-privileged CBTIs were born after 1980--I only met one white-identifying CBTI over 40 years of age between 2016-2018.

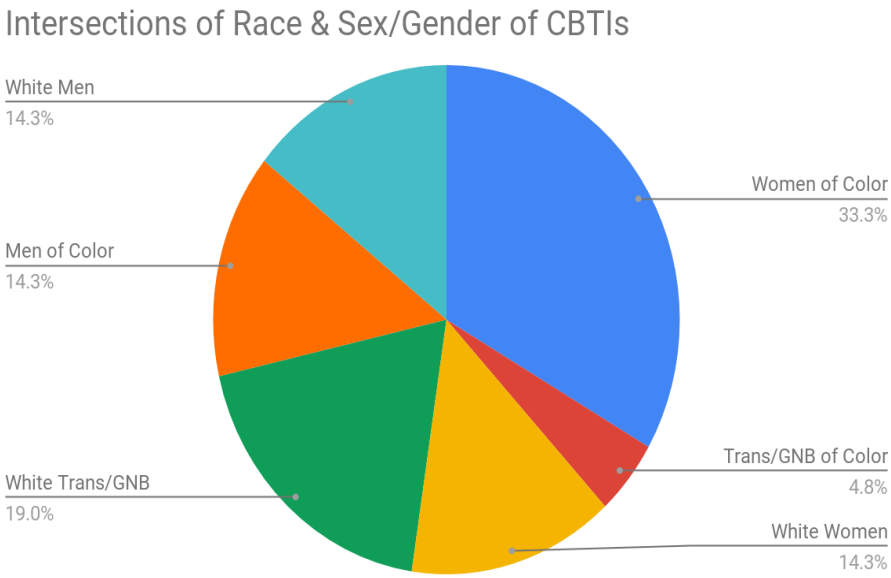


Race & Sex/Gender:

Between 2016-2018, ACAT/ACT was not only a femme/trans/GNB-dominated workplace (15/21) with a majority POC (11/21) staff; but, more than ⅓ of

[97] For the purposes of this research, these two CBTIs will be identified by their experience of racial/ethnic privilege (whiteness), not by their personal/private knowledge of POC-ancestry.

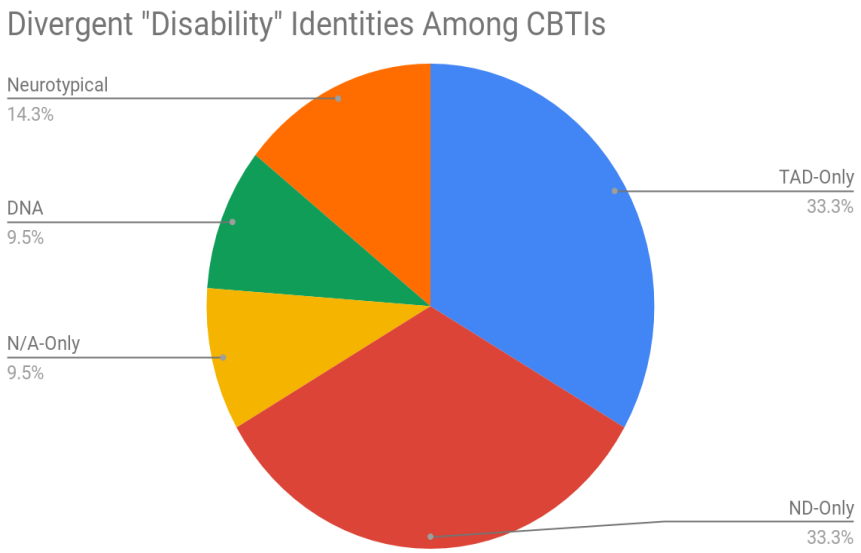
the staff (8/21) identified as women or other sexual minorities of color. Of the eleven POC CBTIs I met: three identified as men, seven identified as women, and one identified as trans.



Among the ten CBTIs whose lived experience working in the community is one of white-privilege: three identified as men, three identified as women, and four identified as trans/GNB.

Disability & Neurodiversity:

Between 2016-2018, approximately 52.3% (11/21) of all CBTIs identified openly with some form of a "neurodivergent" lived experience. Some CBTI's identified as "Neurodivergent-Only" (ND-Only), others identified as "Neurodivergent and Autistic" (N/A-Only), and a similarly small minority identified as "Disabled, Neurodivergent, and Autistic" (DNA).



Among the ten staff members who did not openly identify as "neurodivergent," 70% (7/10) did identify with lived experiences of "trauma, anxiety, and/or depression" (TAD-Only). Only 1/7th (approximately 14%) of the staff identified most closely with a broadly "neurotypical" lived experience.

"Neurotypicals" & "TAD-Only"

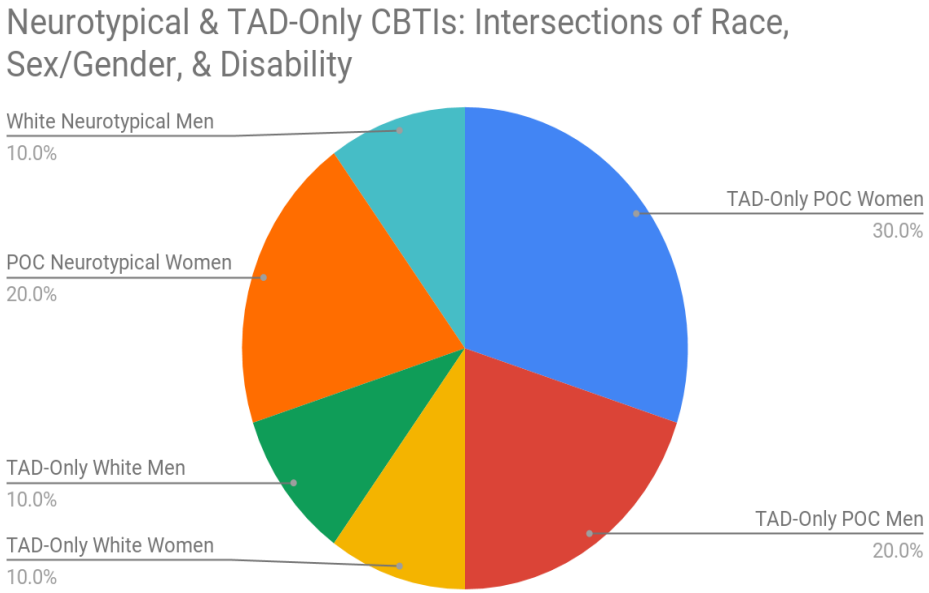
Only one-seventh of all CBTIs (3/21) identified openly as more-or-less "neurotypical" (no lived experiences with TAD either). Through observation, I noted that these three CBTIs often seemed to separate their "work life" and "private life" more strictly than their colleagues or tended to keep their "life outside of work" particularly private. Even during staff meetings, these three CBTIs often elected to sit on the outskirts of the room and somewhat separate from their colleagues. Two

women of color over the age of 40 and one white man in his 20s were working neurotypical CBTIs in the ACAT/ACT programs.

As previously stated, one-third of all CBTIs (7/21) identified with "TAD[98]-only" lived experiences. "TAD-only" must be distinguished from "neurotypical" as much as "neurodivergent" in this case, however. The seven CBTIs with lived experiences of "Trauma, Anxiety, and/or Depression Only" (TAD-only) did not directly connect these experiences to a "disability" and/or "neurodivergent" identity. It is significant to note that the largest group of people who identified as "TAD-only" (5/7 or 71%) were POC CBTIs: three women of color, two men of color, one white woman and one white man identified most closely with "TAD-only" experiences. While these seven CBTIs with lived experiences of TAD-only considered those experiences to be personally and professionally "imperative,"[99] they did not identify their experiences with TAD-only as politically "disabling" in their lives, or in connection to a "neurodivergent" experience. Particularly in the cases of TAD-Only POC CBTIs, racialization was more often recognized as a source of marginalization while working in the community--more often, the work of TAD-Only POC CBTIs in the community was complicated/hindered by the public's racialized assumptions about staff competence. Where I/DD student/client's competencies were often measured by their disability and then augmented by their race and sex in public; staff

[98] The acronym "TAD" here describes people who identify openly with experiences of Trauma, Anxiety, and/or Depression (T.A.D.); however, do not associate these lived experiences with a "disabled, neurodivergent, and/or autistic" identity.
[99] Here, I am playing on the social model's division of "impairment" (impairing) versus "disability" (disabling) as it uncritically (and non-intersectionally) situates/divides the personal and political.

who passed as “non-disabled”--regardless of their experiences with TAD-Only--could expect their competencies to be measured more often according to racial stereotypes. Lastly, no trans/GNB CBTIs associated most closely with TAD-only/neurotypical lived experiences.



In contrast to the ten CBTIs who identified with “TAD-only”/”neurotypical” lived-experiences, a greater proportion of CBTIs did in fact connect their experiences of TAD with “neurodiversity;” especially after working at ACAT/ACT for a few months. It was a common story told among CBTIs: discovering the term “neurodivergence” as the perfect descriptor for their lived experiences only after taking a position with ACAT/ACT and after starting their work with adult I/DD student/clients in the community. However, CBTIs who did connect their experiences

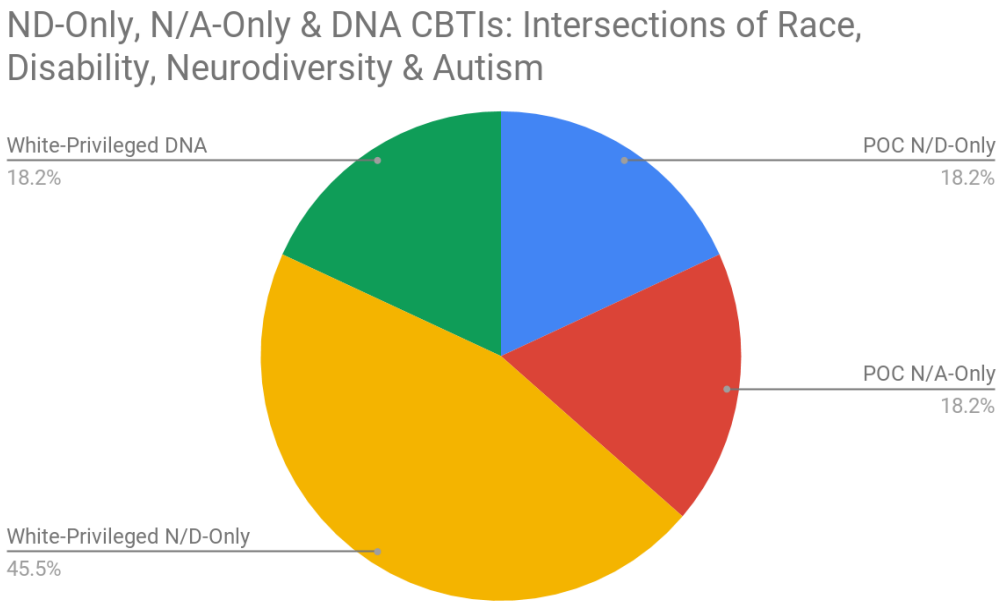
with TAD to neurodiversity, also typically described themselves as "neurodivergent-only"[100] to the exclusion of a "disability" identity.

"Neurodivergent-Only" & "DNA"

One-third of all CBTIs (7/21) identified as "Neurodivergent-only": two were POC and five experienced white privilege. The exclusion of a "disability" identity, in particular, was common to the vast majority of CBTIs, even neurodivergent-identifying. Only two CBTIs (>10%) between 2016-2018 identified with DNA; and, both DNA-identifying CBTIs also experienced everyday white-privilege. Two POC CBTIs identified with "neurodiversity" and "autism;" but did not commonly connect these experiences to a "disability" identity. Eleven (52.3%) of all CBTIs identified as either: "N/D-Only" (7: neurodivergent-only), "N/A-Only" (2: neurodivergent and autistic only), or "DNA" (2: disabled, neurodivergent and autistic).

Not one of the eleven POC CBTIs I met between 2016-2018 openly identified as "disabled" to me. For ACAT/ACT CBTIs, the word "disability" seemed more often than not reserved as a descriptor for ACAT/ACT student/clients; with the exception of two white-privileged CBTIs (in addition to the programs' supervisor and director).

[100] "Neurodivergent-Only" signals that the subject does not identify as "disabled" or "autistic" even if they do identify openly as "neurodivergent." These research participants do not experience these categories intersectionally.



For many CBTIs, this semantic separation was a critically important way of honoring the differences between "staff" and "inmate/client" experiences; particularly as staff witnessed the everyday ableism ACAT/ACT adult I/DD student/clients experienced in the community during program.

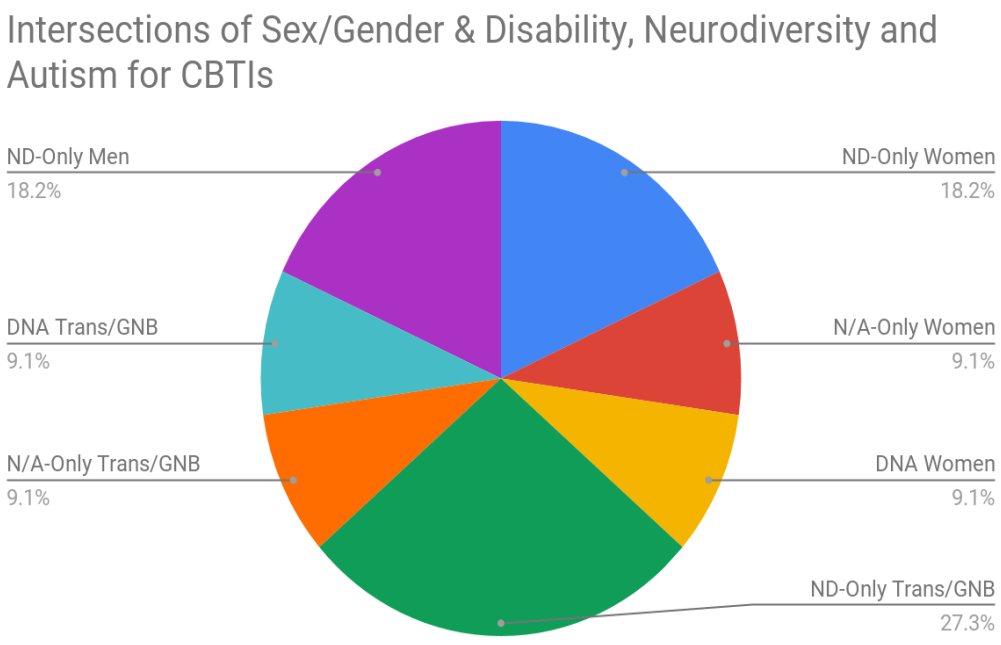
Although two POC CBTIs did identify as "neurodivergent-only" ("ND-only") and, two queer, POC CBTIs identified as both "Autistic" and "Neurodivergent" ("N/A-only"[101]), all four POC CBTIs generally excluded the word "disability" from their identifications. POC CBTIs were more likely to identify with "TAD-Only" experiences; whereas, white privileged CBTIs were more likely to identify with "ND-Only" experiences. At ACAT/ACT, white privileged CBTIs were more likely to

[101] "N/A-only" refers to "neurodivergent and autistic only": the preference of two POC, queer CBTIs only.

identify with any aspect of D/N/A than their POC colleagues. Race is a significant variable impacting disability and neurodivergent identity for CBTIs.

Intersections of Sex/Gender, Disability & Neurodiversity

With this being said, it is still the case that the majority of the ACAT/ACT CBTIs identified as at least broadly "neurodivergent." Eleven CBTIs in total--four POC and seven white-privileged--identified as "at least" broadly "neurodivergent."[102] A total of 82% (9/11) of CBTIs who identified with some form of "neurodivergence" beyond "TAD-Only" experiences were sex/gender and/or racial/ethnic minorities: women, women of color, trans/GNB, and/or trans/GNB POCs. All five trans/GNB CBTIs, regardless of race, identified as "at least" broadly "neurodivergent."



[102] Not including those who identified with experiences of TAD-only.

Only three of the twenty-one staff I met did not identify with any experiences of TAD or DNA--identified as neurotypical[103]; whereas, the other eighteen CBTIs working at ACAT/ACT between 2016-2018 identified openly with lived experiences of trauma, anxiety, depression, disability, neurodivergence, and/or autism; among many others.

Intersections of Race, Disability & Neurodiversity:

While the CBTIs, overall, are predominantly POCs (11/21), gender/sexual minorities (15/21), and broadly Neurodivergent-identifying (11/21) people--these groups do not overlap evenly. More than half of the eleven POC CBTIs identify most closely with TAD-only (5/11) and/or neurotypical (2/11) lived-experiences--this means that 64% (7/11) of POC CBTIs do not identify with disability, neurodiversity, or autism. By contrast, less than 1/3rd (3/10, or 30%) of white-privileged CBTI staff identify as TAD-only (2/10) or neurotypical (1/10). This means that the majority of CBTIs who identify with broad experiences of neurodiversity (-only, or in combination with autism or disability) are also white-privileged. In total, 1/3rd (7/21) of all CBTIs openly identify with intersecting white-privileged and neurodivergent lived experiences. Only three (3/10) white-privileged CBTIs identified with TAD-only and/or distanced themselves from any identification with disability,

[103] For the purposes of this research, "Neurotypicals" are represented by people who do not identify with any experiences of TAD or DNA.

neurodiversity, and/or autism in contrast to seven (7/11) POC CBTIs.

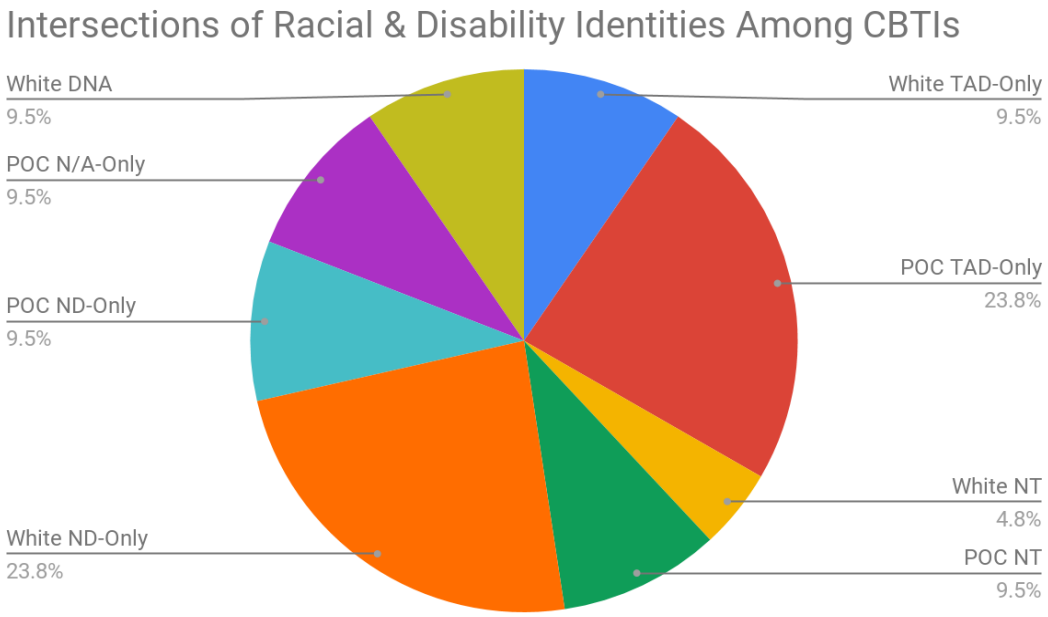


Table 1: Intersections of Race, Disability, Neurodiversity & Autism among ACAT/ACT CBTIs

CBTI Race	DNA	N/A-Only	ND-Only	TAD-Only	NT
POC	0	2	2	**5**	2
White-Privileged	2	0	**5**	2	1

Only four POC-identifying CBTIs identify broadly with neurodivergence; whereas, seven white-privileged CBTIs identify with neurodivergence in some way. Notably, however, three (75%) of the four POC neurodivergent identifying CBTIs, as well as six (86%) of the seven white-privileged neurodivergent-identifying CBTIs,

also identify as sexual/gender minorities (as women and/or trans/GNB). The CBTIs who identified with TAD-only or distanced themselves from disability, neurodiversity, and/or autism altogether--10/21--were a majority POC-identifying (7/10, or 70%). The majority of CBTIs who identified with TAD-only or Neurotypicality were women (6/10, 60%) and/or women of color (5/10, or 50%).

In the ACAT/ACT case, this means the majority POC staff[104] are less likely than their white-privileged colleagues to identify with any lived-experience of DNA; and, are more likely to identify with lived experiences of TAD, or as generally neurotypical. A total of 82% (9/11) of CBTIs who identified with some form of "neurodivergence" beyond "TAD-Only" experiences, however, were sex/gender and/or racial/ethnic minorities: women, women of color, trans/GNB, and/or trans/GNB POCs. Regardless of race, the majority neurodivergent-identifying staff[105] at ACAT/ACT were, overall, more likely than their neurotypical colleagues to identify as LGBTQIA. CBTIs who identified most closely with neurotypicality (10/21) were also typically cis-gender and generally heteronormative.

Disability -versus- Neurodiversity: How much is "Disabled Enough" and Who are "The Most Impacted"

Excerpt from an Interview with an "ND-Only" ACAT/ACT CBTI, July 2018:

LH: "Do you think of your students as neurodivergent?"

CBTI: "I do."

[104] Eleven of the total Twenty-One CBTIs identified as POC between 2016-2018. The other ten identified with experiences of white privilege in their community-based work.

[105] Eleven of the Twenty-One Staff identified as Disabled, Neurodivergent, and/or Autistic between 2016-2018. The other ten identified with TAD and/or as neurotypical.

LH: "So do you think of yourself and your students as part of a similar group?"

CBTI: "I do. Yeah."

LH: "Do you think that your students are also disabled?"

CBTI: "Yeah."

LH: "Okay, so you feel like there's a difference there?"

CBTI: "Mhm… Yeah."

"The second principle is the ***Leadership of Those Most Impacted***. It reflects our understanding of ableism in the context of other historical systemic oppressions, thus we are ***led by those who most know these systems***." (Berne, "10 Principles of Disability Justice," 2015; emphasis added).

When I first encountered the ACAT/ACT programs during the summer of 2016, it was my full intention to become a staff member, and specifically a CBTI. Not only did I have the goal of working with/for disabled people; but, when I found out that ACAT/ACT was a neurodivergent-led non-profit organization, I truly believed I was a "neurodivergent-shoe-in," so to speak, and that I had found my "golden ticket." After shadowing "Joan" for a full working day with a group of I/DD women student/clients, I knew this job was not accessible to me as a neurodivergent person with physical impairments who cannot walk, stand, and/or run on demand or for long periods of time. This baffled me, and left my understanding of the concept and practice of "neurodiversity" as a movement literally "shook."

My mind was swimming in questions: How could the neurodivergent leadership of ACAT/ACT call themselves neurodivergent leaders and refuse to accommodate me at the same time? Why did I feel, as a neurodivergent and disabled person, that I had some kind of "right" to be accommodated there? Aren't physical impairments the most frequently and "easily" accommodated at this point? Why did I

feel this particular neurodivergent workplace "needed" to accommodate me in order to be "legitimately" neurodivergent? Wasn't I neurodivergent enough? Or, was I too disabled?

I refused to assume--but I needed to understand--so I determined to find a way to stick-around. As I began working as a "researcher" with ACAT/ACT--an accessible "working" fit for me and them--I came to observe additionally confusing phenomena:

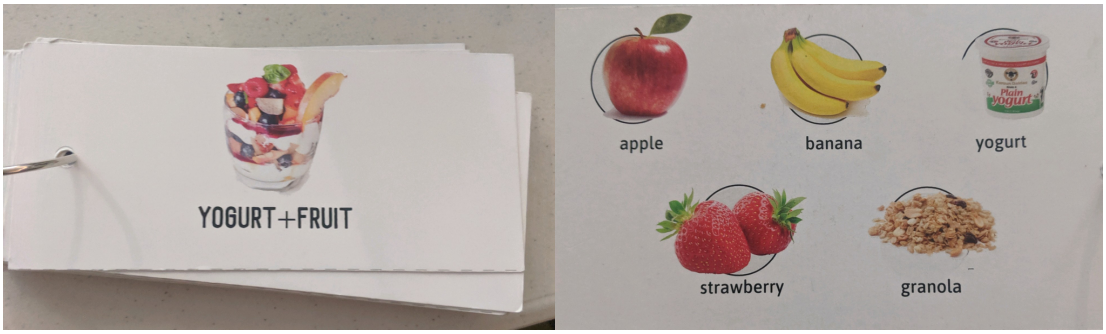
1) Although the director (a white man in his 60s) and supervisor (a white woman in her thirties) identified as DNA, very few staff members (only 2/21) identified as "disabled."
2) No staff (including administrators) had any mobility or other "visible" impairments.
3) The DNA-identifying director and supervisor considered their "white-privilege" and their ability to "pass" as non-disabled to be key to their success in obtaining and expanding leadership positions for neurodivergent people within their niche of the non-profit industrial complex given its historical domination by white neurotypical and/or non-disabled "advocates."
4) The most common "disability" connection with which staff comfortably identified was "neurodiversity"—and most often "neurodiversity-only."
5) By contrast, however, student/clients were most commonly described by staff, administrators, parents and other "special advocates" as intellectually and/or developmentally "disabled"—meaning student/clients were identified as "disabled" first, and perhaps neurodivergent "secondarily."
6) Despite a DNA-identifying leadership, most of the "disabled" people "working for" the ACAT/ACT programs occupied the lowest position of power within the organization's hierarchy as student/clients.
7) "Passing" CBTIs--regardless of their identification with disability, neurodiversity and/or autism (or not)—discussed and recognized their "passing privilege;" and, attempted to mobilize that privilege so that it could "work for," or to the advantage of I/DD student/clients. This was a common topic of discussion, for instance, in mandatory staff meetings and voluntary neurodivergent leadership trainings hosted by the programs' director and supervisor.

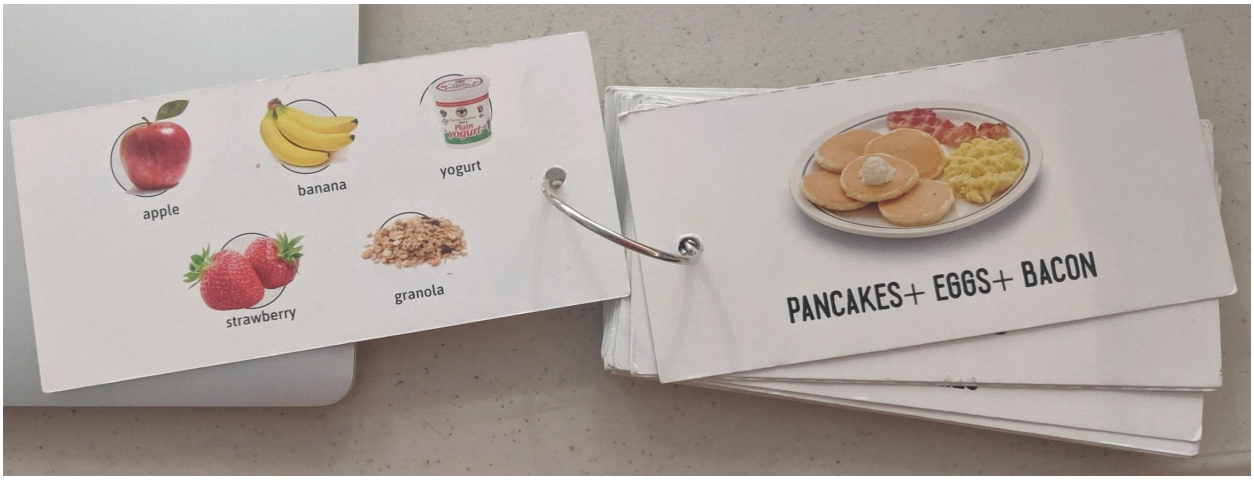
8) It was commonly understood at ACAT/ACT that the "passing privileges" experienced by staff/administrators could not be abdicated--people cannot "refuse" ascribed social statuses--but it could be "redirected" (to appropriate a term common to ABA therapies) "for good, instead of evil."

This was not how I expected "neurodivergent leadership" to work; but, after two years of fieldwork with the ACAT/ACT programs, I also could not deny that something really was working. I had, between 2016-2018, witnessed I/DD student/clients learning self-determination skills and teaching others such skills (including me!) in their community-based work with CBTIs; and, I had also witnessed CBTIs sacrifice the comforts of "passing" neurotypical privileges in service of supporting the divergent access needs and rights of I/DD student/clients.

One example of this always stood out to me. Most I/DD student/clients spend at least one day a week participating in a cooking class while in program. Cooking class in a community-based transition program is not only a lesson in how to cook a meal, however. I/DD student/clients are prompted to determine, as a group (3-6 student/clients), not only what they would like to cook and eat, but also how to do so on a budget. Budgeting is a crucial independent living skill, especially for disabled adults whose means of survival is often limited to a substandard social security income and/or below minimum wages. After choosing a meal to prepare together, I/DD student/clients practice budgeting both before and during a visit to the local grocery store just like any other member of the community: choosing ingredients based on the recipe and figuring out what they can afford to purchase; sometimes by

way of words, sometimes using pictures/images, and sometimes with the support of people who have done it before (their co-teachers).





Images of a teaching tool made by a CBTI for I/DD student/clients in "Cooking Class." I/DD student/clients can use this booklet whether they are able to read or not so as to explore meal ideas, what ingredients go into preparing a given meal, how to imagine all the parts of a meal and steps in a recipe. This booklet can be used by one or more people at a time so groups can explore its contents together or separately

A crucial part of this learning process takes place literally in the grocery store's check-out line and with the cashier--this is where adult I/DD student/clients learn how to use money and work with community authorities (for example, a cashier) to learn the rules involved in exchanging money for goods (for example, groceries). The job of the CBTI is to protect the space in which I/DD student/clients are learning self-determination and independent living skills. In this case, that "space" is the check-out line. What threatens I/DD student/clients' learning experience are community members either in-line or behind the register who do not believe they "need" to respect the fact that I/DD student/clients are learning these independent living skills for the first time as adults. Guided by a neurotypical-dominant logic--no adult is supposed to hold-up the check-out line at the grocery store because they are "having a hard time knowing the rules"--community members most typically attempt to correct the breach in neurotypical practice in classic phenomenological fashion: by asking the "neurotypical passing" worker in closest proximity to the disabled person to "step-in," to "prevent" I/DD student/clients from disrupting the dominant code of practice, and to "protect" community members from being immersed in a neurodivergent breach[106] of the neurotypical norm (ie. getting through the grocery

[106] "Breaching Experiments" reference (Garfinkel, 1967). This discussion includes an experience of "crip time" which does not "move" at the speed of "production" and refers to the different ways in

store line as quickly as "humanly" possible). A CBTI's job is instead to "protect" I/DD student/clients right to learn by refusing to "correct" the breach according to neurotypical expectations wherein the "passing" neurotypical worker is "supposed" to "step in" and do everything to protect the seemingly naturalness of neurotypical norms.

As I/DD student/clients attempt to purchase what they need to prepare a meal and return what they cannot afford within their budget, the check-out line can grow long and an impatient tension within it can quickly be lobbied against I/DD student/clients--this is often the case at fast-food restaurants at lunch time, as well. CBTIs are present to prevent other community members from becoming a barrier to I/DD student/clients community-based learning experience. They do this by "holding space"--literally holding-up the line, refusing to budget items *for* I/DD student/clients, and preventing community-members (cashiers and/or folks in line behind them) from denying I/DD adult student/clients access to the opportunity to safely learn community-based independent-living and self-determination skills.

Unless I/DD student/clients self-advocate for support or face the imminent threat of violence/re-traumatization at the hands of community members, a CBTIs job is to leverage their "passing" privilege to prevent community members from becoming a barrier to I/DD student/clients learning experience--not by stepping in, but by "refusing to step-in or take-over" while simultaneously "holding space." In

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which disabled and neurodivergent communities experience time, often at a different pace than nondisabled/neurotypical expectations (Kafer, 2013).

this way, CBTIs sacrifice the “passing” neurotypical privilege of an independent anonymity when moving through the line at a “productive” speed. CBTIs do not “step in” to hurry I/DD student/clients through their learning experience; they “step in” only to secure I/DD student/clients access to actual experiences in the community by leveraging the presumed authority of a “passing” neurotypical competence. Learning how to grocery shop in the “least restrictive environment” IS learning at the grocery store--where such skills are practiced--and by preventing other community members from “stepping in” to determine the pace/process of that learning experience for I/DD student/clients, CBTI’s demand that community members respect I/DD student/clients pace/learning process; and, neurodivergent practices as legitimate community practices.

In my time doing participatory observational research with ACAT/ACT, I witnessed a different type of schism in formation--different from the discursive schism between self-advocates for “people-first” or “identity-first” language from within which “neurodiversity” as a concept, a practice, and an eventual movement emerged. While the majority of the staff felt a “neurodivergent” community-based connection to their I/DD student/clients, they did not identify that experience as a “disability” community-based connection. For the most part, staff identified as “neurodivergent” people serving I/D “disabled” student/clients—"disabled” first, and “secondarily” neurodivergent (Kaplan, quoting Cunio, 1974). In reality, the term “disability” did not make sense to the vast majority of staff as a self-identification either before or after working with I/DD student/clients at ACAT/ACT.

Because neurodivergent-identifying staff—unlike I/DD student/clients, but like their neurodivergent leaders—are able to "pass"[107] as non-disabled and avoid "disability accommodations" and/or ableism in their neurodivergent-led workplace and the community, they don't feel "disabled enough" to claim a "disability" identity. To many staff, student/clients earn the claim of "disability" identity by their inability to avoid every day, lived experiences with ableist supremacy; or, by their inability to conform to normative standards and expectations of being able to at least "pass" as someone who isn't "having a hard time knowing the rules." To honor and legitimize the lived experiences of I/D "disabled" people—how they earn the claim of a disability identity—is, among the staff at ACAT/ACT, a way of *practicing* neurodiversity that promotes "disability justice." Below: I quote at length an excerpt from an interview with a "neurodivergent-only" CBTI to demonstrate how different forms of "passing" privileges are leveraged by staff in "non-utopic, yet radical" ways so that intersections of privilege can be used "for good, instead of evil"--or, in other words, to do justice to I/DD student/clients instead of doing service to neurotypical systems.

Excerpts from an Interview with a Community-Based Teacher/Instructor 2018

LH: Do you identify as Disabled?

[107] Note: just because someone can "pass" in one situation, does not mean they can "pass" in another. This job may offer the possibility to "pass" more freely than other jobs where "passing" would be more work.

CBTI: "Ah… man, what a question. I wish I chose the other one [question] now. That's hard. That is also context based… I think like… um… yeah, good question… um…

LH: I can break it into two questions if that helps. Some people respond to: Do you identify as Disabled? Some people know better how to respond to: Do you identify as Neurodivergent?

CBTI: Yeah. ***I definitely identify as neurodivergent. That's way easier to do. I think like there's still some like discomfort for me to identify as disabled*** *just cause of like… a lot of things. I think like um… like moving through the world,* ***I just pass as non-disabled*** *so like claiming a disabled identity feels weird in some ways and the* ***"not-disabled-enough"*** *stuff comes in and blah, blah, blah… Um… yeah, so um…* ***Neurodivergent feels more comfortable too because it has this like flexibility. I think disability sounds more like um legally-binding or something****, like its about you needing some kind of designation or something that I don't feel comfortable like… I don't have.*

LH: So you feel like there's kind of a legal context to the notion of disability, like as an experience, that you don't really relate to?

CBTI: Uh...Yeah, I guess so.

LH: Okay. And that's very different to you from neurodivergence. Tell me more about why.

CBTI: Well maybe there's something like more… um, there's something like… such a tough start.... ***Neurodiversity feels like... there's something like less explicit about***

that sort of experience. Whereas disability seems like you… like the world is inaccessible [for disabled people] in ways that the world can identify. And, that's not necessarily true for me [as a neurodivergent person], I don't think. Like I pass well enough in most contexts, that that's [access] not an issue. The fact that passing is still miserable doesn't like… feels like more in the realm of neurodiversity for me for some reason which doesn't necessarily make sense but that's just like the way it feels for me. At least the way the language works for now, for me.

LH: And the question is about how you identify with the language and how you use it. So if you don't walk around identifying as a disabled person, that's exactly what I'm asking you. There are no right or wrong answers. Would you say you do walk around identifying as neurodivergent or do you think that's also context based?

CBTI: ***Yes, I do [identify as neurodivergent]. What's context based is like how explicit I am about naming that identity to others and addressing the ways that it manifests and stuff like that. So, that's a pretty constant [identifier] for me.***

…

LH: Do any aspects of your identity ever complicate how you do your work?

CBTI: Yeah, I think there are some instances where um… I think there are a lot of instances actually where I don't… I think people question why would I be… um, like the accessibility of so many of spaces is a given for me... ***that "I don't actually NEED to be in the space I'm in" kind of thing comes up a lot****…*

LH: Is that part of **the "not-disabled-enough" type stuff**?

CBTI: Yeah, that's partly it.

LH: "Partly it"… What else do you think is involved?

CBTI: I'm like a white guy who went to [college] and I don't NEED to be here. Which is partly true. And... yeah so, that's a thing. ... And like not having… I try to be super aware of that and the way that I move through spaces differently than other people here a lot of the time. But there's only like so much… I can just acknowledge that and that's it.

LH: You mentioned that you specifically walk through space differently than other folks. And, what do you mean? It sounds like you--just to reflect back…

CBTI: Yes! That's what I need--reflect back.

LH: It sounds like you walk around with some privilege...

CBTI: Yes! That's the word!

LH: Privilege that other folks don't have and I'm just wondering what do you think those privileges are? It feels like you feel them and so you know where they are.

CBTI: ***Yeah um… interacting with community members is way easier for me a lot of the time. Or like I can do my [passing] act way better. Which is actually now becoming explicitly my role a lot of the time which is good… so that [passing privilege] can be used for good, instead of evil. Um… but, I think it also takes a while to convince people that I am conscious of like the dynamics of passing and privilege and how those are useful tools or not during the [work] day.*** *I am like self-conscious of the thing, and there is enough similarity with other teachers and students*

that its okay, it just takes some time. And yeah, that idea of like… I think, like with a lot of our students… ***I genuinely don't value like normal or normative roles in our society very much so that never becomes an issue for me, which I think is valuable for teaching…***

Situated within the non-utopic conditions of a non-profit industrial complex, neurodivergent-identifying ACAT/ACT staff and leaders try to leverage their "passing" privilege (in combination with other forms of privilege) in the service of I/D "disabled" student/clients who are "the most impacted" members of the "neurodivergent community." Given the material realities of I/DD student/clients' past-in-present, "special" and on-going institutionalization as mediated by the non-profit industrial complex, neurodivergent staff attempt to acknowledge their "neurodivergent privilege" in escaping the confines of these interlocking systems; at the same time that they attempt to leverage their privilege in what I consider non-utopic, yet radical[108] ways:

> As long as they [I/DD student/clients] have the choice to engage them [social rules] the way that they are. That they have agency and they are making decisions, that's the thing. That's what teaching is (anonymous CBTI).

[108] Working within existing systems known to produce the very same inequalities against which they are struggling. This is "non-utopic" because it does not attempt to work outside the system. It is also "radical" because it works to subvert and/or "disrupt" the system from within.

“Radical” because CBTIs envision that manipulating their privilege in such a way will lead to transformative outcomes for I/DD student/clients—"those most impacted”—and because they do not do this in order to “reform” so much as “disrupt” these interlocking systems.

The next chapter will analyze the Neurodivergent Education Model (NEM) in which all CBTIs are trained. NEM was designed by Brent White (especially in collaboration with Tania Coffield) over years of working with his staff and I/DD student/clients on how to avoid re-/traumatizing each other in doing this work within a system that historically excludes neurodivergent leadership. From these years of collaborative, in-house work, NEM offers CBTIs three primary tools in teaching community-based independent living and self-determination skills to I/DD adults. “*Nothing About Us, Without Us*,” the next chapter, focuses on the first two “STEPS” of NEM. Then, in Chapter Five, I offer an analysis of the third “STEP”: Self-Determination Training. This third “STEP” is practiced interdependently and intersectionally, allowing CBTIs and I/DD student/clients to practice self-determination skills in shared community spaces together and to train each other. NEM, unlike “special” models of education, “makes space” for the historical reality in which teaching takes place—a reality wherein “teachers/instructors” have a lot to learn from their intergenerationally and multiply marginalized “student/clients” about how to practice self-determination skills before, during, and after they “teach” them.

CHAPTER 4:

"Nothing About Us, Without Us":

A Neurodivergent Education Model (NEM)

In this chapter, I begin to unpack the practice of neurodivergent transition-making. The disabled, neurodivergent, and autistic (DNA) leaders of ACAT/ACT designed NEM over years of working with I/DD adults transitioning out of Special Education systems. ACAT/ACT's DNA leaders and I collaborated to document how NEM can be put to practice. In this chapter I unpack the first two out of three (what I call) "STEPS" of NEM: Legitimizing the Practice of Neurodiversity and A Trauma-Informed Perspective on Education. Legitimizing the practice of neurodiversity involves decolonizing medicalized models of disability and recognizing neurodivergent practices as everyday acts of resistance against forced assimilation and dependence. I unpack ACAT/ACT's explanation for "why" and "how" to practice a trauma-informed perspective in education when trauma is a strong unifier under the umbrella of neurodiversity, across/between disability communities, and even outside these two broad communities.

To me, in my head...Neurodiversity is simply the idea that there are not good brains or bad brains, that all brains are legitimate. I hate the word "natural." All brains are "legitimate." So, if you think of brains as good brains or bad brains, then bad brains are something you need to fix. If you think of them as just different, then individuals just need different support in order to be included in society. And that's like super simple... ~ Brent White, 2017

The word had already gotten out about the ACAT/ACT programs' unique methodologies and philosophy by the time I started volunteering with them in early 2017. The administrators at ACAT/ACT were receiving regular invitations from different groups and organizations across the Bay Area (and the US) to present their work as a neurodivergent-designed alternative to "special" methods of education and service provision. One of the first presentations I volunteered to help prepare and organize was for a group of Special Education students enrolled in a local Master's

program, preparing to become "special" teachers. My job was, again, to help the ACAT/ACT programs' director, supervisor, and coordinators prepare an accessible, formal presentation about their methods and philosophy. The first work we set out to do together then, was to map out what the ACAT/ACT team referred to as the program's "Neurodivergent Education Model" (NEM). After a few weeks of discussion, we collaborated to construct a table that would contrast some of the major differences between a "special (medical)" and a "neurodivergent" model of education and/or service provision:

Table 2: Contrasting "Special/Medical" versus "Neurodivergent" Models of Education

"Special"/Medical Education Model	**Neurodivergent Education Model**
Special education and other state providers create narratives of "presumed incompetence"	***Presume neurodivergent people are competent*** to make personal choices about their own lives, even if their choices are counter to the wishes of families, caregivers, and/or state provider "specialists."
Neurodivergent people are framed as helpless and needing the protection, paternalism and pity of the state, leading to learned dependency and situations of forced dependence	By ***focusing on transitioning neurodivergent people out of dependency***, NEM's Practices create spaces and situations within community settings in which people are provided opportunities to confidently make choices, problem solve, risk and fail.
Under these systems, Neurodivergent people are denied agency, supports that enable informed choice, and the right to imagine multiple possible futures	**O*pportunities to safely take risks and/or learn from failures are essential elements of personal growth, empowerment and self-efficacy.***
Institutionalized and/or segregated spaces treat neurodivergent people's bodies as public property without rights of consent.	NEM presumes disabled bodies have ***the right to privacy, personal space, and self-determination.***

As designed and practiced by a neurodivergent leadership at ACAT/ACT, NEM primarily consists of three methodological principles:

> 1) Legitimizing the *Practice* of Neurodiversity [Decolonizing];
> 2) A *Trauma-Informed* Perspective on Education [Relationality]; and
> 3) Training in *Self-Determination Skills* and *Personal Responsibility* [Sovereignty].

As we attempted to move from outlining to defining each of these components of NEM in a document that could be shared publicly, their relationality became something like a fourth component. To legitimize neurodiversity as a "practice" very much depends on a trauma-informed perspective. That same trauma-informed perspective then grounds the practical and historical necessity for self-determination skill training. Self-determination skills are key to healing the intergenerational trauma that has, throughout US history, worked to limit, suppress, and erase neurodivergent culture and cultural practices. Thus, self-determination skills are key to healing intergenerational trauma and to legitimizing the practice of neurodiversity in everyday life.

We agreed, as a team, that the first "word" that needed to be made accessible—ie. that needed to "get out there"—to a group of Bay Area-trained prospective Special Education teachers was simply and in fact: "Neurodiversity." The etiology of the term "neurodiversity" is somewhat debated[109]. Regardless of who is credited with coining the term, most concur that the term emerged as a neologism during the late 1990s (1998-1999) from the work of two white authors collaborating

[109] See Chapter "Neurodivergent Leadership" for a more in depth analysis of this debate regarding Blume (1998) and Singer (1999).

internationally between Australia and the U.S. (Singer, 1999; Blume, 1998). Both writers, in their respective fields, sought to link understandings of autism to concepts of "biodiversity."

More recently, this link between "neurodiversity" and "biodiversity" has been bio-politically mobilized by academics like Nick Walker (2013)[110] in a professionalized "paradigmatic" debate that fails to critically address the actual material conditions that intersect to affect the "most impacted" members of the neurodivergent community—Intellectually and/or Developmentally Disabled People. Occupants of the academic "buffer zone,"[111] like autistic-identifying Nick Walker, argue in favor of the production of a "neurocosmopolitanism" via a disciplinary "neurodiversity paradigm" shift that "works for" those arguably "least impacted" by ableist structures of inequality (for example, segregated systems of education). Neurocosmopolitanism effectively appropriates generations of movement and labor led by I/DD inmates and self-advocates: those *most impacted* by the material conditions of institutionalization and *most* subject to the traumatizing disciplinary techniques of the "pathology paradigm;"[112] people who cannot "pass" as "neurodivergent-only" because they are publicly recognized as intellectually and/or developmentally *disabled* first; people who have historically and to this day been denied access to institutions of (higher and/or general) education where "paradigmatic shifts" are coined by disciplinarians who are buffered by those institutions from

[110] Walker, 2013a; 2013b; 2014a; 2014b.
[111] Kivel, 2007
[112] Walker, Nick. (2013a).

oppressive material conditions that actually inflame social movements. This paradigmatic appropriation then "works for" disciplinary relations of production and passing producers occupying the buffer zone today—occupations (professional positionalities) that were only made possible by the history of social movements led by I/DD self-advocacy leaders, the very existence of whom this appropriation simultaneously (white-)washes away.

The "Disabled, Neurodivergent and Autistic identifying" (DNA) leaders at ACAT/ACT—occupying their niche within the non-profit industrial complex's buffer zone—have little practical use for a discussion of paradigm shifts while immersed within the material conditions of I/DD student/clients lived experiences in their local communities, post-"special" education. In their "work for" and with adult I/DD student/clients in a community-based transition program, ACAT/ACT staff are positioned professionally as "Community-Based Teacher/Instructors" in "co-teaching" pairs. In groups of 4-8[113], CBTIs and adult I/DD student/clients co-learn, through lived experience, how ableist barriers materially affect "those most impacted"—particularly intellectually and/or developmentally disabled women of color, a large proportion of the student/client population at ACAT/ACT—in the local communities in which they live. In this every day, on the ground, materially-situated way, CBTIs and I/DD student/clients can work together to minimize the material consequences of those barriers and to collaboratively construct neurodivergent

[113] Always one teacher to every three students (a group of 4) and never exceeding two-teachers to six students (a group of 8).

"adaptations" in situ that—through everyday *neurodivergent practice* in the community—"work for" a "movement" toward the reconstruction of the material world in which I/DD student/clients must live[114]--not just survive, but *live*.

Neurodiversity as *Practice*, Not Paradigm: "You Get Proud By *Practicing*"[115]

Excerpt from 2017 Interview with ACAT/ACT's DNA-Identifying Administrators: Brent White (Director), Tania Coffield (Supervisor) & "Joan" (Program Coordinator)

J: "***Neurodiversity" is just neurological variation. I think that the paradigm stuff is different.***

BW: ***I hate using the word "paradigm."***

J: ***Me too! And I don't want to call it a theory though either; because it's not a theory, it's a practice.***

…

LH: So, let's actually define this practice then. We already named a couple parts. One is: **non-pathologizing.** So, there is literally an absence of pathologization. Which means, when you are talking about disability, you're talking about it, as you mentioned, as a social construct. And, I'm going to stick with neurodiversity… **So, neurodiversity is a social construct. But, I**

[114] "Le vent se lève! . . . il faut tenter de vivre!" from Paul Valéry's (1922) poem "Le Cimetière marin" and Hiyao Miyazaki's (2013) film "The Wind Rises": "The wind is rising!... We must attempt to live!"
[115] Laura Hershey poem "You Get Proud By Practicing", 1991.

think you want to talk about it as something very real and material, right?

BW & TC: ***Yes!***

LH: And that's why I think you focus on practice, because it's not just a social construct…

TC: ***So, it's like being able to present yourself as you are and not having to wear your mask, or having to try to normalize yourself, or try to fit in or be like everyone else… but allow yourself and the space around you to be neurodivergent. To set things up in a way that works for how your brain actually is, and not how its supposed to be or how people think its supposed to be.***

...

LH: **So, the practice of neurodiversity is oriented toward a social model of disability. We said that means there is an absence of pathologization. Neurodiversity is a social construct with material consequences for neurodivergent people who cannot conform to normative standards of practice. Normalization is a coercive form of harm and violence to the practice of neurodiversity.** So that's kind of spinning the [medical model's] definition of disability... **So disability is not dysfunction or pathologization; it's an "inability to conform."**

J: ***Yes! That's what we've been saying without saying that.***

BW: *Yes!*

…

TC: ***I don't understand material consequence? The word itself.***

J: *Its a highfalutin word.*

BW: ***So material is the world. The world. (knocks on table). It's the solid, it's people, it's buildings, it's lights… it's…***

J: *The **NOT** academic, floaty, let's talk about it, stuff…*

BW: ***So grassroots organizations like this [the ACAT/ACT programs]… this is material. We're always talking about the material and our practice is based in the material. So material consequences would be that you live in a world with too many lights and those lights cause you constant headaches, or causes you to meltdown, or causes you to have stress and anxiety because in the material world nobody thinks about that as legitimate. And so because people don't think of that as a legitimate thing, the world is set up materially for you to fail.*** *I don't know if I articulated that right…*

LH: You were very articulate. That was awesome!

…

BW: ***So, the consequences of a neurotypical world are negative effects on neurodivergent people... Neurodiversity recognizes that that happens.***

…

BW: ***So when we're talking about neurodiversity, everything we're doing is trying to recognize spaces in the world--material: like the way that people teach, the way systems are set-up, the way the world's set-up--will have***

material consequences on our clients or on us. So, recognizing those, and minimizing them where we can, or learning to create adaptations, which is what we do best.

LH: **Which are themselves [neurodivergent adaptations in practice] refashioning the material world. Literally.**

BW: ***That seems so simple and yet it seems so complicated.***

NEM: A *Neurodivergent Education Model* in Three Movements

In the remainder of this chapter, I will focus on the first two parts of ACAT/ACT's Neurodivergent Education Model (NEM). The third part--Self-Determination Skill Training--will be the topic of the next, final chapter in this project. To critically unpack each part of NEM, I will employ a combination of two main sources:

1) A document on which I collaborated along with the ACAT/ACT designer/director (Brent White), now-former supervisor (Tania Coffield), and now-former program coordinator ("Joan") wherein we worked together to define the four major parts of NEM so that it could be presented to the public;[116] and
2) Interviews and conversations I facilitated between the same ACAT/ACT program administrators: Brent White, Tania Coffield, and "Joan."

[116] As previously stated, we started the document in preparation for ACAT/ACT's presentation to a group of Master's students studying to become "special" teachers. We continued developing the document, however, as I transitioned between my status as a program "volunteer" and program "researcher." We continuously returned to and repeatedly modified this document from January 2017-December 2018 as needed. We stopped working on the document in December 2018.

I quote both the collaborative document and interviews extensively so that a multitude of voices can help articulate the ACAT/ACT "vision" for a Neurodivergent Education Model. From this point forward, each part of NEM will be presented in "STEPS"; however, these steps should not be considered "developmental stages." NEM is based on a neurodivergent design and practice, which means:

> **It's also allowing people to get to the same point in different ways, at different times and at different speeds. So its also not forcing compliance.** It's… it's going back to something Laura was talking about earlier as far as time goes… it also allows a different type of time and space around it. **It's not forcing any compliance, its allowing people to arrive at an agreed upon location at their own speed.** (Brent White, 2017 Interview)

Like movements in a musical composition, each can be "heard" and "practiced" for its own sake; however, to fully understand the "work" that NEM does, requires all of the "movements" to be practiced. Each "STEP" begins with an excerpt from the Collaborative Document (highlighted in grey). In addition, each "STEP" will also include excerpts from interviews and conversations I facilitated between administrators as they attempted to explain the process behind each "STEP."

STEP 1: Legitimizing the Practice of Neurodiversity

Excerpt from *Collaborative Document*[117] Outlining and Defining NEM:

> *"Special education and other provider systems are traditionally oriented toward the Medical Model of Disability which views humans as possessing either "good" brains or "bad" brains. "Bad" brains as a consequence need to be "cured," "fixed" or "normalized" in order to be included in society.*

[117] Brent White, Tania Coffield, "Joan" and I collaborated to compose a document defining the four major parts of NEM. The contents of the document came from group discussions in the weeks prior to a speaking engagement where ACAT/ACT would be presenting their work. My role was to help them put all of their ideas into words. We completed work on the document in December, 2018.

People whose brains are categorized as "defective" and cannot be cured or fixed are then separated, institutionalized and excluded from society. [1]

Neurodiversity, on the other hand, is oriented toward the Social Model of Disability and views all brains as legitimate neurological variation. Instead of "fixing" or "curing", neurodiversity approaches uphold the idea that neurological variation is a part of the human experience, according to this view all brains are legitimate and valuable. A Neurodiversity Informed Practice focuses on a person's strengths as opposed to medical diagnoses. [2]

Examples of neurodiversity can include: Autism, PTSD, Bipolar, Borderline Personality, Schizophrenia, ADHD, Dyslexia, Dyscalculia, OCD, Social Anxiety, Depression, CP, Down's Syndrome, ID/DD (in general), Seizure Disorders, or anyone who experiences barriers as a consequence of neurological variation. [3]

NEM recognizes the unique, and often noteworthy, ways in which neurodivergent people adapt to institutions, environments, and social practices designed for and measured by neurotypical competencies. Neurodivergent people adapt and accommodate to environments, and practices which often work against them, and those adaptations are a more important measurement of a neurodivergent person's strengths. Overall NEM focuses on claiming non-normative spaces and competencies as legitimate. [4]

NEM recognizes that the medical Model of disability is a social construct with material consequences for neurodivergent people who cannot conform to normative standards of practice. Normalization is coercive, harmful and violent. For example: those who are non-compliant are viewed and labeled as 'behavioral problems'. [5]

NEM is non-pathologizing. As such program design focuses on the individual as a whole, in that sense the person does not become invisible or subsumed under medicalized generalizations. According to these principles the program design is oriented toward person-centered goals and self determination. [6]

NEM values the lived experiences of neurodivergent people as viable, valid and significant, which is reflected in program management, teaching staff and community partners. [7]"

Here, NEM argues that to understand "neurodivergent practices" as "legitimate" means also understanding these seven claims[118] to be based in "shared" lived experiences of the world. To begin unpacking this analysis of what it means to "legitimize neurodivergent practices"—or, to be "neurodiversity informed"—I will draw two interconnected groups from these seven claims. The first group (consisting of claims: 1, 2, 3, and 6) critically assess the material consequences of the medical model of disability with a particular focus on the everyday effect that diagnosis has on I/DD student/clients. The second group (consisting of claims: 4, 5, and 7) draws critical attention to everyday neurodivergent practices as everyday acts of resistance working against historically intersecting eugenic and assimilationist politics and movements—working for the *decolonization* of disability as augmented by neurodiversity.

The first group of claims[119] critique the medical model of disability as pathologizing in contrast to the social model. I would summarize these four claims as follows:

1. The Medical Model of Disability is "Pathologizing."

    Futures and/or potentialities are determined and foreclosed by the presumptions of incompetence inextricably linked to diagnosis.

2. The Social Model of Disability, augmented by Neurodiversity, can work as a frame for "Neurodivergent Practices."

[118] See the number indicated in brackets at the end of each paragraph in the above quoted excerpt from the collaborative document.
[119] Claims 1, 2, 3 and 6

> Neurodiversity is a practice rooted in the lived-experience of neurotypical structures; it is not a/the problem, and it is not a medical diagnosis.[120]

3. "Neurodivergent people" have lived experiences with ableism and/or sanism.

> The neurodivergent community then could include "*anyone who experiences barriers as a consequence of neurological variation*"—a structural, not a medical, problem (social, not medical, model) which thus does not require or hinge upon medical diagnosis.

4. Person-centered goals should guide self-determination skill training, not diagnostic and/or prognostic presumptions.

> Medical diagnoses/prognoses are no measure of neurodivergent possibilities and often function as medico-legal barriers to neurodivergent self-determination and self-advocacy.

NEM argues that "neurodivergent practices" do not make sense within a medical model of disability, because "neurodiversity" is not a condition of, or determined by, any given medical diagnosis--as evidenced by the myriad of disabilities linking neurodivergent people and communities. The social model of disability, as augmented by neurodiversity, offers a structural frame within which neurodivergent people and practices can be situated; and, depathologized in the process. When depathologized--

[120] Singer, 1999

in program, at least--neurodivergent people and practices are liberated from neurotypical expectations in such a way that their "personhood" (or, sense of "sovereignty" and "self-determination") is no longer confined to diagnostic and prognostic generalizations that foreclose multiple possible futures--especially in the case of those diagnosed with "severe" disabilities. This means that, while in program, I/DD student/clients will be "met where they are at," as neurodivergent and disabled people with multiple possible futures in transition; and, that processes of "transition"-making will be unique to each neurodivergent and disabled person's goals. In practice, NEM argues, I/DD student/clients' shared lived experiences within (and attempting to transition out of) neurotypical structures and "special" relations of power supersede any medical diagnosis in predicting the accessibility of (when, where and how they may learn) self-advocacy and self-determination skills. Understanding neurodivergent transition practices demands a neurodiversity-augmented, social model perspective which privileges *shared structural situations of inequality* over-and-above medical diagnoses in defining disability *and what it means to "work for" transitions out of systems of dependence*.

The second group of claims[121] document how "neurodivergent practices" function as everyday (material) resistance strategies that "work for" disability justice and directly against disciplinary methods of forced assimilation and dependence:

1. Neurodivergent and/or non-normative "competencies" are legitimate "adaptations" to dominant neurotypical structures.

[121] Claims 4, 5, and 6.

For example, “trauma responses” are not “pathological behaviors;” but, they are legitimate and competent “adaptations” to the experience of trauma, common to neurodivergent cultures.

2. “Normalization” is a coercive and punitive method of discipline with an assimilationist

agenda that does violence (including trauma) to neurodivergent people, culture, and cultural practices.

Neurodivergent people who are unable to conform to normative standards of practice--and/or who self-advocate against neurotypical expectations for neurodivergent practices--are punished and ascribed with the label of “Non-Compliant” (replacing the historical term “Sub-Normal” today).

3. Neurodivergent community and leadership are critical to legitimizing neurodivergent practices as they model intergenerational survival skills (adaptations or “resilience”) in a neurotypically dominated world.

Nothing About Us, Without Us[122]:

> First, to understand anything about people with disabilities or the disability rights movement, one must recognize their individual and collective necessities. ‘Nothing About Us Without Us’ forces people to think about the broad implications of ‘nothing’ in various political-economic and cultural contexts. Second, a growing number of people with disabilities have developed a consciousness that transforms the notion and concept of disability from a medical condition to a political and social condition. ‘Nothing About Us Without Us’

[122] This slogan came out of the South African Movement against Apartheid and disabled South Africans (Charlton, 2000: 3, 17, 42).

> requires people with disabilities to recognize their need to control and take responsibility for their own lives. It also forces political-economic and cultural systems to incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in making decisions that affect their lives. Third, while the number of people affected by this epistemological breakthrough is relatively small, a movement has emerged. The disability rights movement has developed its own ideology and politics. It is a liberation movement that is confronting the realpolitik of the world at large. ***The demand 'Nothing About Us Without Us' is a demand for self-determination and a necessary precedent to liberation.*** Fourth, the philosophy and organization that the international DRM [disability rights movement] embraces includes independence and integration, empowerment and human rights, and self-help and self-determination. The demand 'Nothing About Us Without Us' affirms the essence of these principles. Finally, the DRM is one of many emerging movements in which new attitudes and world views are being created. Through its struggle comes a ***vision*** that requires a fundamental reordering of priorities and resources. 'Nothing About Us Without Us' suggests such a sea change in the way disability oppression is conceived and resisted. (Charlton, 2000: 17; emphasis added)

"*Neeeeigh About Us, Without Us*"

> Brent White & Tania Coffield's programmatic figuration of "Horses Helping Horses" in recognition of the historical kinship among neurodivergent people who experience the past-in-present dehumanization standardized within "special" institutions.

To legitimize the practice of neurodiversity is to condemn "applied behavioral therapy," "principles of normalization," and "social role valorization methods" to

their graves[123]. These "special" disciplines, when applied to I/DD populations, do direct harm to neurodivergent cultures and cultural practices by "manufacturing consent" or coercing "compliance" in the name of neoliberal "inclusion" (Culham & Nind, 2003).[124] To coerce compliance is to deny disabled individuals' access to self-determined action; it is to do violence to self-determined neurodivergent practices; and, on a larger scale, it is to exterminate neurodivergent culture by exclusively "valorizing" dominant, neurotypical "social roles"—worker, student, significant other, home-owner, etc--into which "normal" people supposedly just naturally "fit." It is asking a circle to become[125] square, or to shrink, or lose its form so as to fit within a square-shaped hole; and thereby, reify dominant cultural attitudes about the supremacy of being a square: a wage-laborer, a "special" student, a heteronormative "boy"/"girl"-friend, an adult who has "independent" housing from their family, etc. In the following excerpt, ACAT/ACT administrators describe the barriers I/DD student/clients face when coerced (by parents and other neurotypical authorities) to "work for" neurotypical/normative goals; and how ACAT/ACT leaders work instead

[123] ACAT/ACT leaders have no use for Nirje (1969), Wolfensberger (1972), or Lovass (1965; 1969; 1973) in their neurodivergent program design or direction because its neurodivergent leadership makes active efforts to avoid retraumatizing I/DD student/clients as they transition out of "special" systems designed around (and dominated by) normalization, ABA and SRV assimilationist theories. Born out of the 1960s-1970s, these methods of assimilation are rooted in notions of "integration" and "inclusion" that prescribe "passing" as the "cure" to social deviance, degradation and/or devaluation. These methods seek to approximate a "cure" for the disabled individual based on a medical model of disability; while simultaneously reifying ableist structures that produce disability inequality; thus perpetuating that same inequality. Instead of changing structures of neurotypical domination, as would be the case under a social model of disability, Nirje, Wolfensberger, and Lovass argue against "rights-based" agendas and the disability-led movements and models that emerged out of the same decades during which they were doing their research.

[124] Culham & Nind. (2003).
Brown & Smith (1992).

[125] Or, at least "pass" as the dominant expectation

to support I/DD student/clients in "practicing" their neurodivergence and/or learning community-based, self-determination skills in the company of other neurodivergent people who "know these systems" (Berne, 2015).

Excerpt from 2017 Interview with ACAT/ACT's DNA[126]-Identifying Administrators: Brent White (Director), Tania Coffield (Supervisor) & "Joan" (Program Coordinator)

BW: *So its like a personal depth thing. When we think about our education [model], it's not a vertical… you [I/DD student/clients] will go at 22 and find a job. And it's not: at 22 you'll get an apartment.* ***[At ACAT/ACT] We're like: at 22, hopefully you [I/DD student/clients] will be able to say "no," or hopefully you'll be able to ask for space, and know that you can do it, and know that you have a right to do it. To do it with confidence and to do it in a non-shamed way. For us, as neurodivergent people, the single most important moments in our lives is when we understood that we could ask for what we want and not feel shamed by it. I don't know how to explain that to parents, but… to me, that's THE most important thing we can do.*** *And, if you [I/DD student/clients] can get to THAT point…*

TC: ***That's a BIG thing.***

BW: *If you can get there; then, I can probably do a better job of finding you a job. I could do a better job of…*

---

[126] "DNA" refers to "Disabled, Neurodivergent, AND Autistic" self-identification.

TC: [Helping you learn] *Being safe, physically…*

BW: *Yeah, physically safe… Or getting an apartment or being in a relationship. All these things that we talk about, these sort of surface thing. Like getting a job: it's a capitalist society, you're disabled,* ***it's probably not going to happen.*** *Or, getting an apartment, you live in the east bay...*

TC: *Your parents don't trust you…*

BW & TC: ***It's not going to happen.***

BW: ***Or, the only way you can do it*** *is through social security, but you're going to get $1100 [a month][127] and you're going to live in a group home.*

TC: *Yeah.*

BW: ***That's what it means. That's what all that means.***

TC: *Yeah.*

BW: *And getting into a relationship is going to be hard, but* ***we [at ACAT/ACT] believe you can do it, but your parents won't let you leave the house. But what we can do is teach you to say "no" and teach you to say "I want." And teach you to feel like it's okay to do that, to have confidence, and not be shamed.***

TC: ***So… why? What is the importance of that? If they are not going to get the job or the apartment, why does it matter?***

[127] $1100 is a common monthly income for persons dependent on SSDI. This is, to put $1100 into national perspective, very little money in the Bay Area. According to the US Census Bureau, the median gross rent between 2013-2017 in Alameda County (where most ACAT/ACT student/clients live) is $1,547. (Laurence, 2019; U.S. Census Bureau, 2018).

BW: ***Because those are not goals. I mean those are the goals of the system, those are neurotypical goals to me.*** *Like, [imitating a parent] "My kid is going to go out and get this job at 22 working in safeway bagging groceries." Maybe they will, maybe they won't.* ***We don't have any control over that. I can't promise that. The provider system, the special education system, creates systems of dependence: they create dependent individuals who are dependent on the system. So, what we need to do is decrease that dependey. The way that we decrease that dependency is through the idea of self-determination. Creating self-determined individuals who believe they have the agency to create their own lives.***

TC: ***Why does that matter?***

BW: ***Because otherwise they are just dependent wards of the state.***

J: ***Who you have to pay for…***

TC: *There!*

BW: ***Otherwise they just remain dependent.***

J: *And you have to pay for them and you have to be frustrated by it.*

BW: ***You are talking about individuals who could be included into the world. But the world is not willing to include them, but they could be included. But the system is created to create a kind of dependency where they [neurodivergent students] won't ever ask for agency.*** *Its like slavery in that way.*

TC: *I was going to say…* ***Asking for agency is equivalent to being non-compliant and that is written up in your IEP [IDEA-mandated Individualized Education Plan] as like a problem we got to fix.*** (laughs)

J: *And furthermore, in this trauma-informed education research they say that* ***folks who have experienced trauma are less likely already to advocate for themselves or speak up. Like, they already feel like they are silenced so its even more so...***

BW: ***It's a shame system.***

The goals of NEM are not normalization, social role valorization, neurotypical goals, or "passing"—the goal of NEM is to decrease "shame" and "dependence" as it is taught and internalized within "special" systems under which I/DD student/clients are forcibly trapped by medico-legal presumptions of incompetence. To teach I/DD student/clients that their neurodivergent practices are legitimate and that they have a "right" to self-advocate for the opportunity to achieve their own goals as neurodivergent people without having to "pass" for neurotypical in making the transition toward those goals, often starts with teaching I/DD student/clients that they are "allowed" to say "no" to their parents and/or any other medico-legal guardians/conservators upon whom they are forced (set-up) by these "special" systems to depend. I/DD student/clients literally have to learn how to say "no" and/or "I want" after 18+ years of being trapped within legal systems and relationships that

deny rights of consent and rights of refusal under ascribed presumptions of incompetence.

It is an extraordinarily "BIG thing" to transition out of this "special" form of disciplinary confinement and into a neurodivergent-led program where I/DD student/clients are given the "personal responsibility" to "self-advocate" for, and "self-determine" their own interests, goals and desires in the company of their peers. It can also be traumatic for I/DD student/clients to: 1) realize that 18-years immersion within neurotypical cultures of compliance traumatized their sense of "self-determination;" and, 2) practice self-determination and self-advocacy outside of program where neurotypical expectations of compliance and presumptions of incompetence still dominate (even at home, even with their parents/loved ones). A "trauma-informed" perspective becomes a vital transitional tool for staff and students who are then obliged to "teach" their communities (public and private, ex: people at the grocery store and parents) how to help support I/DD student/clients in their self-determined transition toward healing such traumas.

STEP 2: A Trauma-Informed Perspective on Education

Excerpt from a *Collaborative Document*[128] Outlining and Defining NEM:

> *"Based on the historic rates of abuse among neurodivergent people, NEM assumes the existence of trauma. Following on these histories, NEM examines*

[128] Brent White, Tania Coffield, "Joan" and I collaborated to compose a document defining the four major parts of NEM. The contents of the document came from group discussions in the weeks prior to a speaking engagement where ACAT/ACT would be presenting their work. My role was to help them put all of their ideas into words. We completed work on the document in December, 2018.

the forceful socialization of normative behavior among neurodivergent people and thus recognizes the validity of trauma-informed experiences as expressed by autistic and otherwise neurodivergent people.[1]

NEM understands both the physical and psychological effects of trauma on neurodivergent people, and actively seeks to avoid re-traumatization. NEM centers the validity of firsthand experiences by opposing interventions reported as abusive and inhumane by those who have been subjected to them. Interventions such as Behavioral Analysis and other punitive teaching methods are said to force standards of normalization on neurodivergent people. Examples include, quiet hands, long periods of stillness, forced eye contact, physical restraints, hostile sensory environments, and other shaming and exclusionary practices. [2]

NEM begins with asking questions as opposed to reacting to someone, or challenging somatic expression. Instead of punishing, blaming or shaming a neurodivergent person or that person's medical diagnoses for a specific action, NEM poses the following questions:

1. *How can I best support the person in the present?*
2. *Is something in the environment, including me, acting as a trigger?*
3. *What tools can I provide to help them to contextualize their experience and self-regulate in the future? [3]*

Components of Trauma Informed Practice include:

- *Empathy*
- *Nurturance*
- *Compassion*
- *Cooperation*
- *Validation*
- *Relationality [4]"*

In "STEP 2," NEM makes specific arguments for "why" and "how" to become "trauma-informed." Again, I divide the above claims into two groups: claims 1 and 2 offer an explanation for "why," while claims 4 and 5 offer examples of "how" to practice being trauma-informed when working for I/DD and/or neurodivergent communities. Again, "neurodivergent communities" include all people who experience social barriers as a result of neurological variation; including, lived

experiences and responses to trauma, both individual (ex. P/CTSD[129]) and collective (ex. Intergenerational, Identity, and/or Community-Based).

The Judge Rotenberg "Education" Center (JRC)--a day/residential school for "students" ages 5 through adulthood, located in Canton, Massachusetts--is a contemporary case of past-in-present institutionalized trauma. According to the JRC's homepage[130]:

> "Since 1971, JRC has provided very effective education and treatment to both emotionally disturbed students with conduct, behavior, emotional, and/or psychiatric problems, as well as those with intellectual disabilities or on the autism spectrum[131]. Our specific goal is to provide each individual with the least intrusive, most effective form of treatment to ensure his/her safety, the safety of others, and promote healthy growth and development. JRC is committed to providing the most effective educational program possible." (JRC Website)

Despite what they advertise, the JRC is criticized internationally and "believed to be the only school in the world [today] that routinely inflicts high-powered electric shocks as a form of punishment on vulnerable [disabled] children and adults" (Pilkington, 2018[132]).

In 2016, one former-inmate/"student" at the JRC named, Jen Msumba, made a YouTube video[133] to document the traumas she was forced to endure there for seven years, from 2002-2009. I quote her graphic YouTube testimonial at length to evidence

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[129] Post-Traumatic Stress Disorder (PTSD) and/or Continuous Traumatic Stress Disorder (CTSD)
[130] Judge Rotenberg Center's Homepage: https://www.judgerc.org/
[131] Note: students of the JRC are a community of "neurodivergent" children and adults.
[132] Pilkington, Ed. (2018).
[133] Msumba, Jen (2016). "My Life Inside the Judge Rotenberg Center--Skin Shock, Aversives, What It Was Like." Published December, 2016. Msumba's Vlog, "Rebranding Autism," Viewable Here: https://www.youtube.com/channel/UCkrQAGJxuxInf5jNSRfrsyw

histories of "trauma" and "torture" inflicted upon disabled, neurodivergent and/or autistic people as a medico-legally sanctioned form of "help" [Content Warning]:

> *"I was in a state hospital and I got transferred to the Judge Rotenberg Center back in March of 2002, that was now 15 years ago; and, FYI I'm still having nightmares. The most traumatic parts of being at the Judge Rotenberg Center is their use of aversives and that is like they use skin shock and they use food deprivation and they also like have things like loss of privilege which is like the social isolation where you're not allowed to speak to anybody, no one can speak to you, you know you can't participate in any leisure time, and things like that.*
>
> *But I'll start with the worst of it and that would be the skin shock. They put me on that right soon after I got there. And what...what the skin shock is, it's a device that... the original device was developed a long time ago and it was a very, very, very mild shock like I believe, don't quote me, but I believe it was like almost… a strong static shock or something like that really quick quick thing. The JRC um soon realized that that wasn't strong enough to do the job that they wanted it to do so they invented their own device that's only used there called, the "Graduated Electronic Decelerator" or GED for short. And this is what they put me on soon after I got there. And you have to wear up to five electrodes on your body at a time and they're about six inches long. Electrodes themselves are silver contact points and they're six inches apart. Mostly their worn on your leg, on your calf, calf muscle, on your arm either on your upper arm or your lower arm, and around your stomach; and, but they also have electrodes sometimes they'll put on your fingertips, or the bottom of your feet, or on your thigh, or something. That's if you've been getting shocked a lot, or been having a lot of* ***what they call "behaviors."*** *Then they might put those in different areas which like hurt even more basically. I did have them on my fingertips and on the bottom of my feet and I would say it hurts even a lot more there, yeah. But the shocks last up to two seconds and you wear a backpack for 24-hours a day with the batteries inside the backpack and they're … like the size of a paperback book and they're pretty heavy. The whole set with the backpack, the wires, the electrodes... I would say it weighs about 10 pounds for the regular GEDs; and, the GED 4, which is the stronger version, probably weighs about like 12 pounds once you get all that stuff on. That's if you have five of them [electrodes], but you don't always have five. You could have one, one or two or three depending on how your um how your time has been going there.*
>
> *So, um I went you know back and forth. Sometimes I'd have five, sometimes I'd have one if things were going well. But, the shock is meant to hurt and they believe that by giving painful shocks whenever you exhibit a "behavior" that they consider undesirable that it will like cure you; or, you know, that you will get better from whatever is your issues. The shocks hurt a*

lot. And they um... it's very scary to wear the device because, you know, they try to make it secret when they shock you. They don't really want you to know when it's coming. A lot of times you will know because maybe you know that you did something, or you'll see that they're about to do it. You don't always know though because lots of times they snuck up on me. I had no idea I even did anything wrong and they snuck up and shocked me. So it's like always anxiety wearing that thing. And a lot of, like several times, that thing went off just by itself, for no reason, I haven't even done anything wrong and they will have to take it off and find a new one to put on because it went off by itself. The shock is really painful. They say it's not that painful, but it's very painful: it's like, it's like it's ripping out your skin and pulling at you, your whole muscle just tenses like this for that whole two seconds while its going off, and it feels a lot longer than two seconds when it's going off. And you have to wear that all the time, even when you're sleeping. Even when you're in the shower they put one on your arm and then lock your arm outside of the shower. I don't know if they still do that, a lot of things have changed I heard; but um, when I was there that was very common to do.

And um I got shock for many many many different things. Some of them were like big things that you might think are like would be obvious like you know ***if you hurt yourself or hit your head****; but um other ones were like* ***talking loud, or waving hands in front of your face, or tensing up your body, or doing little tick like movements, body movements, swearing, not answering staff within five seconds, saying more than five talk outs in an hour.*** *Any little thing that they wanted to add on there, I mean they were shocking for everything; especially when I first got there, anything you did that was annoying to them they would add to be shocked. And then they added to my program that for certain behaviors like* ***health dangerous behaviors,*** *I will go on the 4-point board which is a restraint point.*[134] *I don't know if you know what four-point restraints are. But they would restrain you on the board first, and then they would shock you for ten minutes, every... they would shock you five times within that ten minutes and you would never know when it was coming. And they put me in this room and Sherry, she had my device--devices is a box where they keep the remotes for the shock--and she was walking around me like a shark in circles, walking around, walking around, looking at her stupid watch, or her stupid shoes clicking on the floor; and, then she would shock me [makes sound to imitate the shock] out of no where. And then I would be breathing so fast, and my heart was pounding and sweating; and, it's just the scariest thing because you don't know when it's coming and it's like mind and body torture. And they were doing this in the name of helping people. This is their idea. The year was 2002, 2003, 2004, 2005, this is what they're doing.* ***You think that would not be allowed but that it would be illegal, that people will go to jail for doing such things to other people. But***

[134] This testimony reinforces NEM's second claim for why and how to become trauma informed.

no. Judges were... judges were approving of this behavior... of this, of this treatment to people. *Judges are approving, it has to get approved by a judge; of course, everybody gets approved. But it's just 'oh okay, yeah go ahead,' and sign a paper and stamp it or whatever. It's not like it's some process where they highly consider every factor, no. And if you already have anxiety or depression it'll make you a lot worse. I mean, in my opinion and what I've seen, it made me a lot worse and I didn't want to live when I was there.*

They also do food deprivation. I was on it for just a short period of time but I've seen people be on that for years. And that's where if you have one of those "behaviors" they don't want you to, they'll make you stand up and throw away your meal, or you'll lose your next meal, or you'll lose pieces of your meal. Like your meal will be divided-up into little cups ***and each time you do one little thing--like rocking in your chair or wave your hands or talk without permission--you have to get up and throw one away, get up and throw one away. Or, you stopped work for five seconds or, you know, you're staring at the wall for five seconds, throw your food away, throw your food away, until you have no food left.*** *And then at the end of the day they'll give you a nasty concoction with liver powder all over it and that's going to be your food. But you wouldn't eat until seven o'clock that night if you lost all of your portions of food.* ***And that way of living just makes you obsessed about food. Like when I finally left there I was always hoarding food because I'm afraid of people taking my food and throwing it away and it took me a long time to get out of that you know[135].*** *And yeah so, that's a little bit about what's going on at the Judge Rotenberg Center; or, what went on when I was there. Like I said, I know things have changed a bit, but I know they are still using skin shock and and all those things so I don't really know how much can have gotten better if they're still using that because it's a terrible, it's a terrible, terrible treatment. I don't even like to call it "treatment," but that's what they're calling it. But it's a terrible thing to do to people. And it's not mild it's very painful. It's scary, makes you sad and depressed, makes you not want to live, makes you not trust people, makes you afraid all the time, and I still have nightmares [diagnostic symptoms of trauma]... right up until last night, I have nightmares every single night. Every single night they've got that device on me, and they're shocking me, or they're chasing me, or I'm trying to get away... every night. Its 2017, it's almost 2017, and I'm still dreaming about what happened there. That's how much it affected me and I think people should hurry."*

[135] Several ACAT/ACT student/clients worked with their CBTIs to "get out of that" especially in the community where taking food (especially when it does not belong to them or when taking more than what authorities decide as their portion) can be both dangerous and come with legal ramifications.

Even today, in 2019, the *Autistic Self-Advocacy Network* (ASAN) is forced to continue to publicly condemn the JRC and the *Association for Behavior Analysis International* (ABAI)[136]--which recently featured the JRC in their annual conference--for the entire discipline's "continued pattern of complicity in the torture of the very population that they claim to serve."

But, ASAN is not alone in this struggle to close the JRC and abolish torture tactics as standardized "teaching" tools for disabled, neurodivergent and/or autistic students:

- Former inmates like Msumba (quoted at length above), offer "first-hand" testimonials about their lived experiences—"*opposing interventions" she is "report[ing] as abusive and inhumane" as someone who has "been subjected to them*."

- Parents of child/adult inmates who have attempted to sue the JRC (but settled).[137]

- The *UN*'s special rapporteur on torture condemned the JRC and formally filed "precautionary measures" with the *International Commission on Human Rights* (IACHR) calling for the abolition of electric shock treatments because they do violence to inmates' "right to personal integrity which may be subjected to a form of torture."

[136] Autistic Self Advocacy Network, (2019c)
[137] One example, the Andre McCollins case (HuffPost, Author Unknown, 2012) was accompanied by highly graphic video of McCollins being shocked 31 times consecutively. See also: Gonnerman, 2007.

- The FDA[138] filed a proposal in 2016 to "ban electrical stimulation devices (ESDs) used for self-injurious or aggressive behavior because they present an unreasonable and substantial risk to public health that cannot be corrected or eliminated through changes to the labeling."

- Disability Rights International[139] (DRI) has filed petitions and reports (starting in 2010 and on-going today) demanding the institution/school be closed forever.

- Decades of Disability Rights activists have formed campaigns--as particularly led by leaders of the Anti-Psychiatry, Mad Pride, and Autism Movements--against methods of Applied Behavior Analysis (ABA, for example, "aversive therapies") as well as methods of Normalization and/or Social Role Valorization.

This autistic-led activism is a movement that has been making its way through multiple scales of socio-political action and actors for decades now. Movement, however, is glacial precisely because of the "presumed incompetence" of its victims: disabled, neurodivergent, and/or autistic self-advocacy leaders.

Part of promoting a "trauma-informed" perspective depends on believing victims experiences with trauma, designing educational methods that are "person-centered," and refusing to ignore, erase or disregard "person-centered" responses to

[138] U.S. FDA, 2016
[139] Disability Rights International, 2014

those traumas. [140] ASAN and other leaders in the Autistc Movement are dedicated to legitimizing "first-hand experiences," exposing the traumas inflicted by various forms of behavioral "treatment" methods and the past-in-present histories of "torture" and "trauma" upon which contemporary ABA, or "autistic conversion"[141] methods are modelled:

> ABA [Applied Behavior Analysis] was founded by O. Ivar Lovaas, and derived from the same principles as conversion therapy, of which he was a co-creator.[142] Conversion therapy for LGBTQ[IA] individuals[143] has since been condemned as a form of torture, and survivors describe conversion therapy and ABA as having similar traumatizing consequences.[144] Yet ABAI routinely ignores the voices of autistic self-advocates who challenge the harmful methods that ABA practitioners use every day. By hiding behind the claim that ABA is "evidence-based", ABAI continues to avoid accountability for ABA's abusive history and current practices. (ASAN, 2019c)

Unlike ABAI, the autistic leaders of both ASAN and ACAT/ACT recognize "the validity of trauma-informed experiences as expressed by autistic and otherwise neurodivergent people" and "the validity of firsthand experiences" especially in "opposing interventions reported as abusive and inhumane by those who have been subjected to them" (*Collaborative Document* on NEM). Legitimizing and validating the firsthand experiences of survivors includes the everyday, community-based forms

[140] Determined by personal goals, interests and desires; not by diagnostic/prognostic generalizations. No diagnosis determines the multiple possible futures accessible to any person in a "person-centered" and "trauma-informed" model of education.
[141] Sequenzia, 2019; Kronstein, 2018
[142] Larsson & Wright, 2011.
[143] LGBTQIA identities were only demedicalized and depathologized in 1973. Prior to this, the DSM pathologized nonheteronormative sexual identities as symptoms of mental illness and deviance. LGBTQIA share a medicalized institutional history with neurodivergent communities.
[144] Human Rights Campaign, 2019.

of abuse and trauma experienced by I/DD student/clients--not just the more politically and internationally visible cases, like that of the JRC.

The *National Crime Victimization Survey* only began including questions about disability in 2007, making longitudinal analyses very limited. Data consistently demonstrates, however, significantly high rates of victimization among disabled communities:

> Studies consistently demonstrate that people with intellectual disabilities are sexually victimized more often than others who do not have a disability (Furey, 1994). For example, one study reported that **25 percent of girls and women** with intellectual disabilities who were referred for birth control had a history of sexual violence (Sobsey, 1994). ***Other studies suggest that 49 percent of people with intellectual disabilities will experience 10 or more sexually abusive incidents*** *[in their lifetime] (Sobsey & Doe, 1991).* **Any type of disability appears to contribute to higher risk of victimization but intellectual disabilities**, **communication disorders, and behavioral disorders appear to contribute to very high levels of risk, and having multiple disabilities (e.g., intellectual disabilities and behavior disorders) result in even higher risk levels** (Sullivan & Knutson, 2000). **Children with intellectual disabilities** are also at risk of being sexually abused. A study of approximately 55,000 children in Nebraska found that **children with intellectual disabilities were 4.0 times as likely as children without disabilities to be sexually abused** (Sullivan & Knutson, 2000). **Women** are sexually assaulted more often when compared to men whether they have a disability or not, so men with disabilities are often overlooked. Researchers have found that **men with disabilities** are twice as likely to become a victim of sexual violence compared to men without disabilities (The Roeher Institute, 1995).[145]

The above statistics were gathered and distributed by the ARC in "People with Intellectual Disabilities and Sexual Violence" [146] (Davis, 2011).

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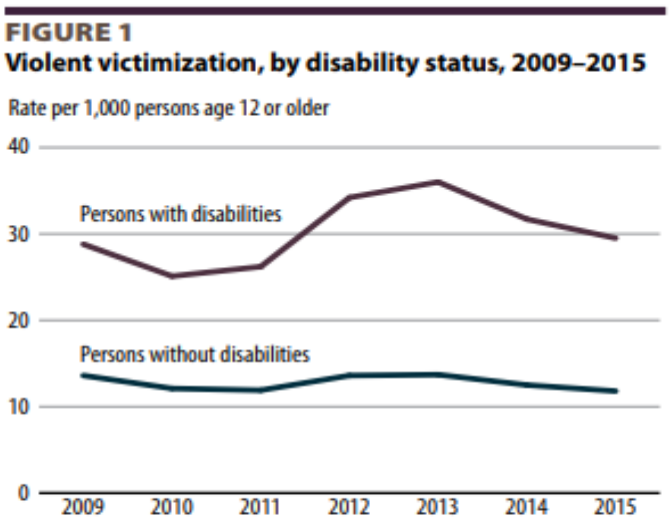
[145] Davis, 2011; via The ARC.
[146] Davis, 2011; via The ARC

According to the *Bureau of Justice's* (BJS) 2017 report, between 2009-2015 disabled people experienced significantly higher rates of everyday, community-based violence than their non-disabled peers in the US (see BJS[147]: "Figure 1: Violent Victimization, by Disability Status, 2009-2015). As reported during the 2018 *National Crime Victims Rights Week* (NCVRW) focusing on disabled victims of violence:



> Between 2009 and 2015, individuals with disabilities were **at least twice** as likely to be victims of violent victimization as people without disabilities. In 2015, nearly **30 of every 1,000 people age 12 or older with a disability** reported violent victimization, **compared to 12 of every 1,000 people age 12 or older without a disability**" (National Center for Victims of Crime, 2018)[148]

The BJS reports that, between 2011-2015, persons with cognitive disabilities[149]

[147] Harrell, 2017: BJS Data 2009-2015
[148] National Center for Victims of Crime, 2018
[149] BJS, 2017: "Disabilities are classified according to six limitations: hearing (deafness or serious difficulty hearing), vision (blindness or serious difficulty seeing, even when wearing glasses), cognitive (serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition), ambulatory (difficulty walking or climbing stairs), self-care (a condition that causes difficulty dressing or bathing), and independent living (physical, mental, or emotional condition that impedes doing errands alone, such as visiting a doctor or shopping)." (Harrell, 2017).

experienced the "highest rates of total violent crime, serious violent crime and simple assault" among all disability types included in the data measures.[150]

The adult I/DD student/clients at ACAT/ACT would primarily be considered members of the BJS's "cognitive" disability group; however, most are immersed in a community-based "transition" program precisely because they have been systematically denied access to experiential education in "independent living" skills. The NCVRW 2018 "Resource Guide" for "Crimes Against People with Disabilities" justly highlights the fact that:

> "People with multiple disabilities [ex. The majority of ACAT/ACT student/clients] are more frequently victims of rape and sexual assault [and all other forms of "violent crime"] compared to victims with only one form of disability. Between 2011 and 2015, 65% of rape/sexual assault victims with a disability had multiple types of disability" (NCVRW, 2018).[151]

Most I/DD student/clients at ACAT/ACT have multiple disabilities not limited to "cognitive" or "independent living" categories as measured by the BJS—the legal definition of disability continues to fail to represent the lived experiences of most disabled people who cannot be confined within categories empty of material reality.

The Bureau of Justice (2017) data presented in "Table 4: Rate of Violent Victimization Against Persons with Disabilities, By Disability Type and Type of

[150] BJS, 2017: "This report details the rates of nonfatal violent victimization against persons with and without disabilities, describes types of disabilities, and compares victim characteristics. Nonfatal violent crimes include rape or sexual assault, robbery, aggravated assault, and simple assault. Findings are based on the Bureau of Justice Statistics' (BJS) National Crime Victimization Survey (NCVS), a household survey that collects data on U.S. residents age 12 or older (excluding those living in institutions)." (Harrell, 2017).
[151] National Center for Victims of Crime, 2018.

Crime, 2011-2015,"[152] provides statistical evidence proving that "cognitively" disabled people experience significantly higher rates of violent crime--total, serious and simple--than any other group of disabled people and/or non-disabled people as represented by the "Hearing" comparison group (Harrell, 2017). Focusing on the group labelled with "cognitive" disabilities in this BJS data set (See: BJS, Table 4), what should stand out as most significantly disturbing are the "total violent crime" rates experienced by people with "cognitive" disabilities: between 2011-2015, approximately 60 out of every 1000 cognitively disabled people ages 12 and older in the US have experienced violent victimization.

TABLE 4
Rate of violent victimization against persons with disabilities, by disability type and type of crime, 2011–2015

Disability type	Total violent crime	Serious violent crime	Simple assault
Cognitive	57.9 †	22.3 †	35.6 †
Independent living	30.8 †	12.1 †	18.8 †
Ambulatory	29.4 †	13.1 †	16.3 †
Vision	28.8 †	11.3 †	17.6 †
Self-care	25.9 †	9.9	16.0 †
Hearing*	15.7	7.8	7.9

Note: Based on the noninstitutionalized U.S. residential population age 12 or older. Includes persons with multiple disability types. Rates presented per 1,000 persons age 12 or older, except for independent living disabilities, which is per 1,000 persons age 15 or older. See *Methodology*. Serious violent crime includes rape or sexual assault, robbery, and aggravated assault. See appendix table 9 for standard errors.

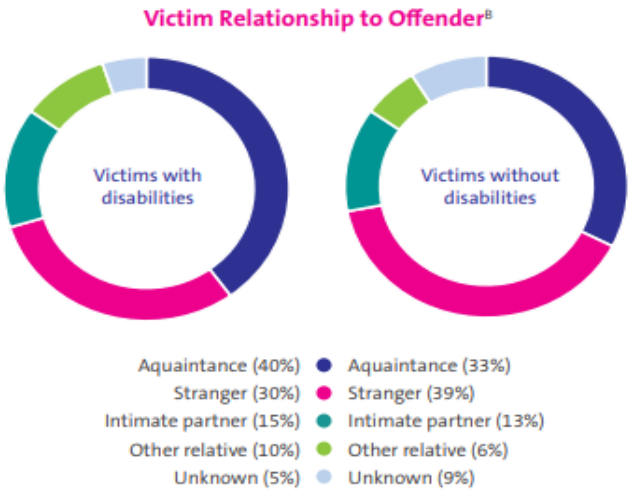
*Comparison group.

†Significant difference from comparison group at 95% confidence level.

Source: Bureau of Justice Statistics, National Crime Victimization Survey, 2011–2015; and U.S. Census Bureau, American Community Survey, 2011–2015.

As illustrated in the NCVRW's resource guide, equally alarming is the fact that 95% of disabled people who experience violent victimization are victimized by

[152] Harrell, 2017.



someone they know well and can identify; including: relatives (for example parents, siblings, children, other extended family members), acquaintances (for example caregivers, neighbors), intimate partners, and others, including local community members (NCVRW, 2018; see graphic titled: "Victim Relationship to Offender").[153] Twenty-one percent (⅕) of disabled victims did not report to the police because "the [disabled] victim did not think the police would help." Disabled people are more likely overall to "receive assistance from a non-police victim service agency" after being "seriously" victimized than their non-disabled peers (Harrell, 2017).

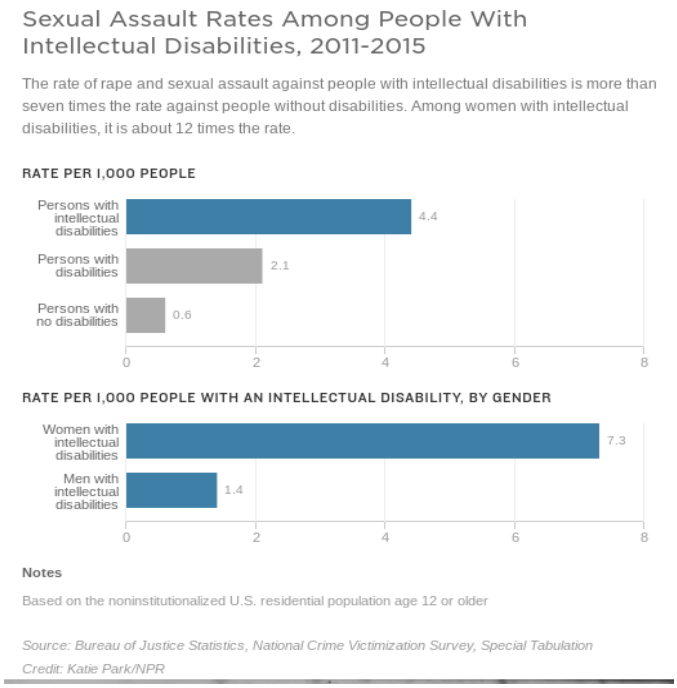
In 2018, *NPR* ran an article titled "The Sexual Assault Epidemic No One Talks About" after a yearlong investigation to highlight "that there is little recognition of **a group of Americans that is one of the most at risk**: ***people with intellectual disabilities."***

- People with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities. That number comes from data run for NPR by the Justice Department from unpublished federal crime data.
- People with intellectual disabilities are at heightened risk at all moments of their daily lives. The NPR data show they are more likely to be assaulted by someone they know and during daytime hours.

[153] National Center for Victims of Crime, 2018; Harrell, 2017

- Predators target people with intellectual disabilities because they know they are easily manipulated and will have difficulty testifying later. These crimes go mostly unrecognized, unprosecuted and unpunished. And the abuser is free to abuse again.
- Police and prosecutors are often reluctant to take these cases because they are difficult to win in court. [154]

Using the very same BJS findings—and other "unreported" and "unpublished" BJS data, including a breakout of sex crimes from other types of "serious violent crimes"—NPR correspondent and Disability Historian/Scholar Joseph Shapiro highlighted one of the most "stunning" findings: the rate of rape and sexual assault for women with intellectual disabilities is about 12 times the rate for people without disabilities. *ASAN,*[155] however, reports intersections of class and race with these findings in their "Autism and Safety Toolkit: Research Overview on Autism and Safety"[156] highlighting at least two critical racial intersections:



1. The police often use excessive force against people with disabilities. People with disabilities are also more likely to be killed by the police.

[154] Shapiro, 2018.
[155] Autistic Self Advocacy Network, 2019d.
[156] Autistic Self Advocacy Network, 2019e.

This pattern is especially pronounced for people with mental health disabilities and people of color with disabilities.

2. Children with disabilities, particularly children of color, are referred to law enforcement or arrested at school at disproportionate rates. This phenomenon is referred to as the school-to-prison pipeline and is a threat to the academic and social well-being of children with disabilities. [157]

Neither the BJS data set, nor the NRP study, elaborates on class and/or racial intersections with these rates of rape and sexual assault.

Based on my observations of I/DD student/clients in the ACAT/ACT program over a two-year span, I would argue that: 1) I/DD women of color are most likely to experience both every day and serious sexual harassment, assault, and violence; 2) I/DD men of color are most likely to be victims of "excessive force" at the hands of law enforcement; 3) I/DD student/clients of color are less likely overall to feel safe reporting crime to the police and/or seeking support, protection or "justice" from the police; and, 4) police/security are more likely to presume the incompetence of I/DD student/clients and/or blame I/DD student/clients for reported incidents of crime even when I/DD student/clients are victims. For instance, three out of the four incidents between I/DD student/clients and police officers I witnessed involved I/DD men of color. In all four cases, CBTIs and/or ACAT/ACT administrators had to convince police officers that I/DD student/clients were not presumably "guilty" and/or behaving "aggressively" because they were displaying overt symptoms of anxiety, fear, trauma, and/or difficulty in processing information. More often than not, I observed police and security officials presume that trauma-responses were overt signs

[157] Autistic Self Advocacy Network, 2019e.

of I/DD student/clients' "guilt" and/or "aggression" instead of their "trauma" and/or "victimization."

These are all reasons "why" a "trauma-informed" perspective that is "person-centered" (not diagnosis-centered) is absolutely critical to legitimizing neurodivergent practices and/or promoting the self-determination of I/DD student/clients. To practice being trauma-informed then begins with believing, validating and legitimizing neurodivergent lived experiences. In this case, that means literally assuming that I/DD communities "stunning" rates of lived experiences with violent, trauma-inducing, serious crimes would necessitate, validate, and legitimize culturally-specific, neurodivergent "trauma-responses." These neurodivergent trauma-responses are "culturally competent" responses to a neurotypically dominated world. To "pathologize" such trauma responses--as I observed police doing in the case of I/DD student/clients--is to simultaneously delegitimize neurodivergent competencies and to "blame" victims of intersecting systems of oppression. Pathologizing trauma-responses according to the medical model's prescription is a neurotypical and ableist form of "cultural incompetence" that dominates the special education and service provision systems upon which I/DD student/clients are systematically forced to depend. Because such enforceable and (literally) police-able "neurotypical competencies"—for example, the pathologization of trauma/responses—dominate the community settings in which I/DD student/clients must[158] attempt to learn

[158] LRE: Least Restrictive Environment Possible; IDEAAA mandate.

neurodivergent self-determination skills, I/DD student/clients face danger and the risk of re-traumatization (literally) every day and everywhere they go.

It is because these violent material realities in the lives of adult I/DD student/clients are irrefutable that ACAT/ACT administrators and CBTIs train to become "trauma-informed;" so as to better serve and "work for" the neurodivergent communities "most at risk"[159] and "most impacted"[160] by intersecting systems of oppression (disability, sex, race, class, age, etc). It is not enough to "work for" the decolonization of neurodivergent lived experiences when those experiences are so deeply mired in past-in-present, on-going, intergenerational traumas. To support this process of decolonizing disability by legitimizing neurodivergent lived experiences[161], ACAT/ACT administrators and CBTIs practice a form of "relationality" that is necessarily "community-based;" or, literally/materially-rooted in the situated knowledge[162] and lived experiences of adult I/DD student/clients in the communities in which they "must live" (not just survive) everyday.

To practice a trauma-informed perspective, in the case of the ACAT/ACT programs, is to focus on *the relationship between* adult I/DD student/clients and the situated/structured environments in which they must attempt to "live." A neurodiversity augmented social model of disability redistributes its traditional focus on architecture and physical barriers by highlighting interaction rituals, communities of people, and sensory environments which often include architectural (ex.

[159] Shapiro, 2018
[160] Berne, "Disability Justice," 2015:
[161] Depathologizing and demedicalizing as a minimum.
[162] Haraway, 1988.

Fluorescent Lighting) and ecological (ex. Chemical Exposure) elements. To become trauma-informed is to practice "relationality" in such a way that refuses pathologization; or, that refuses to "punish, blame or shame" I/DD student/clients for the ways in which they experience community and/or "neurohostility" (Brent White). CBTIs are trained under a DNA-leadership to "support" and center the self-advocated support needs of I/DD student/clients.

Lesson #1 in this training, then, is that I/DD student/clients are more likely than not to have triggering experiences in making the attempt to transition out of "special" systems and into non-segregated, community environments designed for neurotypical adults (ex. the grocery store, the public library, local restaurants, volunteer work sites). From their years of experience in service provision, ACAT/ACT's DNA leaders argue that it is safe to assume I/DD members of the neurodivergent community already have lived experiences with trauma prior to entering the program at age 18--as is also proven statistically likely according to BJS data. The goal is not to "cure" such traumas, because that would be antithetical to neurodivergent culture and an act of erasure in the lived experiences of I/DD student/clients. Instead, the goal is to work together--CBTIs with I/DD student/clients--to identify environmental "triggers" and teach each other accessible modes of "self-regulation" that do not erect and/or reify existing barriers to neurodivergent "self-determination" and personal safety.

Lesson #2 involves taking accountability: part of training to become a neurodivergent leader and/or NEM practitioner is learning how to take accountability

for the rates of abuse and trauma that have been statistically "normal" in the lives of I/DD members of the neurodivergent community for generations. To legitimize and respect neurodivergent practices (including trauma responses) is also to accept collective accountability for the histories of trauma I/DD communities and cultures have been forced to survive for generations. To be trauma-informed is to recognize and respect I/DD student/clients' trauma responses as vital survival tactics they learned under "special" institutionalized conditions of coerced compliance and presumed incompetence as means of resistance and resilience. This is not to valorize trauma's negative impacts or the responses it may trigger; this is to respect the lifetime (18+ years) of work it took for I/DD student/clients to survive such traumas and to fashion responses that could "work for" the preservation of their sense of "person"-hood, "self-determination" and resilience.

To provide a respectful kind of support that honors the work I/DD student/clients have done to find ways to respond to the everyday traumas they are so likely to experience, and must learn to "live" with (as a consequence of their statistical normativity), DNA leaders train ACAT/ACT CBTIs in **Lesson #3**: practicing "empathy, nurturance, compassion, cooperation, validation, and relationality." When confronted by I/DD student/client's somatic expressions (ex. trauma responses) in community environments dominated by neurotypical expectations--and thus phenomenologically disrupted by neurodivergent practices--CBTIs are trained to "hold space" for the breach to take place and to "support" I/DD student/clients in the moment by legitimizing that breach with them. This--CBTIs are

trained--is a rare "moment of opportunity" in the lives of I/DD student/clients: an "opportunity" to be supported instead of "punished, blamed, or shamed" for having lived experiences with trauma and culturally competent, learned responses to them.

Sometimes, supporting I/DD student/clients also requires CBTIs to recognize themselves as that which is triggering--just as a person does not have to be racist in order to enact racism; CBTIs do not have to be ableist in order to enact ableism. CBTIs are trained to think of themselves as part of the dominant cultural environment[163] through which I/DD student/clients cannot "pass;" and, thus, capable of becoming a barrier to I/DD student/clients who are trying to practice neurodiversity, regardless of CBTIs intentions to "help." These three lessons then add up to a method for "presuming the competence" of adult I/DD student/clients, even (sometimes especially) when doing so seems to spit in the face of medical, legal and/or culturally neurotypical expectations.

The job of the CBTI is not to restore neurotypical expectations of interaction. Neurotypical "passing" CBTIs "hold space" for I/DD student/clients neurodivergent somatic expressions. By refusing to impose neurotypical expectations upon I/DD student/clients and/or protect neurotypical community members from a neurodivergent breach in normative community-based expectations, CBTIs practice centering neurodivergent support needs and expectations in the moment. When in the community[164]--in moments when I/DD student/clients' neurodivergent somatic

[163] Because CBTIs are people who experience the privilege of "passing" for neurotypical/non-disabled and/or neurodivergent-only; and, as paid "workers."
[164] Ex. at the entrance to the Downtown Oakland Public Library, in the check-out line at the grocery store, and/or during interactions with neurotypical work-site staff members

expressions breach neurotypical, normative expectations[165]--CBTIs are trained to search for ways to support I/DD student/clients in their efforts to communicate (their traumas, that which triggers them, and their support needs) in the neurodivergent ways that are most accessible to student/clients in the moment (ie. when they are already triggered). By offering support in such "moments of opportunity,"[166] over time, I/DD student/clients and CBTIs establish relational and neurodivergent-accessible means of communicating about trauma, environmental triggers, and the kinds of "tools"/"skills" CBTIs are capable of teaching student/clients in "self-determining" how to "self-regulate" in the future;[167] especially, so as to stay safe when triggered in the community (ie. when unable to pass as nondisabled/neurotypical in the world).

The goals of practicing a trauma-informed perspective that centers I/DD student/clients neurodivergent support needs are two-fold according to NEM:

[165] Some examples I observed: when students refuse to comply with inaccessible directives from work-site staff; when students become overstimulated and literally run away without warning; when students punch a CBTI after witnessing them talking about them without them; when students hold-up the check-out line at the grocery store because they are learning how to use money; when students "get stuck" and cannot transition into next steps right away when confronted with unexpected change; when students stim with their bodies or their voices in ways that are "too much" according to neurotypical expectations; etc.

[166] By refusing to "punish, shame or blame" I/DD student/clients for: refusing directives (ie. acts of typically classified as "noncompliance"); running away; physically confronting staff members (ex. Punching, slapping, kicking, spitting, cursing, etc.); holding-up or slowing the pace of community-immersive activities; getting "stuck," overstimulated or momentously confused; stimming with passion (ex. "Loudly" or in ways that confuse others); being "too much" even for CBTIs in the moment; "meltdowns," etc.

[167] The statistical probability of which is extremely high for I/DD communities.

1) Legitimize I/DD student/clients lived experiences with trauma and the incredible "work" it takes to respond to, and "live" with such traumas every day; and,
2) Reduce the frequency of trauma's negative impacts on I/DD student/clients (ex. Being victimized, arrested, institutionalized/incarcerated, re-traumatized, and/or murdered).

These goals are not easily accomplished when the majority of "special" educators and/or service providers refuse to believe victims and more often than not "punish, blame and shame" victims who do report. To become "trauma-informed," according to NEM, is to presume the competence of I/DD student/clients in self-determining what is traumatizing and who is traumatizing--even if this leads to a redefinition of what abuse is and how "abusers" are traditionally identified.

Excerpts from 2017 Interview with ACAT/ACT's DNA-Identifying Administrators: Brent White (Director) & "Joan" (Program Coordinator)

B: ***In the design of the program, actually, trauma-informed came first****. But those are like philosophical underpinnings of the program and the rest of it--I mean self-determination is also philosophical underpinning--but parts about personal responsibility and person-centered learning are very specific to what we [at ACAT/ACT] do. And I feel like all of it should tie back to these first two [neurodiversity and trauma-informed] things. So, if you want to understand what we do: first you need to know what this [neurodiversity] is, then you*

need to know what this [trauma-informed perspective] is, then you can see what this [self-determination] is.

…

Me: I'm breaking down these three parts into word bits. We're defining what the neurodivergent education model is and we said there are three main components. The first component we started out talking about was the process of legitimizing the practice of neurodiversity. So this is the first aspect under what a neurodivergent education model is. What does that mean? All it means is that you understand the process of normalization does violence to neurodivergent people. So, legitimizing the practice of neurodiversity is also talking about normalization as a harmful process. ***The second component is a trauma-informed perspective on education. And listening to the three of you talk… a trauma informed perspective on education is basically the assumption of trauma among neurodiverse people because neurodiverse people are forced to live under neurotypical standards of competence; which is normalization.***

J & BW: *Yes!*

J: (snapping fingers) *Snap, snap, snap!*

BW: *Wow… that's such a nice bridge!*

…

J: *So trauma informed education and the neurodivergent education model address both the mind and the body. [There are] two things we do with*

trauma informed education or the neurodivergent education model. ***One, we understand and appropriately respond to trauma.*** *Why? Because we see better responses when putting this method into practice in the field.*

LH: Hold on… what are "better" responses?

J: *...aka. Non-trauma responses.* ***The second thing we want to do in trauma informed education is reduce trauma's negative impact. ...So, [trauma's negative impacts can include] meltdowns and responses caused by triggers during say student, teacher, or administrator interactions. We practice relationality which means understanding, learning, and empathy are at the ethical core of our communication and response. This response, when compared to alternative methods of approach, reduces frequency of trauma response when practiced in the moments of opportunity over time...***

…

LH: So [to repeat] there's these **two practices** involved in trauma informed education. **One** is understanding and appropriately responding to trauma because it produces better results in the field. And then, **two**: reducing trauma's negative impacts. Part of reducing trauma's negative impacts is addressing meltdowns and responses caused by triggers during student, teacher, and administrative interactions; and, practicing relationality which includes understanding, learning and empathy as the ethical core of communications and responses.

J: *We can say ethical core of our educator communication and response.* ***So understanding, learning, and empathy are all tools that educators use and transmit then to students which creates the fun pot of stuff. So basically utilizing this, the outcome is that the frequency of the trauma response and trigger feeling is decreased whenever these responses of educators are practiced over time. Meaning its ongoing, over time, to produce results, like non-traumatizing results.*** *Whenever I talk about this though, I don't want it to be about what we don't do or necessarily want to undo--not because it's not important--I want to address those things; but,* ***I also think its really important to say what we do instead of what we don't do or want to avoid.***

LH: I feel like what you are saying is that communicating in these ways is not adding to trauma… not adding to existing trauma.

BW: ***Actively trying to NOT re-traumatize.***

LH: **Reduces the likelihood of additional trauma and…**

J: ***...And addresses current experiences of post-traumatic stress.***

LH: Cool. **Educators commitment to these practices--which include understanding and appropriately responding to trauma because it produces better results by reducing trauma's negative impacts--reduces the likelihood of additional trauma and addresses current experiences of post-traumatic stress.**

J: *Beautiful… Yes, yes!*

LH: Cool, I just wanted to make sure I had it right.

J: *Yes...So,* ***we believe and have witnessed and have historic record of common practices in psychology and special education which contribute to physical and psychological abuse. Physical restraint of kinetic, autistic, neurodivergent people in the practice of ABA, or therapy, or disciplining disruptive behavior are examples of this abuse. People committing these abuses are not people we would typically see as abusers. So, for example, a typical educational response would be: "what's wrong with you? Why can't you get this right? Why can't you stop moving? Why can't you be like your peers?" Etcetera. And so a neurodivergent education approach would be: "My student's action is a result of their experience. Is there something in the current sensory environment--including me--that could be contributing to this response? Are there events in the past that contributed to this action? How can I best support this student presently?"*** *Do you want to unpack that?*

LH: I'm trying… **So, what I'm hearing is a redefinition of abuser and abused.** So part of this education model is **redefining the relationship between abuser and abused**. So, **part of critiquing the medical model is also calling out medical practices as abusive** in which case normative practices like physical restraints are going to be viewed in a very different light; thus, contributing to, and adding to trauma. So, **traditional responses to neurodivergent behavior are not acceptable because you are defining them as violent.**

J: *Exactly.*

LH: **So, in the process of redefining specifically the abuser and what abuse is, your primary focus is the environment, including the authorities in the environment. So, abuse then becomes defined by how it cannot support an individual.** So abuse would be defined on an individual basis in that case... which, I think, makes sense because you are talking about trauma and trauma--like anything else--you can't really generalize how anyone else would respond to the same trigger. **And, then this comes back to the orientation of person-centered learning, I think, in terms of that person [ie. I/DD student/client] also defining what abuse is. So, an abuser cannot tell you what abuse is or is not. Which is a big saying now which I think you are actually reiterating in a new way--Abusers cannot define what abuse is. So the person-centered [and trauma-informed] model is also about that person [I/DD student/client] defining, and having the authority to define, what abuse is and isn't.**

J: *I also just want* ***to shed light on the historical context of this and that this is such a common practice and is THE practice in special education. And that its not just evil people locking people in basements or abusive parents… it includes people who are super normal, probably super sweet, and have no clue that they are tormenting folks.***

LH: The historical context of how these forms of abuse and violence became normative.

BW: *And, acceptable.*

J: *Yeah. And then I move onto* ***tools that we use to respond and support folks in neurodivergent education: empathy, validation, relationality, compassion, nurturance, and cooperation.***

NEM's "trauma-informed" training is critical and literally lifesaving. The ACAT/ACT programs are not alone in attempting to reduce the frequency of violent responses to breaches in neurotypical expectations for community participation. Attempting to prevent police, family, and/or caregivers from punishing I/DD student/clients (too often, to death) for their responses to lived experiences with trauma and/or for being disabled in the first place is a goal ACAT/ACT leaders share with the leaders of ASAN:

> We see the same pattern repeating over and over again. A parent kills their disabled child. The media portrays these murders as justifiable and inevitable due to the 'burden' of having a disabled person in the family. If the parent stands trial, they are given sympathy and comparatively lighter sentences, if they are sentenced at all. The victims are disregarded, blamed for their own murder at the hands of the person they should have been able to trust the most, and ultimately forgotten. And then the cycle repeats (ASAN, "2019 Anti-Fillicide Toolkit").[168]

In addition to these egregious patterns of filicide and filicidal-impunity, ASAN highlights the fact that disabled people cannot count on law enforcement officials for protection:

- The police often use excessive force against people with disabilities. People with disabilities are also more likely to be killed by the police. This pattern is especially pronounced for people with mental health disabilities and people of color with disabilities.

[168] Autistic Self Advocacy Network, 2019f

- When a person with a disability has a fatal or violent encounter with the police, media outlets initially place the blame on the person's disability rather than on the officer(s) who hurt that person. (ASAN, 2019e: 5).[169]

Every year, Autistic leaders organize "Day of Mourning" Vigils around the world and across the US to honor members of the disability community who have been murdered for being disabled--a gathering to mourn trauma inflicted on neurodivergent communities and cultures. ASAN has compiled a list of 650 disabled people murdered[170] by their family/caregivers between 2014-2019 alone. For several years, the ACAT/ACT programs and Brent White (DNA director) helped organize a Day of Mourning Vigil at the Ed Roberts Campus to honor I/DD and/or Autistic people murdered for being disabled.

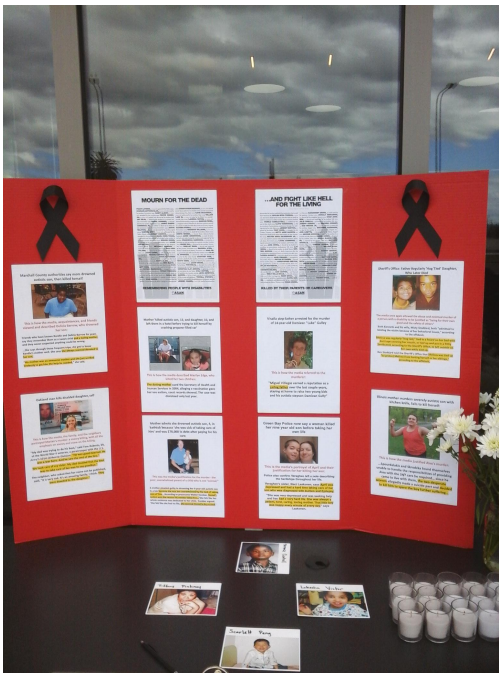


Figure 10: Image of ACAT/ACT visual presented at 2015 Day of Mourning Vigil at the Ed Roberts Campus to honor disabled murder victims, their lives and their deaths.[171]

[169] Autistic Self Advocacy Network, 2019e
[170] Autistic Self Advocacy Network, 2019f
[171] ACAT, 2015.

Transitioning to STEP 3 in the Next Chapter:

To legitimize and respect neurodivergent practices is also to accept accountability for the histories of trauma neurodivergent communities and cultures have been forced to survive for generations. This requires an acknowledgement of "neurodivergent practices" as hard-earned cultural expressions forged from within an on-going cultural history of neurodivergent peoples' survival. Neurodivergent practices do not represent "pathological" cases of "behaviors," personal "preferences," "special" privileges, undue "luxuries," or lifestyle "choices." Even (or, perhaps especially!) when born from lived experiences of trauma, neurodivergent practices are part of neurodivergent culture--this past-in-present history of trauma directly informs neurodivergent cultural practices.

Trauma-informed educators—ie. educators versed in the past-in-present histories of institutionalized trauma from which neurodivergent communities emerge and work to form solidarity—design trauma-informed educational materials and curricula. Deinstitutionalizing (ie. de-standardizing) curricular practices known within neurodivergent communities to be traumatizing, triggering, and/or just plain inaccessible is the first step to legitimizing neurodivergent community practices and cultures and, thereby, the first step to healing the intergenerational trauma that such traumatizing practices inevitably standardize. Any curriculum that attempts to deinstitutionalize standardized practices of re-/traumatization in an effort to legitimize neurodivergent practices begins with self-determination as a means of empowering

traumatized people to "dis-internalize" that trauma. I said "dis-internalize" trauma, not "de-internalize," on purpose. This trauma is part of disability and neurodivergent communities' history and culture--it has become part of how we live, because what defines "how" we survive is partially determined by the particular forms (material conditions) of trauma we must survive.

Community-determined means of resilience born against, or in the face of, situated forms of oppression and trauma cannot (and should not) be erased, forgotten, or white-washed--to do so would be to extinguish what flames some of the most powerfully resilient neurodivergent practices. To be trauma-informed is also to respect the labor histories that gave way to community-based trauma responses. Generations of labor and experience go into surviving everyday, past-in-present histories of trauma. Respecting neurodivergent cultural responses to such traumas (including "trauma-responses") is critical to legitimizing neurodivergent practices and to advocating for self-determination within and between neurodivergent communities. To shame or pathologize trauma--or, to desire a "cure" (erasure) for its history, past-in-present--is antithetical to neurodivergent culture and cultural practices. Trauma-responses are community-based and self-determined survival skills that must be legitimized[172] as cultural practices--grounded in the material realities of institutionalization--through a trauma-informed perspective. "Inclusion" initiatives then must "hold space" for neurodivergent cultural expressions, even in the form of

[172] To legitimize is to respect, not to idolize or "naturalize." It is to ascribe historical and cultural value, to take accountability, and to refuse erasure.

trauma responses. To "include" such neurodivergent cultural practices and trauma-informed perspectives--or, to legitimize such cultural practices in local and global institutions (ex. in schools as much as the grocery store check-out line)--would be a "radical" transition in the history of "inclusion"-based politics if it could refuse liberal assimilationist-agendas.

With a firm understanding of STEPS 1 & 2 here detailed, the next chapter will further STEP 3: Self-Determination Training in relation to NEM as a whole.

CHAPTER 5:

Self-Determination Training:

Trauma-Informed Practices, *Interdependent*

Transitions & Multiple Possible Futures

I complete my analysis of NEM with perhaps the most important "STEP": Training in Self-Determination Skills and Personal Responsibility." Before I unpack ACAT/ACT's methods of self-determination skill training as described in the same collaborative document containing "STEPS" 1 & 2, I offer a deep analysis (or deconstruction) of Michael Wehmeyer's definition, functionalist model, and historical analysis of "self-determination" particularly as he presents them in a lecture sponsored by the National Gateway to Self-Determination (1999, 2005, 2007, 2011). In my attempt to decolonize the history of self-determination as outlined by Wehmeyer (2011), I work to legitimize neurodivergent practices throughout that same history and to demonstrate a trauma-informed perspective that focuses on the lived experiences of generations of I/DD people. In the process, my analysis comes to represent a history of the Western appropriation of "self-determination," particularly in terms of how this appropriation "functions" as a primary tactic in past-in-present, on-going processes of colonization and intergenerational trauma—the medicalization of which is but a more recent manifestation within a much longer history. Through this analysis, I argue that "colonization"—characterized as it is by efforts to dominate, exploit and violate norms (now, UN sanctioned "human rights") of self-determination—is built upon the imposition of culturally-biased (ie. supremacist) presumptions of incompetence (racial, intellectual, spiritual, biological, etc. inferiority) that "function" to medico-legally trans-substantiate political movements into "personal" (biological, psychological, intellectual, spiritual) deficits; or, disability. With a critique of this appropriation firmly situated in a decolonized history, I then present ACAT/ACT's work toward training I/DD adults in self-determination skills and personal responsibility—particularly through the example of their controversial "no hugging" rule.

Excerpt from an Interview with the ACAT/ACT Programs' DNA-Identifying Brent White (Director) and Tania Coffield (Supervisor)

BW: ...And, I always used self-determination as a way to… ***when people would talk about independence, I would talk about self-determination. Because I think independence is a false concept.***

TC: Yeah, ***it's a neurotypical standard*** *and an unrealistic one.* ***It's not even real.***

Prior to beginning my work with the ACAT/ACT programs, I had only heard about "self-determination" in conversations about decolonization; and, specifically as a kind of synonym for a nation's political "independence." As a citizen of the U.S., I especially contextualized this understanding in the national independence movements that swept the African continent particularly during the second half of the 20th century; and, in the sovereignty movements led by Indigenous Nations of the North American continent working to protect their cultures' sacred relationships with lands and waters from colonial and capitalist encroachment. In my mind then, nations--and/or, the people who live within their geographic borders--could gain self-determination or "political independence" through processes of decolonization. My understanding was additionally impacted by decolonial, third-wave feminists who operationalized the concept of "intersectionality" in demonstrating that "the personal is political" in ways that white, second-wave feminists could not imagine as a consequence of their racial privilege--Nothing about us, politically, is not also about us, personally.

As I entered my fieldwork with the ACAT/ACT programs, I had my biases: my understanding was already oriented toward "personal as political" self-determination because I had been immersed for years in learning from decolonial, feminist teachers and mentors in graduate school. My training as a sociologist only reinforced this conceptualization whereby personal and political actions or lived experiences are always also already "social." There is no such thing as truly "independent" or "individual" action in sociology--the study of the *relationship* between the "individual" and society--as there is in disciplinary fields like psychology and/or political sciences. "Individual" actions are always, already rooted in social life and inter-action--it is a relationship "outside" of which we cannot move and in which we are situated and socialized as individual "social actors." Learning from the DNA-leaders at ACAT/ACT, however, I was introduced to a different concept of "self-determination." Within a Neurodivergent Education Model (NEM), self-determination is understood as an *interdependent practice*: a neurodivergent practice which does not value, comply with, depend upon, and/or reify neurotypically Western expectations of individualism and/or independence.

Excerpt from 2017 Interview with ACAT/ACT's DNA-Identifying: Brent White (Director), Tania Coffield (Supervisor) & "Joan" (Program Coordinator)

> LH: So, we now have three [parts to NEM], I think. One is legitimizing the practice of neurodiversity. Two is trauma-informed perspective on education. And, three, is self-determination as the hope and the goal, or the outcome.
>
> TC: *Oh?! Self-determination itself? Okay…*

BW: *Yeah, you know we talk about it all the time...* ***I say it all the time: I don't care if people get jobs, I don't care if people… like that's not the goal. The goal is to create self-determined individuals. The goal is to create self-determined, neurodivergent individuals.***

TC: *No, I get it.* ***I just don't think of self-determination like um… a thing****, so much as a list of words that you are working on.* ***Not something you ever achieve, but something you are always constantly doing.*** *That's why I didn't….*

BW: *Yeah, I mean* ***self-determination is practice.***

TC: *Mhm.*

…

LH: And so **the third component is self-determination** as the hope, goal or outcome. And we talked about how "outcome" sounds a little like you're going to have this product that you bought and you're walking away with it and [that] that's misleading. So, maybe to extend that: self-determination as the hope, goal, or outcome really means creating a safe space to start exploring practices of empowerment and agency. **So, if everyone walks away with the ability to create safe spaces to practice those things, um… then, that is the closest to creating self-determination that maybe this program can accomplish, or a neurodivergent education model can accomplish. We can't make the world safe, that's not really an option. What is an option is giving people tools to create their own safe spaces.** So, I'm

thinking [about] when I shadowed with Joan. I'm thinking especially of a moment when we were waiting for the BART and I was standing a little too close to someone and they were like "Hey, personal space, personal space, come on!" And I was like: I'm sorry, I wasn't even thinking about that, I really apologize. But my real reaction was: You just made that safe space for yourself![173]

TC: *Mhhmm!* [agreeing with enthusiasm]

LH: And I don't know if you [the I/DD student] always knew you could do that or had the space to do that. So, if all that comes out of this program is **"I'm allowed to do that, I have a right to do that, I can empower myself to do that."**

TC: *Yes, I will be respected. Yes!*

LH: Maybe that's **what self-determination is as an outcome, like.. Having the ability to claim safe space.**

TC: ***Yes, that's a big part of what we are doing and one of the first things we talk about, that idea of safe space. And, how to create it and how to respect that, as teachers and educators, because of the high rates of abuse and trauma that come from those spaces not being respected.*** *This is really great!*

...

BW: *But* ***when we talk about self-determination then we are talking about agency and self-efficacy.*** *The example that you [Laura] just gave…* ***so we***

[173] See Introductory Chapter for a more detailed description of this interaction.

have our self-determination broken down into eight components but the ultimate outcome is self-efficacy. The best thing we can do is help them be effical: to be able to believe in themselves, to believe and have the confidence that they have the agency to create their own lives and create their own situations.

As Brent White--the programs' DNA-identifying designer and director--explained to me early-on in our work together:

> "...Self-determination is a thing I study, but not a thing that I sort of made-up. The rest of it is just stuff I figured out [through my own lived experiences as an Autistic]. So, [self-determination is] weird in that sense."

Knowing my own biases, I asked Brent to introduce me to the sources he used to study self-determination as it pertains to I/DD student/clients in the ACAT/ACT programs. Brent directed me to Michael Wehmeyer whose work on self-determination in Special Education is extensive[174] and widely utilized. Wehmeyer completed his education throughout the 1980s, a decade when the deinstitutionalization and disability rights movements were in full swing and U.S. legislation was slowly transitioning between the *Education for All Handicapped Children Act* (EHA, PL 94-142: 1975) and the *Rehabilitation Act of 1973* to the *Individuals with Disabilities Education Act* (IDEA, PL 101-476: 1990) and the *Americans with Disabilities Act of 1990* (ADA, 1990). While Wehmeyer's work on

[174] See: Beach Center on Disability, "Michael Wehmeyer"

self-determination for transitioning adults is key to Brent's understanding of these concepts; the ACAT/ACT "practice of self-determination" significantly diverges from the path laid out by Wehmeyer. When situated within a Neurodivergent Education Model and practiced within the material conditions of a Berkeley-based transition program for I/DD adults, Wehmeyer's work is critiqued literally "from the ground up:" from its philosophical underpinnings to its practical application. To ensure that this grounded critique is clear, I begin with an analysis of Michael Wehmeyer's history of the concept as it lead him to develop a "Functionalist Model of Self-Determination"—a journey that will take us into the history of eugenics as well. Following this critical analysis, I contrast Wehmeyer's "Functionalist Model" with ACAT/ACT's "Neurodivergent Practice" of self-determination training under their "Neurodivergent Model of Education" (NEM). In my analysis of NEM's STEP 3, I will particularly focus on the example of ACAT/ACT's "No hugging" rule.

Michael Wehmeyer's Functionalist Model of Self-Determination

Trained in special education (focus: "mental retardation"), human development ("developmental psychopathology, neurobiology of behavior, social and personality psychology"), communication sciences, and experimental positive psychology, Michael Wehmeyer approaches the concept of "self-determination" from a behavioral perspective; or, as a "class of behavior": "self-determined *behavior* refers to *volitional actions* that enable one to act as the primary *causal agent* in one's

life and *to maintain or improve one's quality of life*" (Wehmeyer, 2005: 117).[175] He further narrows his definition of "self-determined behavior" to "actions that are identified by four essential characteristics" which "describe *the function* of the behavior that makes it self-determined or not" (italics added).[176] Self-determination, in Wehmeyer's model, is *a "function"* or "product" of a particular class of behavioral discipline.[177]

The following four learned characteristics or dispositions are the "functions" behaviors are, in this model, supposed to produce in order to qualify as "self-determined" behaviors:

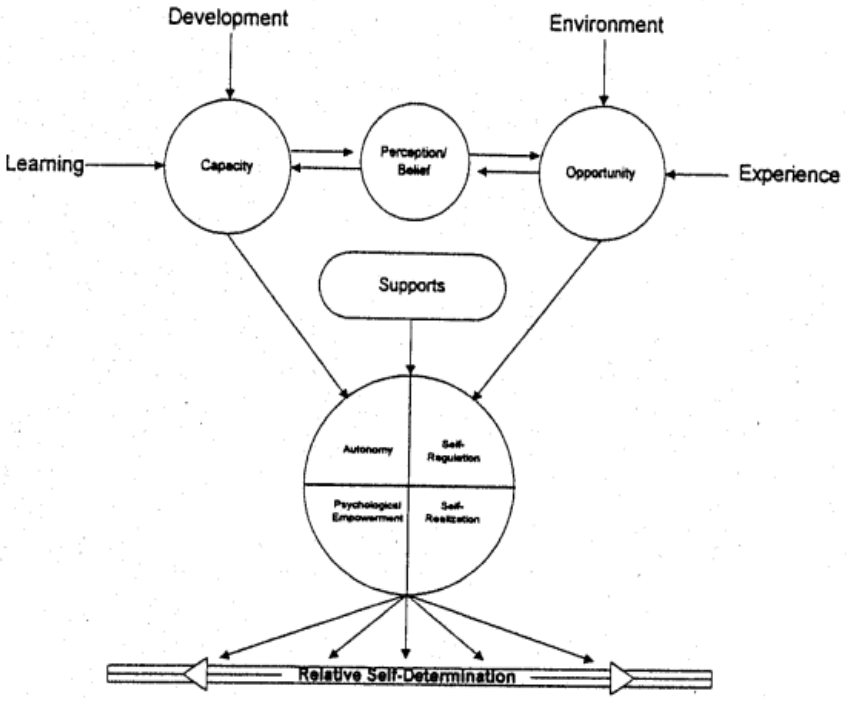
1) "The person acted ***autonomously***." The "autonomous" person acts:
    a) "According *to his or her own preferences, interests, and/or abilities*; and,
    b) *Independently*, free from undue external influence or interference."
2) "The behavior(s) are ***self-regulated***." To be a "self-regulated" person, a person must be able to *"examine their environments and their repertoires of responses* for coping with those environments *to make decisions about how to act, to act, to evaluate the desirability of the outcomes of the action, and to revise their plans as necessary*."
3) "The person initiated and responded to the event(s) in a ***psychologically empowered*** manner." To be a "psychologically empowered" person is *to engage with "various dimensions of perceived control"* based on the "belief" that:
    a) "They have the capacity to perform behaviors needed to influence outcomes in their environment; and,
    b) If they perform such behaviors, anticipated outcomes will result."
4) "The person acted in a ***self-realizing*** manner." In this functional model of self-determination, "self-knowledge forms through experience with, and interpretation of, one's environment and is influenced by evaluations of others, reinforcements, and attributions of one's own behavior." Thus, to become "self-realizing," a person must "*use a comprehensive, and reasonably*

[175] Wehmeyer, Michael. (2005
[176] Wehmeyer, Michael & Sharon L Field. (2007).
[177] Recall here Tania Coffield's resistance to self-determination as a "product" as opposed to a "practice"

accurate, knowledge of themselves and their strengths and limitations *to act in such a manner as to capitalize on this knowledge in a beneficial way*."[178]

According to Wehmeyer's Functional Model of Self-Determination, if/when behaviors function in these four ways, they can be characterized as relatively "self-determined behaviors;" thus, self-determination is a function of four particular forms of behavioral discipline and/or modification, described as: autonomy, self-regulation, personal empowerment, and self-realization. Wehmeyer illustrates[179] his functional model of self-determination in "Figure 1: A functionalist model of self-determination" (below).

FIGURE 1. A functional model of self-determination.



"Figure 1: A functionalist Model of Self-Determination" by Michael Wehmeyer, 1999

[178] Wehmeyer, Michael & Sharon L Field. (2007).
[179] Wehmeyer, Michael. (1999).

From a different perspective, these four "functions" can be understood to produce a form of "self-determined behavior" legitimized by (or neuro-"typically" conforming to) classically Western philosophies defining determinism, utilitarianism, (rugged) individualism, in/dependence, and "in/competence" (Jenkins, 1998[180]). Such Western philosophies have been in formation within the medico-legal institutions of Western societies since at least the 16th Century. These philosophies--for example, those defining medio-legal "in/competence" as an indicator of socio-political "in/dependence"--became the solid, material, or "concrete arrangements" of Western disciplinary and discursive practices known in the US today primarily between the 16th-20th Centuries; and, especially with the advent of the Trans-Atlantic Slave Trade (1526-1865), Western Imperialism, (esp. Settler) Colonialism, and the "urbanization" upon which the "development" or "progress" of the Industrial Revolution depended:

> "In the modern world, the attribution of (in)competence is unlikely [to] be a purely local matter. **Indigenous or local models** may be at odds with external or metropolitan models, over response and treatment as well as classification and diagnosis. ...***Metropolitan models--particularly in-so-far as they are Western scientific bio-medical models, bound up with the organisational practices of the state--are likely to be consequential in different ways, and to different degrees, than local models or indigenous knowledge***. …[And] ***the damaging internalisation of metropolitan models in the ex-colonial periphery***… where the majority of the population can be said to fall short of metropolitan ideals of competence [and "development," means that] some of the *extremes* of incompetence may be less visible. … [Even in a single country, ex. the US] ***At different times, more or less people and different kinds of people have fallen under the purview--the gaze--of the institutional and bureaucratic systems that have been developed to address the problem of incompetence.*** ...The long-term

[180] Jenkins, Richard. (1998).

> trend over this [modern] period has [been] an expanding proportion of the population of the industrialised democracies to be classified as intellectually incompetent in various ways and to varying degrees. ...The gradual expansion, responding to general labor market changes, of the general category of people classified as 'disabled'.... [shows that] ***many people who are today in receipt of services for the 'mentally retarded' or 'people with learning disabilities,' had they lived a century or two ago would have been*** earning their living, albeit in precarious unskilled poverty, as ***relatively unremarkable members of the community***[181]" (Jenkins, 1998: 7).

The historical formation of these philosophies and their materialization into the culturally dominant structures we know today coincided with the formation of "***the great territorial, administrative, and colonial states***" and the Trans-Atlantic Slave Trade; in-so that, Western concepts of in/competence have become critical to the maintenance of colonial, racial, sexual, economic, "development," and disability hierarchies that structure social inequalities world-wide. "Developmental models" of human beings and human societies--value-laden "scientific" theories imposing a normative, predeterministic, linear narrative over people, communities, and nations in terms of how they are "supposed" to grow, change over time, or "*be able to work themselves back into contributing members of the international community*"[182]--connect concepts of "under/development" with "in/competence" to create hierarchies of "in/dependence" mobilized in the denial of personal/political "self-determination" (Jenkins, 1998).[183]

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[181] Here, I recall Garfinkel's attempt to understand how "Agnes" could "pass" as an "unremarkable woman" and the labor "Agnes" invested in that "passage" (Garfinkel, 1967; Manning, 2017).
[182] Michael Wehmeyer, Section 2 of National Gateway to Self-Determination lecture "What is Self-Determination?" titled "Defining Self-Determination." Wehmeyer, Youtube, 2011.
[183] Here, I am linking David Harvey's (2005, 2007) discussion of Neoliberalism and the "New Imperialism" imposed with neoliberalism and the IMF (for instance) on "underdeveloped" nations with the "New Psychiatry" movements, like Behaviorism (ABA), imposed upon supposedly

To more clearly illustrate these philosophical underpinnings as they impact the practical implications of a "functional model of self-determination," I quote Michael Wehmeyer's lecture, "Defining Self-Determination" (2011), produced in conjunction with the *National Gateway to Self-Determination,* at length below. In this lecture, Wehmeyer describes the historical emergence of national, political, collective, personal, and psychological (behavioral) concepts of "self-determination" in Europe and the U.S. since (at least) the 16th century. Read through a decolonial, intersectional feminist, disability perspective, Wehmeyer's functionalist interpretation of the history of this "behavior" uncritically segregates "personal" from "political" lived experiences with self-determination practices; and, effectively denudes the disciplinary conflation of "(em)power(ment)" and "control." A conflation that "works for" the solidification of professionals' biopolitical power[184] to control the lives/futures of politically (especially, intellectually and/or developmentally and/or "severely") disabled people. In his behaviorist and functionalist model of self-determination, Wehmeyer ignores what he admits "advocates, people with disabilities" demand in classic third wave feminist fashion: the *personal is political*. Personal self-determination cannot be "functionally" segregated from lived experiences with political self-determination--to deny one, is also to deny the other in

"underdeveloped" (disabled) people; particularly in terms of how access to self-determination is denied in both cases and on both social scales as a consequence of supposed underdevelopment (biomedical/biopower disciplinary models) and imposed restrictions "for your own good" (hierarchies of dependence/competence).

[184] Foucault, 1978, 1995, 2004.

the guise of offering a "professional" service. Below, I will break Wehmeyer's history into sections so as to analyze each phase of his historical description in detail.

Michael Wehmeyer Lecture: "Defining Self-Determination"[185]

> **This national, political, or collective sense [of self-determination]** emerged really in the 18th century as people began to proclaim that it was their right to self-governance and not the rights of monarchs that was important. So we saw the movement across history… the movement from, you know, rulers, monarchs, kings and queens and such to democracies and other forms of more representative democracy. And, you know, this kind of **codified throughout the 19th and into the 20th century: the belief that people should have the right and opportunity to determine their own government that began to spread and gain wide approval. The catalyst for the political use of the term self-determination as it relates to the independence and freedom of people's in a nation** really springs from **Woodrow Wilson's speech in 1917**: the 14 points that he proposed as a means to settle the outcome of World War I, half of which basically referred to returning the rights of self-determination to these countries that had been conquered [and colonized]. **His argument was that, if we tried to, you know, hover-over and control them, that these peoples are going to revolt; but, *if we enable them to continue self-governance then they are going to be able to work themselves back into contributing members of the international community.***

Here, Wehmeyer offers a history of the "national, political or collective"[186] discourse of "self-determination" which aligns with Michel Foucault's genealogical analysis of the Western shift from sovereign to disciplinary power. In Foucault's work, however, the transition (from the 1600s through the early-1900s) between the

[185] Michael Wehmeyer, October 13, 2011, "Wehmeyer Lecture, Section 2: Defining Self-Determination" Posted by National Gateway and Retrieved August 13, 2019, Here: https://www.youtube.com/watch?v=VC2SLLHMsHo
This lecture is the second in a series titled "What is Self-Determination and Why is it Important?" sponsored by the National Gateway to Self-Determination. Main source here: http://ngsd.org/news/self-determination-and-self-advocacy

[186] Which he also at times refers to as a "Corporate" sense of "self-determination" in the same lecture.

sovereign power to "*take* life or l*et* live" to the disciplinary and biopolitical power of "governmentality"[187] is situated "at the point of intersection of two movements, two processes":

> There is, of course, the process that, dismantling feudal structures, organizes and sets up the great territorial, administrative, and colonial states. Then there is a completely different movement, but with complex interactions with the first… with the Reformation and then the Counter Reformation, [that] questions how one wishes to be spiritually directed here on earth for one's salvation. On the one hand, there is **the movement of *state centralization***, and, on the other, one of ***religious dispersion and dissidence***: I think **it is at the meeting point of these two movements that the problem arises**, with particular intensity in the sixteenth century, of "how to be governed, by whom, to what extent, to what ends, and by what methods." (Foucault, 2004)

Wehmeyer's history, however, ignores critical intersections between Western movements for political and spiritual "self-determination"--divergent and conflicting attempts to access "salvation" via: monarch, family, church, "the" book/testament, state, "good" works, etc.

According to Foucault's genealogy of the West--and in line with Weber's analysis of the "protestant ethic" as it colonized North America--Christian sectarian colonizers were attempting to practice new kinds of spiritual self-determination with/against the Protestant Reformation and the Catholic Revival. Wehmeyer's telling effectively removes the history of *nations*' movements for *spiritual* "self-determination" as these movements intersect with the emergence of colonial *state*

[187] "How to govern oneself, how to be governed, by whom should we accept to be governed, how to be the best possible governor?"
Foucault, 2004.
Adams, 2017.

formations and movements for *political* "self-determination." Marx's critical, yet secular, analysis of "alienation" as it accompanied the rise of capitalism, as well as Weber's study of the "spirit of capitalism," can be linked to the mass "spiritual dissidence" Foucault argues intersected with the shift from feudal modes of production to disciplinary biopower in a capitalist mode of production: "[t]his bio-power was without question an indispensable element in the development of capitalism' which made possible 'the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes" (Foucault, 1978; Adams, 2017; Weber, 1905; Marx, 1844; Harvey, 2005).[188] Without recognition of this spiritual dissidence or dispersion--movements for, dare I say, "neurodiversity" in "spiritual" (personal/political) self-determination[189]--that which grounds movements for political self-determination is lost; and, historical movements for liberation from sovereign powers are mistaken as advocacy movements for capitalism and/or the idea that becoming "contributing members of the international community" is equivalent to political "salvation." I would argue that such a historically-reductive analysis on Wehmeyer's part reflects a deeply "colonial mentality"[190] which most post-1917 movements for self-

[188] Foucault, Michel, 1978:140-141.
Adams, 2017.
[189] Who is allowed to talk to "God"? Who is capable of receiving messages from God and translating them for others? Who is considered "blessed/holy" versus "insane/damned" for their lived experiences of direct/personal communion and/or communication with God? Who has the competence to interpret "God's" will for "man" on earth? What is the difference between a monarch, a priest, and "a person with delusions of grandeur"? Who is invested with "divine rights" and afforded personal and political self-determination in practicing those "divine rights?"
[190] Fanon, Frantz, 1963.
Fela Kuti. (1977). "Colonial Mentality."

determination world-wide have fought to resist and delegitimize using local models of personal/political (and spiritual) competence (Fanon, 1963; Kuti, 1977).

Michael Wehmeyer Lecture: "Defining Self-Determination"[191]

> **The <u>personal or individual sense of the term [self-determination]</u>**… well it emerged in the late-1600s; but in terms of practice **you see the field of social work and social welfare [1920s] sort of leading the way in that.** There was a book that was published in 1978 [Biestek & Gehrig[192]] that was titled the 75-years of self-determination in the field of social work, basically. And in this book, the authors talk about **client self-determination as the focal point of the values system in social work. Without self-determination, human dignity and worth are meaningless.** So again, those issues of social dignity and worth… so, **within the field of social work and social welfare we see self-determination as a basic value in how people are intervened with, if you will: a respect for the rights of people to make their own decisions and to make their own choices.** ***And so, what we saw emerging as practice to operationalize this kind of value is a big emphasis on client participation, great involvement in plan making, and responsibility for plan making by people who are in part being supported in the social work. Lots of focus on self-help and self-direction and self-expression. And these are similar strategies you see being repeated today in education and in the education of students with disabilities*** we see the same kinds of emphasis. **And, I think we need to understand,** ***we need to acknowledge that there is a basic tension between this value for self-determination*** **and issues that become very difficult.** ***At what point...*** if there is somebody who is on the street, who is homeless, who has a mental illness, and you know that if that person were to take medication that they could in fact get their life back in order… at what point ***do you begin to force somebody*** to take that medication? And of course, in general, that only… **the line that is crossed is when that person becomes overtly harmful** to him or herself; or harmful to somebody nearby. Otherwise, there is **a recognition that people have the right to deny basically treatment. And, I think we have a lot to learn… "we" meaning "education" has a lot to learn from the experiences overtime from the field of social work and social welfare in how you really honor these kinds of, and value people's rights, if you will, to self-determination.**

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[191] Wehmeyer, 2011

[192] Biestek & Gehrig. (1978). *Client Self-Determination in Social Work: 50 Year History*. Chicago: Loyola University.

Wehmeyer situates "personal or individual" concepts of self-determination within the twin discursive practices of social work and social welfare as organized during the early 20th Century. These discursive practices (social work/welfare) were still in transitional formation between the 16th-18th centuries in accordance with the anti-feudal shift toward disciplinary and biopolitical arrangements of power: "these two poles of power [the disciplinary and biopolitical] were 'still… clearly separate in the 18th century,' before starting to join together 'in the form of concrete arrangements that would go to make up the great technology of power of the nineteenth'" and 20th centuries (Adams, 2017; Foucault, 1998).[193] The bio-powered discourses of social work and social welfare came into dominant "practice" in the US by the 1920s—post-WWI, during the interwar-period (according to Wehmeyer)—representing concrete aspects of the epistemological shift from social "relief systems" of Poor Laws (often organized by "parish," 1597/1601) to the "administration" of Social Security (state-organization, 1935) between the 1600s and 1900s. What Wehmeyer leaves out of this description of the transition between systems of "social welfare"--from poor laws (1600s) to social security (1900s)--is the emergence of custodial "care" institutions and state-led efforts to sort growing "populations" of "un/deserving poor" alienated by the rise of industrialization and urbanization: the entire "social welfare movement" from indoor and outdoor relief to almshouses, workhouses, and custodial institutions; particularly, post-Civil War (1861-5) and Black Reconstruction (1863-77) in the U.S. By the mid-1800s, social welfare and

[193] Foucault, 1978; Adams, Rachel, 2017

"common school movement" leaders were together advocating for segregated institutions where disabled, "dependent," and/or "delinquent" populations could receive a "special," segregated education.

Dr. Abe Bortz, "the first" Social Security historian, fills in some of the blanks left in Wehmeyer's description of social work and social welfare as they were linked to "changing concepts of the *causes* of dependency" taking shape during the formation of the U.S.; especially, during its first century of formal statehood (1789-1880s), already almost two-full-centuries into the (settler) colonization carried out against indigenous North Americans across the continent:

> The almshouse, infirmary, asylum, poorhouse, poor farm, county farm, county home--whatever you want to call it, and what it was called differed in various parts of the country--was the first and for many years the only public charitable institution. In the workhouses were thrown together the petty criminals, the insane, the ne'er-do-well, the aged, the infirm, and those only temporarily in need. **So that beginning about the time of the Constitution[194] [late-18th C.], we came to recognize the need for differentiation among the poor and for treatment of each major group among them in accordance with their peculiar conditions and needs….** ***In the decades after 1820*** **[early-mid 19th C.],** ***America turned with unprecedented enthusiasm and energy to the construction of custodial institutions for the poor, the insane, the orphan and the criminal. Institutionalization now became the first rather than the last resort. The institution and not the household became the preferred setting. The use of custodial institutions in the United States seems intimately connected to <u>the community's changing concepts of the causes of dependency.</u>*** It appears that ***the post-Revolutionary War generations [post-1780s]*** *were far more prepared than their*

[194] "It was not until after the adoption of the Constitution (and note the preamble to the Constitution which sets forth 6 purposes for its adoption and the formation of the Government of U.S., one of these being to "promote the general welfare." And among the powers conferred by the Constitution upon the Congress is the power "to lay and collect taxes for the general welfare of the U.S.")... that we began to differentiate among the great mass of the poor. The old poor law had made no differentiation except between the "sturdy beggars," who were to be put to work, and "the deserving poor," who were to be relieved without work…" (Bortz, 1970).

> *predecessors to assign a larger share of responsibility for dependent behavior to the structure of society itself rather than to individual idiosyncrasy,* ***choosing to locate in existing social arrangements the essential causes of the problem***. **As they viewed it,** ***American society was so open and unstructured*****--filled with limitless opportunities for achievement and vice--*****and its members so inadequately prepared to cope with it--since neither church nor school, nor, above all else, family provided the necessary discipline*****--that poverty, crime and insanity** ***threatened*** **the welfare of the new republic. Concomitantly, Americans during these years also seem to have** ***shared a confidence in the ability to design an environment and construct a setting in which these faults could be eliminated and the causes of dependency thus eradicated***[195]**. Their** ***diagnosis*** **gave them the confidence to attempt cures and reform and also enabled them to appeal successfully to private philanthropists and State legislators for the funds to** ***construct and maintain custodial institutions.*** And, understandably, with the beginnings of a factory system, ***the institutions built after 1820 were more influenced by and more nearly resembled the factory***; whereas *those built before 1820 more nearly resembled the household.*"[196]

Bortz focuses on custodial institutionalization (post-1820s) as key to the emergence of state systems for the administration of social security and social welfare, as highlighted by Wehmeyer (post-1920s). Institutionalization was a key technique in the shift from colonial to state structures--by the 1870s, for instance, American Indian Boarding Schools (custodial institutions) were used to forcibly assimilate indigenous children formerly living with their families and tribes in "reservations" where "residents" (tribal nations) to this day, exercise only a "conditional liberty" or state-managed "sovereignty." Post-Revolutionary War concepts of "in/dependence"--and, I argue, "in/competence"--during the first century in the formation of the U.S. literally

[195] Religious and utopian societies, movements to construct versions of "heaven on earth," swept through the US throughout the 19th Century.
[196] Bortz, Abe. (1970). "Historical Development of the Social Security Act."

and figuratively became "concrete" structures in the United States between the early-mid 19th and 20th centuries.

In the century of biopolitical incubation between the emergence of segregated institutions for the "idiot" and the "insane" (1847/8) and the passage of the first Social Security Act (1935) in the US, *familial/kin-based self-determination*—ie. hereditary reproduction, or a family's determination about when, how often, and with whom to reproduce—took on a pseudo-scientific "function" with the growing study of "dependent populations." Neither Wehmeyer nor Bortz draw necessary critical attention to an international movement that directly intersected with the shift from family/home-based care and work (family-facilitated self-determination) to public/state-sponsored institutional care and factory work (factory-productions of self-determination): the Eugenics Movement. A "scientific" movement--with U.S. federal/state administrative offices from 1910-1939--of eugenic practices that dominated agents/agencies of social security and welfare from at least the 1880s-1940s; curtailed largely only by the international trauma incurred after witnessing the eugenic horrors of WWII.

By 1866--the year Edouard Seguin published *Idiocy and its Treatment by the Physiological Method*, one year after the end of the U.S. Civil War (1861-65) and as Black Reconstruction (1863-77) emerged in the midst of a national economic recession--Seguin and postbellum American reformers, including Samuel Gridley Howe, together "advocated an institution as an instrument for the treatment of children who were too severely mentally retarded to profit from normal classroom

instruction" (Harris, 1998: 92; Trent, 1994: 68; Alexander, 2010: 32). With the shift from phrenological to eugenic theories of social and human development by the 1880s, institutional superintendents' emphasis on education was pessimistically abandoned in the name of a strictly permanent custodialism (Trent, 1994; Ferguson, 1994). Post-Civil War generations[197] were taught, by way of eugenic propaganda, to feel "threatened" by "the criminal, the poor, and the insane" because they were supposed "menaces" to the spiritual, racial, and genetic "purity" and progress of the state--heredity (family facilitated self-determination) was a "threat" to state/national self-determination and economic progress (factory produced self-determination) (Beckwith, 2016; Carlson, 2010; Schweik, 2009; Snyder & Mitchell, 2006; Trent, 1994). Wehmeyer conveniently neglects to mention this period in the history of U.S. social work and welfare, particularly from the 1890s through the 1940s, when eugenics dominated the administration of social welfare in the US and became an international "scientific" movement. With this omission, Wehmeyer erases the *material* ("concrete") emergence of a more modern disciplinary and biopolitical process of dehumanization and estrangement that functioned to *traumatize the very core capacities for self-determination ("species-being") accessible to its disabled (especially I/DD) inmates for generations*.

"Colony planning"[198] was a "borrowed tool" originally developed "as a result of the great debate in the post [Civil] war period over how to cope with the growing

[197] Distinct from the post-Revolutionary War generations described by Bortz (1970).
[198] "Lincoln State School and Colony in Illinois, founded in 1891, "claimed credit for being the first" farm colony "in the world" to become "successful with the exclusive use of residents for farm production to the point of self-sufficiency" (Beckwith, 2016: 18). Also see Ferguson, 1994; 2014.

number of *chronically insane*" but then employed in the control and care of segregated "neurodivergent" populations by the turn of the 20th Century (Trent, 1994: 93-4; italic emphasis added). The organizational scheme afforded by the "colony plan" reflected "***a new vision of feeblemindedness emerging among superintendents and social welfare reformers, one of care and control based on differentiation, efficiency, and permanence***"--and new visions of self-determination for inmate populations produced from the union of eugenic, custodial, and factory models of social welfare[199] (Trent, 1994: 80, 88, 92; Foucault, 1995). In 1912, superintendent Charles Bernstein of the *Rome Asylum* in New York came to "pioneer" the colony system as a means of exploiting I/DD inmate labor. Bernstein expanded this exploitation into a sterilization-dependent system of "paroling" inmates--only by abdicating familial/hereditary self-determination (forced sterilization) and demonstrating a "high-functioning" capacity for labor (involuntary servitude) could an inmate "earn" a "conditional" experience of self-determination (parole) in lieu of pay.

For institutional superintendents in the first decades of the 20th Century--the same time when social welfare and social work emerged as disciplines according to Wehmeyer--the goal of this disciplined "training" of inmates on the "in"-side of the institution and its colonies was:

[199] In this union, we can recognize the intersecting emergence of both the prison and medical industrial complexes as disciplinary and biopolitical relations of power in "concrete" form.

1) to expand institutional-disciplines and institutionalists authority/power into the community (i.e. "out"-side of the institution); while,

2) making space on the "in"-side for increasing numbers of new admitants of the "custodial" ("uneducable/untrainable," "low-functioning," or "severely" dependent) class, who could then be cared for by "high-grade" ("trainable"/exploitable, "high-functioning," or "conditionally" dependent/competent) inmates denied remuneration and/or the possibility of parole under the medico-legal authority of superintendents; and,

3) thus, securing and "protecting" the disciplinary "indispensability" of these new professionals (institutional superintendents) for generations to come in the name of social "welfare," "progress," and "security."

The policy of parole declined rapidly with the onset of the Great Depression (post-1920s[200]). Because the Great Depression left the availability of work in the community (for anyone) at all-time lows, it also put superintendent's economic dependence upon institutionally-confined, indentured servants at all-time highs (Trent, 1994: 208). Throughout the 1930s and 1940s, parole (a "conditional" liberty) became rare; however, forced sterilization practices (denial of familial self-determination) continued to become increasingly standardized and prescribed as a "protective" or "security" measure "for their [inmates'] own good." The belief that people with intellectual and/or developmental disabilities "should not" be allowed to

[200] Same time when Wehmeyer cites the emergence of social work/welfare and their appropriation of concepts of self-determination, putting political concepts of self-determination through the proverbial medical model wringer.

reproduce freely (a lived experience of familial self-determination) was born out of the Eugenics movement; and, like sterilization practices, is alive and "well" today: "non-consensual sterilizations that are performed today are typically done so at the request of a disabled person's parents or guardians, who believe that sterilization (hysterectomies, vasectomies, etc.) will improve their child/ward's quality of life and/or make them easier to care for" (ABC Law Centers[201], 2018; Gill, 2015). Forced sterilizations are justified and court ordered, to this day, as a "social welfare" measure: as a means of supposedly improving the "child/ward's quality of life" and/or making the care work of "parents or guardians" just "easier."

Most institutional superintendents of the early 20th century justified colony plans, situations of indentured servitude, and parole systems as "a half-way setting" in that they could provide a "transition" between "the institution and local community" at the same time that they could promote the Mental Hygiene Movement's emphasis on "adjustment and adaptation"[202]--a movement driven by (typically eugenic and racist) agents in the emerging fields of social welfare and social work who sought to "protect and improve the family structure" and "preventing mental illness" so often linked at this time to sexually-transmitted diseases and/or sexual "deviance"[203]. Even before 1920, "superintendents began to shift from an emphasis on the 'menace of the feebleminded' [eugenics] to themes of adapting and adjusting mental defectives

[201] ABC Law Centers (2018). "Involuntary Sterilization of Disabled Americans: A Historical Overview."
[202] Precursor and contemporary of Behaviorism (behavioral conditioning/modification), Normalization, and Social Role Valorization theories.
[203] Focal issues ranged from that of punishing prostitution to promoting anti-miscengentation laws.

[mental hygiene] for institutional and extrainstitutional environments" (Trent, 1994: 212). The mingling or intersections of eugenics (a "medico-legal" movement), mental hygiene (led by social work/welfare agents), and "new psychiatry" movements (esp. "behaviorism"[204] and "personality" psychology in the US) thus afforded institutional superintendents new "ways of enlarging their spheres of influence to extrainstitutional [community-based] settings" throughout the first half of the 20th century.

In this way, early 20th Century processes of *community-based transitions* (most often a medico-legally sanctioned institutional parole preceded by forced sterilization) that fell under superintendents' institutionalized "expert" authority were further "concretized" with the advent of social work and welfare agencies operating under avowedly-eugenic state/federal authorities (Trent, 1994: 205, 212). As a matter of fact, institutional superintendents' attempts to expand their sphere of disciplinary influence outside the confines of the institution and to secure the supposed indispensability of their authority over increasingly "functionally" differentiated inmate populations--whether "high-/low-functioning," incarcerated, paroled, or yet unidentified and "passing"--made possible the emergence of social workers and social welfare agents as disciplinary authorities in the lives of I/DD populations on the "out"-side. Social workers and welfare agents--whose discipline emerged, according

[204] For example:
1897: Pavlov's Dog
1913: Watson launches the "behavioral school" of psychology
1920: Watson & Raynor condition a child orphan "Albert B" to fear a white rat
1936: B.F. Skinner introduces "operant conditioning" and "shaping"--Applied Behavior Analysis
1948: B.F. Skinner publishes *Walden Two* advocating "Radical Behaviorism"
1963: Bandura published *Social Learning Theory and Personality Development* to combine behaviorism with emerging cognitive studies.

to Wehmeyer, as dominant U.S. practice during the 1920s, during the eugenics and mental hygiene movements, and in the midst of a failed experiment in proto-deinstitutionalization in the form of a sterilization-dependent parole system--came to "work for" institutional superintendents on the "out"-side. Social welfare agencies expanded the biopolitical and disciplinary power of institutionalists into the communities and public spaces "out"-side institutional confines where former-I/DD inmates could only "self-determine" a sterilization-dependent and conditional liberty (ex. parole) under the supervision of medico-legal agents tasked with "protecting" social welfare and progress from the "threat" of the same populations they also claimed to serve/help/"work for"; but also, and increasingly, where "passing" prospective-inmates could be monitored, identified, sorted, sterilized, and forcibly institutionalized.

Like "special" educators, social workers and social welfare agents owe their disciplinary methods, longevity, and administrative "successes" since the early-20th Century to the professional ambitions of institutional superintendents who foresaw the end of their reign (even before the Great Depression and the Two World Wars hit the nation) and thus sought to secure new positions of power on the "out"-side. To carry out this professional and disciplinary expansion, institutionalists, social workers, social welfare agents, and emerging "special" educators affected a near-complete erasure/white-washing of the "personally/politically" traumatizing conditions under which (current, former, prospective) institutional inmates' were forced to attempt to practice culturally "common" forms of self-determination (ex.

reproduction, geographic mobility, compensatory labor, education, social services, medical care, spiritual freedom, etc.). The emergence of behaviorism and personality psychology during the early-mid 20th Century would cement this erasure/white-washing.

By identifying the collective, intergenerational trauma experienced by institutional inmates as a "personal" problem for disabled people--supposedly "caused" by their disabilities, instead of a "personal/political" problem "caused" by traumatizing, medico-legal structures of inequality--personality psychologists, behaviorists, social workers, "special" educators, and other 20th-Century emergent medico-legal agencies/agents effectively appropriated the self-determination of disabled people in the U.S. With these "new psychiatry" movements came the perfect tool to transform intergenerationally lived experiences with institutionalized trauma into "symptoms" of "behavioral" and/or "personality" disorders that "threaten" community safety and workplace efficiency. Personality psychology created the perfect tool to maintain political (medico-legal) control over the entire population of segregated neurodivergent people thence forth diagnosed with divergent mental/intellectual "personal" deficits[205] and "presumed incompetent" in any attempt to resist personal/lived experiences with "political" inequality--ie. denied the right to self-determine the distinction between abuse and care. As Wehmeyer inadvertently explains below: attempts made by I/DD people to resist medical colonization[206] are

[205] The medicalization of trauma.
[206] I.e. Neurodivergent self-determination practices.

considered "self-caused" behavioral/personality issues (ie. disability-caused and/or volitional non-compliance) in need of "other-caused" modification and/or redirection (ie. disciplinary and biopolitical conditions of control) toward sanctioned and/or normalized "behaviors" (typically "valorized" within specific culturally-determined "social roles") in order to qualify as a "competent" form of "self-determined action."

Michael Wehmeyer Lecture: "Defining Self-Determination"[207]

> **It [the concept of self-determination] emerged <u>in psychology as a psychological construct as personality psychology emerged</u>** [1930s-1940s] as a discipline distinct from general psychology. General psychology kind of emerged out of philosophy and took an experimental approach to answering questions that philosophy had tried to answer through um... well bluntly non-experimental means, through thinking and logic and whatever else. By the late 1800s, 1880s, people like William James who had been trained as a philosopher were writing. James wrote what is generally agreed to be the first english language textbook on psychology. So by the time that psychology as a discipline was maybe fifty years old in the 1920s, 1930s, and 1940s, subdisciplines begin to emerge and among those was this broader field of personality psychology. ***And personality psychology focused on self-determination as a major focus of explaining why people behave in the ways that they do, that's the point of personality psychology.*** **And, these early conceptualizations of self-determination took up on and from a philosophical doctrine and that doctrine is determinism.** And that leads us to really, I think, getting at ***the root of what we mean by self-determination. Self-determination as a personality construct argues that one's course is determined--and by determined we mean 'caused'--*****by*** factors that are either autonomous within oneself or heteronomous, external to oneself. So its **either self-caused or other-caused actions** and ***we can begin to consider human behavior by those kind of gross divisions of: is this self-caused or is this other-caused?*** And in the early writings that was 'autonomous determinism' or 'heteronomous determinism.' **The notion of determinism is derived from the philosophical doctrine of determinism that suggests that all action--and in this case human behavior--is caused.** So, when we talk about self-determination, what we really want to be thinking about is: is this notion of self-determinism, self-caused action. ***So self-determination [in personality***

[207] Michael Wehmeyer, 2011

> ***psychology and behaviorism] is fundamentally about self-caused versus other-caused action.*** So that is the first point to make as we explore what we mean by this...

To further rationalize and concretize the socio-historical erasure/white-washing of past-in-present institutionalized trauma (as demonstrated by Wehmeyer's omission of custodial institutionalization and the eugenics movement in the previous section), institutionalists-- transitioning their careers from secluded institutions and into community-based "care," "special" education, and "social welfare work"--mobilized the emerging field of "behaviorism" within "personality psychology" to effectively blame former-inmates for the intergenerational traumas they survived. Today's "special" education and service provision leaders are trained within these disciplines--particularly Applied Behavior Analysis (ABA)--and to identify personal/political attempts to practice neurodivergent (non-neurotypical or disabled) self-determination as "behaviors," "dispositional" deficiencies, and/or "volitional" acts of "non-compliance" (but never to identify them as personal/political self-determination practices in resistance to intergenerationally lived experiences of past-in-present trauma). Personality Psychology and Applied Behavior Analysis--especially as a standardized practice in compulsory systems of "special" education--are the principal disciplinary tools in use today that effectively pathologize ("blame, shame, and punish") neurodivergent self-determination practices that resist past-in-present histories of intergenerational trauma.

The origins of "personality psychology" lie within the professional debates over the "causes" of "hysteria"--neurological versus psychological--particularly as observed and recorded to affect institutionalized women under the "care" of Jean Marie Charcot[208] (1825-1893) in the neurological clinic at the Salpêtrière in France; and, his student from 1885-1886, Sigmund Freud, a visiting scholar from Germany (1856-1939). Freud's experience working with Charcot lead him to convert from a neurologist to a psychologist. Eventually, Freud coined "psychoanalysis," which gave way to the "psychodynamic approach" of understanding "personality"—the dominant approach even today.

Charcot is widely considered "the father of neurology" and Freud was far from his only famous student. Alfred Binet, a French psychologist who transitioned between psychology and into the emerging field of development studies after his work with Charcot during the mid-1880s, eventually became a pioneer in experimental, developmental, educational, social, and differential psychology. In 1904, Binet was commissioned by the French Ministry of Education to develop the first IQ-test in support of state efforts to identify and sort French children by intelligence and to segregate "normal children" from those considered "abnormal." Psychologists' mission to measure intelligence largely began with Charcot's predecessors at the Salpetriere and fellow French institutionalists, like Itard, Esquirol and Seguin: "pioneers" in the segregation of the "idiot" from the "insane" and in the

[208] One of my disabilities, Charcot-Marie-Tooth Disorder, was "coined" by Charcot in conjunction with Pierre Marie and Henry Howard Tooth at the Salpêtrière. Here, again, I draw attention to the neurodivergent roots of self-determination practices as a form of institutional resistance--in another life, born in France, I might have been one of those women Charcot "treated."

institution of "special" education. These earlier attempts to measure intelligence spread to the UK via Francis Galton[209] and then to the U.S. via Galton's student, psychologist James McKeen Cattell, who coined the term "mental tests" (1890). As "mental tests" and other Galtonian measures fell out of favor in the early 20th Century, Binet was commissioned by the French government to develop new tests. Binet was particularly intent on studying "normal" children, unlike the majority of his colleagues, conducting experimentation upon "abnormal," "aberrant" or "deviant"[210] children. With his colleague Theodore Simon in France, Binet famously designed the "Simon-Binet Scale" in 1905 with subsequent revisions in 1908 and 1911.

The "Simon-Binet" IQ-Test made its way into the U.S. in 1908 via Henry Goddard--an American doctor of psychology, avowed eugenicist, and Director of Research at the *Vineland Training School for Feeble-Minded Girls and Boys* in Vineland, New Jersey from 1906-1918. Goddard originally translated the Simon-Binet scale from French with a combination of racist and ableist ambitions: 1) he believed the scale could provide scientific evidence for his belief in the intellectual superiority of white races; and, 2) he was confident in the scale's ability to help sort, identify, and segregate the "feebleminded" from the general population. As a "pioneer" in Pedigree Studies[211], Goddard spent much of his career attempting to mobilize eugenic science (ex. IQ Tests) to prevent "feebleminded" people from being

[209] Who also coined "Eugenics."
[210] It is important to note that Emile Durkheim was defining some of the "Rules of Sociological Method," concepts of social "deviance," and what we now consider a "functionalist" approach to social problems in France at this same time (1895, 1897).
[211] Goddard, 1912

able to procreate and pass-on hereditary disabilities to future generations--he was a major proponent of both institutionalization and sterilization as was common among U.S. psychologists and eugenicists of the early 20th Century.

At the 1910 annual meeting of the *American Association for the Study of Feeblemindedness*, Goddard proposed using the Simon-Binet scale to administer a new "industrial classification system" that would aid American social workers, welfare agents, and school teachers--in public spaces and schools on the "out"-side of institutions--to identify, sort, segregate, institutionalize and sterilize three distinct groups of I/DD people:

1) "Idiots" whose IQ scores range from 0-25;
2) "Imbeciles" whose IQ scores range from 26-50; and,
3) "Morons" whose IQ scores range from 51-70.

In coining the then-scientific and diagnostic term "moron," Goddard argued that "morons"--people whose disability often escaped the notice of experts in so that they could "pass" for "normal" and reproduce "freely" in their local communities-- were a grave "menace" to social progress. Psychologists—like Binet, Simon, Goddard, Doll, Terman, and Yerkes (just to name a few)—put the IQ test to international work as a disciplinary technology in such a ubiquitous way that Jean Piaget was, within two decades, describing a "theory of cognitive development" (1936)[212] based on patterns in children's responses to IQ test questions; thus, marking the advent of the "cognitive revolution" in psychology[213] that would not truly take hold until the 1950s.

[212] Piaget, J. (1963). *The origins of intelligence in children*. New York: Norton. (Original work published in 1936).
[213] Note also that theories of "human cognitive development" emerged directly from data collected in the earliest iterations of the IQ test. Such tests were then, and are still today, culturally skewed and

The "cognitive revolution," like most intellectual movements unsponsored by the "Third Reich," was stalled by two World Wars. Many European scientists refused to take the route Hans Asperger[214] took and refused to collaborate with the Nazi regime. As a consequence of their non-compliance with the disciplinary objectives of the Nazi "authoritarian" and "totalitarian" regime, intellectual leaders of various ilks--including Freud, major members of the Frankfurt School of Sociologists, and eventually Hannah Arendt too, among many others--fled to the U.S. for "asylum." While Asperger was immersed in the observation and testing of institutionalized disabled children for whom his clinic was dedicated to developing "individualized approaches to education," the locus of scientific and global economic dominance was shifting to the U.S. with the tides of war (Silberman, 2016: 104). It was during his tenure there, that Asperger coined "Childhood Autistic Psychopathology"—known today as "Asperger's Syndrome" along the "high-functioning" end of the "Autism Spectrum" (Asperger, 1944; Wing, 1981; Frith, 1991; DSM-IV, 1994).

At the same time that proto-developmental/-cognitive and personality psychologists were stalled in "revolutionizing" their discipline, particularly in Europe (ex. Piaget, 1936), the disciplinary field of Behaviorism dominated U.S. psychology in a way it never has in Europe, even to this day. While Piaget was working in France, U.S. psychologist and eugenicist Edgar Doll published the "Vineland Social Maturity Scale" (1935) to massive acclaim and B.F. Skinner (1938) coined "operant

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often only measure certain kinds of cultural competence that may not have anything to do with processes of "human development" and much to do with social inequalities.

[214] An Austrian pediatrician, eugenicist, and medical chair of "Heilpädagogik Station," in the Children's Clinic at the University of Vienna from the 1930s-1950s

conditioning" and "shaping" in contrast to "classical conditioning" (Pavlov, 1897; Clark, 2004). Behaviorism--an international discipline today--was incubated among U.S. eugenic psychologists and social welfare agents throughout the first half of the 20th Century. By the 1930s and 1940s,[215] Behaviorists (most famously B.F. Skinner) attempted to make a "radical behavioral shift" in personality psychology: away from Freudian studies of the "unconscious" and/or Jungian "psychological types;" and, toward measurable experimentation with stimulus/response patterns and the "radical" possibilities of social and behavioral control. These experimental efforts toward social control via un/conscious behavioral conditioning and modification began, however, in Russia with a dog.

Just prior to the turn of the 20th Century, a Russian physiologist, Ivan Pavlov (1897) successfully conditioned a dog to salivate on command. The famous "Pavlov's Dog" experiments introduced the world to the disciplinary possibilities of what became known thereafter as "classical conditioning." Following on Pavlov's experimental approach, John Watson published his "Behaviorist Manifesto" in 1913--just three years after Goddard proposed his "industrial classification system"--arguing for a behaviorist approach to education, jurisprudence, medicine, and business:

> Psychology as the behaviorist views it is a purely objective experimental branch of natural science. ***Its theoretical goal is the prediction and control of behavior.*** Introspection forms no essential part of its methods, nor is the scientific value of its data dependent upon the readiness with which they lend themselves to interpretation in terms of consciousness. ***The behaviorist, in his efforts to get a unitary***

[215] During the Great Depression and the advent of WWII. The same time when Wehmeyer argues "Personality Psychology" adopted/appropriated "self-determination" as one of its key values in service provision.

> ***scheme of animal response, recognizes no dividing line between man and brute.***… My final reason for this [proposal to shift toward behaviorism] is ***to learn general and particular methods by which I may control behavior.*** My goal is not 'the description and explanation of states of consciousness as such'… ***If psychology would follow the plan I suggest, the educator, the physician, the jurist and the business man could utilize our data in a practical way***, as soon as we are able, experimentally, to obtain them. Those who have occasion to apply psychological principles practically would find no need to complain as they do at the present time. ***Ask any physician or jurist today [1913] whether scientific psychology plays a practical part in his daily routine and you will hear him deny that the psychology of the laboratories finds a place in his scheme of work. I think the criticism is extremely just. ...What gives me hope that the behaviorist's position is a defensible one… Experimental pedagogy, the psychology of drugs, the psychology of advertising, legal psychology, the psychology of tests, and psychopathology are all vigorous growths [of the behavioral paradigm]***. These are sometimes wrongly called 'practical' or 'applied' psychology. Surely there was never a worse misnomer. ***In the future there may grow up vocational bureaus which really apply psychology [ex. Special Education today].*** **At present [1913] these fields are truly scientific and are in search of broad generalizations which will lead to the control of human behavior.** (Watson, 1913).

With Watson's work on "psychology as behavior," behaviorism quickly came to the fore in the U.S. The first professor of "applied psychology," Walter Dill Scott was hired through the Carnegie Institute of Technology and helped develop tests for the selection of WWI military captains. Watson's main goal, however, was creating a brand of "behavioral" psychology that could then be sold and practiced "out"-side the behaviorists' experimental laboratory and "in"-side classrooms, courtrooms, business meetings, police stations, etc. The goal, in Watson's mind, was to make behaviorism a practically indispensable discipline in modern bureaucracies (Weber, 1922).

With growing disciplinary support, experimentation continued. By 1920, Watson and Raynor infamously conditioned a nine-month old child orphan they

named “Albert B” to fear a white rat (among many other things) using behavioral conditioning. While the “Little Albert” experiments are now considered one of the most unethical psychological experiments “*of all time*,”[216] it was in 1920 a breakthrough for behaviorists, demonstrating the “truly scientific” nature of the discipline (APA Timeline, 2019). The 1930s would offer a platform for the practices of behaviorism to be disseminated “out”-side purely psychological disciplines and laboratories, just as Watson had intended; and, especially in the military and public schools where recruits and children, required to submit to intelligence testing, could be sorted into new “behavioral” and “intelligence” classifications and biopolitical hierarchies. It was during the interim between the two World Wars (1918-1939)[217] that IQ tests became a standard tool in sorting U.S. children into segregated[218] compulsory education.

It was not until B.F. Skinner published *The Behavior of Organisms* in 1938, however, that behaviorism--driven by laboratory research and experiments--took-off in the U.S. and took-over personality psychology. With his 1938 book, Skinner introduced the world to “operant conditioning” or “instrumental conditioning” and “shaping” in direct contrast to Pavlovian “classical conditioning”:

> [Instrumental conditioning is] any form of conditioning in which ***the correct [ie. sanctioned] response is essential for reinforcement***. Instrumental conditioning is similar to operant conditioning and usually involves complex activities in order to reach a goal, such as when a rat is trained to navigate a maze to obtain food[219]. It contrasts with classical conditioning, in which reinforcement is given regardless

[216] Watson & Raynor, 1920; American Psychological Association, 2017; DeAngelis, 2012.
[217] The first SAT, for instance, was administered in 1927.
[218] Intersections of segregation by disability, race and sex at this time in U.S. history were standard.
[219] Recall Jen Msumba’s experiences with food deprivation at the *JRC*

> of the response… [Operant conditioning is] ***the process in which behavioral change (i.e., learning) occurs as a function of the consequences of behavior.*** Examples are teaching a dog to do tricks and rewarding behavioral change in a misbehaving child. (APA Dictionary of Psychology, 2018)[220]

From a classic sociological perspective rooted in a Weberian concept of "social action" as opposed to "individual behavior" (a psychological concept), "behaviorism" largely works to condition "instrumental" and/or "traditional" rationalities as the only sanctioned/correct response to environmental stimuli; and to condition negative associations ("consequences") with affective and/or value-based rationalities (Weber, 1922). Behaviorists reduce the process of learning to a process of observable "behavioral change" and "control" that depends, for its "function," upon externally imposed "consequences" in the form of "aversives, unpleasant stimuli, negative reinforcement and positive punishment." It was under these conditions--and eugenic efforts to control the socio-economic and political effects of mass poverty caused by the Great Depression and two World Wars--that "self-determination" as a concept was appropriated by the field of psychology; personality psychology and behaviorism, specifically.

Psychologists attempts to mobilize self-determination as a concept during the first half of the 20th Century "functioned" to produce an experience of "enclosure" for I/DD people, whether living in the community under the surveillance of social workers, welfare agents and other eugenic authorities (ex. teachers, doctors, etc.), or confined within segregated institutions and limited to the environmental stimuli

[220] American Psychological Association, 2018a, 2018b.

accessible therein.[221] Like land owners in 13th Century England who consolidated small landholdings into large farms so as to control who owned that land and who could commonly "function" off of that land, early-mid 20th Century psychologists (ex. superintendents, behaviorists, social workers, welfare agents, etc. immersed in the eugenics and mental hygiene movements) consolidated smaller groups of disabled people into larger, bio-politically mediated populations[222] subject to their disciplinary "expertise." Psychologists practice this self-proclaimed "expertise" as a kind of "ownership," appropriating "common" experiences of self-determination as property/products. Once "enclosed" within a particular population or disciplinary institution, disabled people's self-determination became restricted: available only to the "owners" (disciplinary "experts") of the means of production (involuntary labor of disabled inmates), and redistributed only by the owner's "legitimized authority" (science/law). Access to "self-determination" (ex. ability to grow food for subsistence, to reproduce your family, to move/travel freely, to make decisions about your life, to practice religion without persecution, etc.) became inaccessible to the "commoners" who were forced to become wage laborers for their survival--labor appropriated, unpaid, or sub-minimally compensated in the case of disabled populations--and in order to gain access to (personal, not political) self-determination

[221] A contemporary example: You have no choice to refuse to attend your IEP meeting, but you can "choose" (with the permissions) whether you'd like to sit in this chair or that chair for the duration of our discussion about you.
[222] Examples: Goddard's Industrial Classification System; Hans Asperger's work which segregated "low-functioning" from "high-functioning" inmates; Edgar Doll's "Vineland Social Maturity Scale;" etc. Also see: Beckwith, 2016: 13.

practices in the form of a "conditional liberty" (Federici, 2004; Harvey, 2007; Foucault, 1995)

Wehmeyer sites the emergence of a concept of "self-determination" in psychology between 1930-1940; but fails to cite this emergence within the context of the emergence of Behaviorism, WWII, the Great Depression, the Eugenics and Social Hygiene Movements. With an enclosed, commodified, or conditional concept of self-determination now in their disciplinary toolboxes, psychologists (especially institutional superintendents and behaviorists), social workers and social welfare agencies were supported in their expansion efforts when, in the decades following, "between 1950-1970, state authorities built, refurbished and added to more public facilities than in any other period of their American history:

> Between 1946 and 1967, the populations of institutions for intellectually disabled people rose from 116,828 to 193,188, an increase of 65 percent and nearly twice the rate of increase in the general population. Each year, two thousand to five thousand new residents joined America's intellectual disability institutional population." (Trent, 1994: 240-1).

Psychologists, social workers, and social welfare agents of the early-mid 20th Century were investing in a process of consolidating their power over the dehumanized (commodified) property/product upon which their professions were built--the bodyminds of generations of disabled patients, students, and inmates turned involuntary laborers--into larger disciplinary relations of power over increasingly bio-politically mediated "populations," both "in"-/"out"-side their disciplinary confines.

As behaviorism and psychoanalysis took hold over U.S. psychology (and advertising) beginning in the early-mid 20th Century, two World Wars further

encouraged investigation into aspects of behavioral/attitudinal control and the possibility of producing mass conformity and/or compliance. It was after 1930 in U.S. psychology that behaviorists like B.F. Skinner were at the height of their careers, conducting laboratory experiments to test the limits of conditioning behavioral modification and compliance--particularly the compliance of those presumed too personally/politically incompetent for modern life, ie. disabled people. Between the 1950s and 1960s, behaviorists[223] organized a *Society for the Experimental Analysis of Behavior* (1957) so as to publish two new academic journals--the *Journal of the Experimental Analysis of Behavior* (JEAB, 1958) and the *Journal of Applied Behavior Analysis* (JABA, 1968)—focusing exclusively on publishing their experimental research. With the incredible success of these journals, the *American Psychological Association* (APA) founded a *Division for the Experimental Analysis of Behavior* (1964), followed by the formation of the *Association of Professional Behavior Analysts* (late-1970s). The *Association for Behavior Analysis International* (ABAI) was founded in 1974—the leading professional organization in the

[223] "As we have seen, the group [who founded the Society for the Experimental Analysis of Behavior in 1957] was quite homogeneous. Ferster, Boren, Schoenfeld, Sidman, and Verhave earned their doctorates at Columbia. Keller, of course, was on the faculty at Columbia, where he and Schoenfeld had been responsible for training all the other Columbia members of the Board. There were nine Harvard PhDs: Anger, Anliker, Azrin, Blough, Herrnstein, Keller, Lindsley, Morse, and Skinner. Only Dews, from the Department of Pharmacology at Harvard Medical School, whose physiology PhD was from Minnesota following an English medical degree, and Brady, who trained at the University of Chicago in physiological psychology, came from different backgrounds. There were cross connections here, too. Ferster hadjust finished five years working at Harvard with Skinner; Anger had been an undergraduate at Columbia."
Laties, Victor. (1987). "Society for the Experimental Analysis of Behavior: The First 30 Years (1957-1987)." Journal of the Experimental Analysis of Behavior, 48:3, 495-512.

international field of behaviorism (especially, ABA) today despite public criticism from Autistic leaders and organizations like ASAN (ASAN, 2019c).

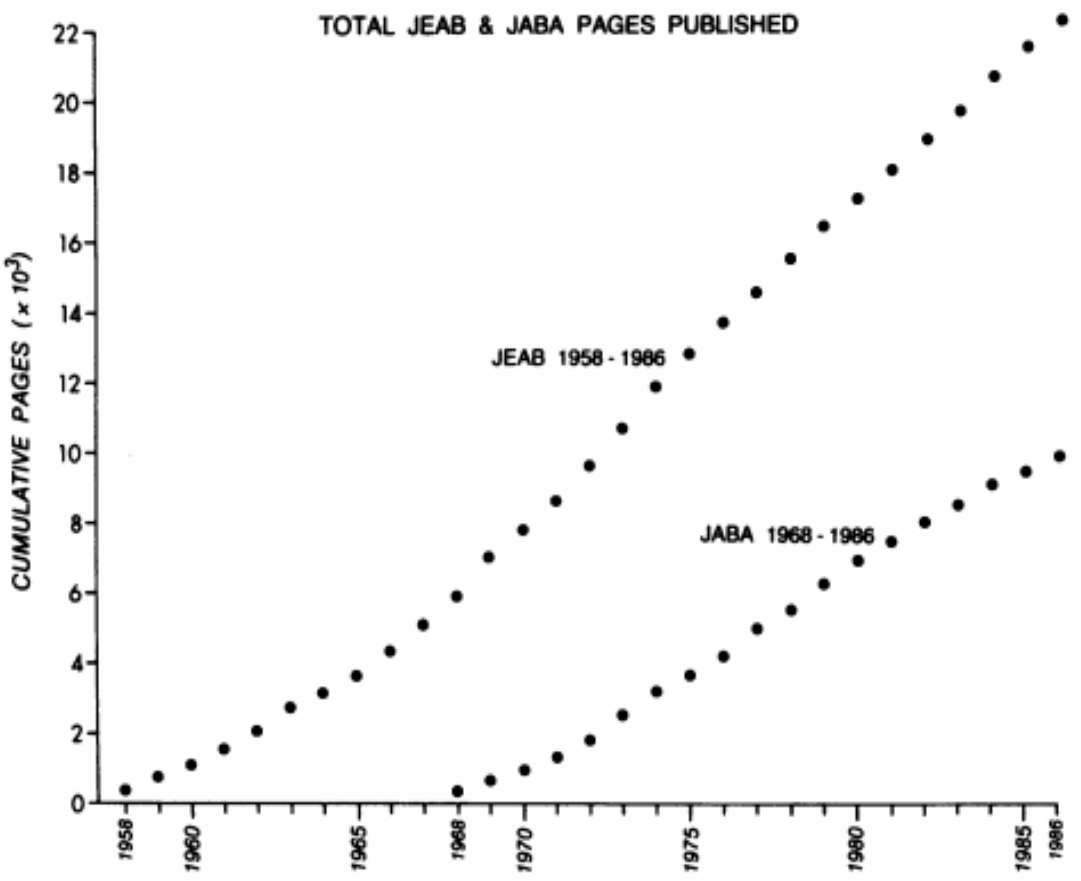

Figure 7: Cumulative pages published by the Journal of the Experimental Analysis of Behavior (JEAB) and by the Journal of Applied Behavior Analysis (JABA) between 1958-1996; taken from: Laties, 1987: 511.

Psychologists (particularly behaviorists and other personality psychologists after 1930) transformed self-determination into a product of disciplinary production that disabled people could never "own" but could/"should" spend their lives "working for" or laboring toward. As long as disabled people learned to be "compliant" with the behavioral expectations of the owners of disciplinary production, and "worked

for" the professional ambitions of their (behavioral) managers, they could earn "personal" (not political) experiences with self-determination in lieu of wages and/or any form of compensation/reparation for the disciplinary structures built on their backs. "Self-determination" became a "valuable" concept for social workers, psychologists, and medical superintendents working to secure their professions by white-washing/erasing the intergenerational traumas these forms of biopolitical surveillance, environmental and behavioral control actually "function" to produce and perpetuate.

After WWII, between 1940-1960, the Frankfurt School of Sociologists (highly influenced by psychoanalysis after many fled to the U.S.) were personally/politically invested in understanding "the origins of totalitarianism" and "authoritarian personalities" as they impact group (ex. families, communities, states, etc) compliance with state politics--ex. Nazism or Eugenics--and the "psychological aspects of social control, delusion and conformity" more generally (Adorno, 1950; Arendt, 1951; Fromm, 1957). Heralded by the death groans of the Eugenics Movement, post-WWII sociologists--reviving Marx's conflict perspective on social problems in the company of psychoanalytic theory while transitioning into the second half of the 20th Century--were attempting to analyze the conditions under which mass conformity and behavioral compliance is produced; how authoritarian or "total" behavioral control over populations is achieved. As sociologists who narrowly escaped the Nazi regime, they were not willing to accept/believe that Nazism and the Eugenics Movement were the effects of "self-caused" or "self-determined" actions,

individuals acting out of their own volition. The issue at hand for these critical thinkers--after witnessing the collective, international traumas of Nazism, and the Eugenics Movement upon which it depended--was not personal deficits in self-determination (psychology), but the problem of "social control."

Michael Wehmeyer Lecture: "Defining Self-Determination"[224]

> Let me speak for a moment about **what self-determination is not** so that we can kind of move past that. People tend to equate self-determination as meaning something other than self-caused action. And in fact, when you think about the meaning of the english word determination, you get a sense of why those misunderstandings occur. **In the english language, determination can refer to:**
>
> 1. **A judgement or a decision**: so a judge determines a sentence, hands it down, makes that judgement. So self-determination could in fact mean making a decision yourself.
>
> Or, "determination" also in the english language refers to this idea that:
>
> 2. We persevere, we keep after it, we go for it in spite of, you know, barriers, we're persistent, we're determined. So self-determination can refer to that **characteristic of being persistent.** And in fact, self-determined people probably do make decisions more than people who are not very self-determined and they probably are more persistent.
>
> **But, neither of those really get at the root, you know.** ***The broader meaning of the term relates to this notion of self-caused action; so it's not just about making a decision and it's not just about keeping after something and being persistent.***
>
> Now one of the things that people think of when they think of issues of self-determination is this **notion of control.** And they begin to equate self-determination as meaning control. ***And that, I think, is something you see a lot in the disability… in fact, if you listen to advocates, people with disabilities, talking about this, you'll hear that kind of language. They talk about "we have the right to control our own lives and our own destinies." But what you have to recognize is that its really more using that in the political sense of the term [self-determination]. And, its not very helpful if we understand the personal sense of the term in that way because first of all its inaccurate; and secondly its limiting.*** Because, you know, when self-determination is equated with control at the personal level um you know that typically… when you think about controlling your life what does that imply:

[224] Michael Wehmeyer, 2011

you're making complex, difficult decisions, right? You're solving difficult problems, you're engaged in a number of cognitively complex behaviors. And really, whether its accurate or not, ***when you begin to think about people who are in control of their lives you begin to equate that with people who are quite capable; and, you begin to think about people who don't have as much capacity as perhaps not being able to be very self-determined.***[225] ***You know, the notion that if you can't solve complex problems; does that mean you can't be self-determined? It probably means that you can't really be in control of your life; if, in fact, anyone is in control of their life***[226]***, but that's not today's argument. So the problem is that when we think about self-determination as control fundamentally we are limiting the degree to which this is applicable to a wide array of people, in fact, all people. There are some people who simply will never be in control of their lives.***

Now there's a somewhat pedantic and narrow argument that talks about what "control" really means. Control really means **having contingency over outcomes in your life,** is what control is really about. And, **so that you can make happen what you want to make happen. But it's that contingent, *you* are doing that. Whereas self-determination is about self-caused action. Self-caused, not doing it necessarily yourself.** So, a psychologist writing about this issue, Edward Deci, whose written extensively about self-determination in general psychology and mainly as a feature of the internal motivation of people. [He] says **you can instruct somebody,** you could say: you will get a candy bar if you wash your face, comb your hair, and brush your teeth right now. **And that person could control the outcome** of getting a candy bar **by doing what was required, right?** So you have control. **And yet in no way does that reflect self-caused action or behavior. That is other-caused action.** You are acting in a certain way because somebody else told you to do this. ***And if you spent ANY time in institutions for people with developmental disabilities, or group homes, or other congregate settings, you see these kinds of contingency kinds of things--do this and you will do this--and you begin to get a sense of what a controlling environment many of these places are. The control being really on the part of the professionals and those people who are trying to provide the kinds of support and services in those kinds of settings. And so, you know, there are, we could come up with other examples, but fundamentally being self-determined really has***

[225] Here is a clear demonstration of ableism (ie. only nondisabled people have the capacity to experience control over their lives). The collective imagination of an individual who is in control of their own lives is always an ablebodied/nondisabled person in Wehmeyer's estimation here.

[226] I would argue that Wehmeyer's concept of "control" is skewed by ableism. By ableist standards, some people are "in control of their own lives" and/or "self-cause" their actions in this ideal form of "self-determined" behaviors. When ableism is removed from the equation (ex. No action is "self-caused" all actions are social actions; independence is a myth, interdependence is life), Wehmeyer's concept of "self-determination" in terms of "control" is shown for its cultural bias. Why are disabled people measured against an impossible ("if in fact anyone is") and ableist standard that is clearly unattainable for anyone (disabled or not)?

nothing to do with being in control. Its causing things to happen in your life.

In Wehmeyer's attempt to define "what self-determination *is not*," his cultural bias and commitment to ableist concepts of "individualism" and "independence," grounded in Western doctrines of determinism, become more apparent. As a sociologist, I struggle to imagine an example of what Wehmeyer would consider a "self-caused action" (even in my own life!) whereby individuals, disabled or not, go about "causing things to happen in [their] life" supposedly "independently, free from undue external influence or interference." In the sociological discipline, there is no "functional" segregation of "other-caused" from "self-caused" actions--all actions are "social actions" because they do not and cannot exist in a vacuum[227]; because they are always socially-situated and/or learned (ie. socialization). The "father" of the functionalist paradigm in sociology, Emile Durkheim (1858-1917), attempted to demonstrate this "social fact" by way of what many (especially psychologists) would consider *the most* "individual" action possible: suicide. As a matter of fact, Durkehim wrote *Suicide* (1897)--the same year "Pavlov's Dog" became one of the most infamous behavioral experiments of all time--in an attempt to prove the absolute indisolvability of the relationship between the individual and society to emerging psychological disciplinarians in France and as a postitivist demonstration of the "rules

[227] No experiment, behavioral or otherwise, can "control" for all external influence, interference, and/or researcher bias. Controlled experiments are not social vacuums, they are saturated in cultural assumptions and socially constructed by virtue of being "controlled."

of sociological method" (1895). Early behaviorists' laboratory experiments attempted to "control" environmental stimuli at the same time that they imposed their disciplinary techniques as a "controlled environment" for the observation of behavior. Even 21st-century psychologists invested in behaviorism, social psychology, social learning theories, and developmental cognition recognize that actions are always situated in an environment and thus "conditioned" and/or learned to varying degrees.

Since the 1890s, but particularly with the advent of WWII, behaviorists--particularly Applied Behavior Analysts--have focused on how to condition individuals ("brute or man") to internalize socio-disciplinary rules of behavior (ex. "Quiet Hands"[228]); whereas, sociologists have sought to analyze how groups are socialized to become "docile" and/or compliant "by/for" disciplinary authorities (ex. where Totalitarianism & Total Institutions meet).[229] While both disciplines recognize the power environments have to "shape" behavior (individual) and "guide" action (social), psychology (behaviorism and ABA, in particular) attempts to "condition" (control/modify) behavior while sociology attempts to "situate" (position/account for) actions. Each discipline is invested in the eco-paradigm shift discussed previously[230]; however, the "problem" each identifies differs substantially. Psychologists argue that the problem is individual/behavioral; whereas, sociologists argue that the problem is one of social structure/situation. Psychologists and Applied Behavioral Therapists

[228] Bascom, 2012
[229] Here, I am attempting to bring Julia Bascom, Cal Montgomery, Erving Goffman, Hannah Arendt, Michel Foucault, and Ole Ivar Lovaas into conversation.
[230] Recall the eco-paradigm shift in which I situate neurodiversity and the social model of disability as well

take "control" by conditioning behavior with/by "controlled environments" (laboratories, institutions, "special" classrooms, group homes, etc.). Sociologists analyze how power is distributed unequally by authorities with the power to control environments (ex. Behaviorists, guardians/conservators, institutionalists, etc.). The "solution" in each disciplinary case of the "problem" is also different: psychologists solve the problem by changing and/or normalizing individual behaviors; whereas, sociologists solve the problem by changing and/or deconstructing social structures, relations of power, rules and rituals of interaction. It is unsurprising, then, that the Social Model of Disability emerged from the field of sociology[231] (not psychology) during the 1970s and has "worked for" disability advocates and movement leaders in their efforts to compel psychology--as one of the dominant disciplinary structures in the lives of neurodivergent people--to alter its methods (ex. deinstitutionalization).

"Social action" is a fundamental tenet of the sociological canon that clearly distinguishes it from psychology. Action is never simply "individual" or "independent," it is always socially "situated," and "interacting" with/in and/or conditioned by existing/changing relations of power/knowledge (Weber, 1922; Haraway, 1988; Foucault, 1980). Beyond sociology, Third and Fourth World scholars have argued for generations that "self-determination," and "sovereignty" (more specifically), rest upon a fundamental rejection of the Western concepts of "independence," "individualism," and "self" upon which colonial notions of

[231] Mike Oliver (1981, 1990) coined the Social Model of Disability only after his work with UPIAS (Shakespeare, 2010; 2013). The Social Model of Disability has, from its disciplinary debut on, been a concept grounded in social movement action and organization.

"progress" are built. Psychology appropriated the concept of "self-determination" after WWI to perpetuate and concretize their efforts to colonize disabled populations in the U.S. and to produce a system of dependence that could "protect" or contain disabled populations' "freedoms:"

> Though **colonialism** has been defined in various ways, a common element in those definitions is ***domination and exploitation, usually by an alien (foreign) power.*** Domination alone can cause violations of the most essential human rights, including freedom and equality, but **colonialism also typically causes a particular violation of the norm of self-determination**. There are many variations of colonial governing structures that excluded the colonized population. The foreign power may, for example, establish a governing structure by putting a foreign 'king' in place or even set up a 'democracy' while disallowing or devaluing the dominated population's vote. When put in place without meaningful participation by the dominated group, these types of systems deny the colonized peoples' right to self-determination. They are denied, to use the words of the United Nations, the right to 'freely determine their political status and freely pursue their social, economic, and cultural development.' In the context of self-determination, ***it is this suppression of the right to participate that makes colonialism a violation of the norm of self-determination***. (Roy, 1998)[232]

Psychologists', social workers', social welfare agents' and "special" educators' gradual appropriation of the concept of "self-determination" as a form of "personal" "*autonomy, self-regulation, psychological empowerment, and self-realization*" since the early-mid 20th-Century--as cited by Wehmeyer and in connection with both World Wars--only functions to pervert the concept, to control (ie. prevent) and colonize social movements for personal/political self-determination that challenge Western/colonial ("neurotypical") notions of "progress."

[232] Roy, Audrey Jane. (1998).

Even Wehmeyer refuses to listen to disabled people and/or movements led by disabled people demanding personal AND political self-determination when he repeatedly:

1) omits the past-in-present history of the trauma caused by institutions and professions he openly admits continue to this day to cultivate "undue" control over the bodyminds of disabled people within their confines; and,

2) appropriates concepts of "self-determination" as "personal" (psychological) in service of professional ambitions (disciplinary production) that "function" to delegitimize the (personal/)political self-determination practices of disabled people (disciplinary subjects).

Wehmeyer fails to presume the competence of disabled people--as a political minority population of the U.S.--to self-advocate and/or self-determine the conditions of their own community-based deinstitutionalization, reparation, and/or liberation. He reduces the entire history of globally intersecting movements for self-determination to individual "control" issues, medical (disability) and/or personal (psychological) problems--functionally white-washing/erasing by medicalizing/pathologizing their existence as legitimate socio-political movements.

In effect, Wehmeyer's concept of "self-determination" will then "function" to reproduce systems of dependence and the disciplinary subjects upon which those non-/for-profit systems depend for their possibility of existence and potential population control. In Wehmeyer's appropriation,--and, Wehmeyer is only one representative in this type of disciplinary production--"self-determination" is commodified and de-

politicized so that it can "function" as a disciplinary product only obtainable by way of disciplinary compliance. While the DNA-identifying leaders at ACAT have studied Wehmeyer's work and mobilize much of the same language, they teach self-determination skills as a "practice," not a product or "thing" that could ever be standardized, possessed, or owned. As Tania Coffield pointed out during an interview quoted earlier in this chapter: "***I just don't think of self-determination like um… a thing****, so much as a list of words that you are working on.* ***Not something you ever achieve, but something you are always constantly doing."***

At ACAT, self-determination is a "neurodivergent practice" that can "work for" the liberation of I/DD student/clients. A "liberation" from systems of dependence that force disabled and neurodivergent people to pursue (and often inevitably fail in their pursuit toward) neurotypical goals, roles, and/or expectations built upon and measured according to exclusively neurotypical competencies. NEM-trained staff and I/DD student/clients work interdependently toward making what I call "multiple possible futures" accessible and to resist medico-legal foreclosures upon possible neurodivergent futures. By interdependently claiming safe spaces for community-based practices of neurodivergent self-determination[233]--a process that requires the collaboration, cooperation, and participation of all involved in the community space,

[233] Here, I seek to draw parallels between indigenous movements to "p/reserve" and claim land/sacred spaces for future generations--often misappropriated by state authorities as a "right" reserved for a minority population and/or "privilege" preserved by the state--and disabled people's attempts to gain access to society, to desegregate spaces and make them accessible (not just physically) to disabled and neurodivergent people who cannot conform to neurotypical/Western standards of progress and productivity and who challenge eugenics by claiming a "right" to futurity, and multiple possible futures.

whether I/DD student/clients, ACAT/ACT staff, community members, and/or public/private authorities--I/DD student/clients can safely explore the possibilities of having "*the agency to create their own lives and create their own situations"* (Brent White, ACAT/ACT Director/Designer).

ACAT/ACT's Neurodivergent Self-Determination Practices

STEP 3: <u>Training in Self-Determination Skills and Personal Responsibility</u>

Excerpt from a Collaborative Document[234] Outlining and Defining NEM:

> *"Through the lens of the medical model, special education and other state providers create narratives of presumed incompetence. Neurodivergent people are framed as helpless and needing the protection, paternalism and pity of the state. Under these systems, which lead to learned dependency, neurodivergent people are denied agency, supports that enable informed choice, and the right to imagine multiple futures for themselves. Institutionalized and/or segregated spaces treat neurodivergent people's bodies as public property. [1]*
>
> *NEM presumes neurodivergent people are competent to make personal choices about their own lives, even if their choices are counter to the wishes of families, caregivers, and/or state provider "specialists." Supporting the transition of neurodivergent people out of systems of dependency, NEM's practices create spaces and situations within community settings in which people are provided opportunities to confidently make choices, problem solve, risk and fail. Risk and failure are essential elements of personal growth, empowerment and self-efficacy. NEM presumes disabled bodies have the right to privacy, personal space, and self determination. The component skills of*

[234] Brent White, Tania Coffield, "Joan" and I collaborated to compose a document defining the four major parts of NEM. The contents of the document came from group discussions in the weeks prior to a speaking engagement where ACAT/ACT would be presenting their work. My role was to help them put all of their ideas into words. We completed work on the document in December, 2018.

self-determination are woven into every aspect of the community-based program's structure. [2]

The Component Skills of Self-Determination include:

- *Choice Making*
- *Decision Making*
- *Problem Solving*
- *Goal Setting and Attaining*
- *Self-Advocacy*
- *Self-Regulation*
- *Self-Awareness*
- *Personal Responsibility*
- *Self-Efficacy [3]"*

To "presume competence" is NOT to pretend that a person can independently "control" all significant variables affecting their life in order to ensure a specific and personally desirable outcome. To do so would be, to paraphrase Wehmeyer, to "equate" control with able-body/mindedness (ability/capacity); an unfair and patently untrue (ableist) presumption for anyone, disabled or not. What Wehmeyer, medical practitioners, special educators, and service providers so consistently and uncritically fail to do is to draw relevant distinctions between "control" and "power." Highlighted by ACAT/ACT leaders in the excerpt from our collaborative document above is the medical model's neglect or conflation of critical sociological distinctions between

"power,"[235] "legitimate authority[236]" and "coercion/domination[237]" as outlined by classical social theorist Max Weber (1922, 1958); and, in Michel Foucault's genealogical analyses of the "productive" relationship between "power" and "knowledge" in the context of disciplinary and biopolitical forms of governmentality (1980; Dean, 2009).

Unlike practitioners of the medical model of disability, ACAT/ACT's neurodivergent model of self-determination presumes the competence of I/DD student/clients in all areas of their life. To presume competence is not the same as subscribing to "boot-strap"-style, "rugged individualism" or a Western notion of "independence" built upon hierarchical categories of "in/competence":

> '**Competence**' is the capacity or potential for adequate functioning-in-context as a socialised human. It is generally taken for granted and axiomatic. In this definition, *capacities, potentials, and adequacies* are to be understood as socially constructed and ascribed--and hence locally variable--rather than 'objective' attributes of persons. *Axiomatic* suggests that the competence of most individuals is not in doubt until it *is* in doubt: in the absence of evidence to the contrary,

[235]Weber defines "power" as the capacity (access to the resources needed) to carry out a social action even in the presence of resistance. "Power" resides in "legitimacy"--subjects' perception of the "legitimacy of authorities" distinguishes "power" from "coercion," "domination," and "control" (Weber). "Legitimacy" is often a production of discourse--ex. law and science (Foucault). Foucault's discursive and genealogical analyses demonstrate how modern power has been decentralized (killed the king for the state); and how the knowledge and/or force ("power/knowledge") to "control" populations via processes/technologies of "normalization" produce "regimes of truth" (legitimacies) with the capacity to "discipline" entire populations (Weber, 1922, 1958; Foucault, 1995, 2004).

[236] "Legitimacy" distinguishes "power" from "coercion" and Weber identities three ideal types of "legitimate authorities" in modern bureaucratic societies (West) that do not require "coercion" in order to exercise "power": traditional, rational-legal, and charismatic authorities.

[237] A form of "power" that is taken by force or by the threat of force (ex. violence) without consent of those who would be subject to it and thus considered by them an "illegitimate" form of authority. Discourse can be mobilized to "legitimize" forms/practices of "coercion, domination, and control" as "normal" and/or "natural;" thus, neutralizing subjects' resistance to their discursive practice—ex. Psychologists mobilizations of "science" in advocating ABA and/or "cures" for autism as normal and natural uses of disciplinary power; versus, ASAN and other Autistics' resistance to ABA and refusal to acknowledge non-Autists as legitimate authorities in determining the "naturalness" or "normality" of Autistic ways of being in the world.

> competence can be presumed, by self and others. ***In all local settings there are, however, those to whom the presumption of competence is not extended or from whom it has been withdrawn. That they must strive to be competent--more accurately, to be seen to be competent--is among the most telling indicators of their exclusion from the fellowship of competence***… **Categorisations of incompetence** may ***have historical affinities with other categorisations of persons.*** In any local cultural context, what it means to be 'properly' human in the abstract, and the particular meaning(s) of individual human-ness, are typically the taken-for-granted bedrock upon which mutual sociality is constructed. But human-ness is socially defined and culturally variable. ***Doubt--or more than doubt--about the full humanity of some individuals or collectivities appears to be common. Historically, cross-culturally, and in our own backyards today, there are many instances in which individuals and collectivities have been, or are, denied their full humanity by others.*** A familiar case is racism. Here members of entire social categories are defined as inhuman or as inferior humans and treated accordingly.[238] The categorisation of persons as fundamentally incompetent has, indeed, some things in common with racism[239] [and, colonization]... ***In the contemporary world local political economies of (in)competence are… [as in a case study in Belize] located within wider racialised hierarchies of dependency and underdevelopment that have their roots in colonialism and empire.*** (Jenkins, 1998: 1-4).

Historically, Western medical models for "presumptions of incompetence"--whether they be nose shapes/sizes, skin pigmentations, spiritual beliefs/practices,

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[238] Consider here, in relation to Jenkins (1998) work on "in/competence," Sylvia Wynter's work on "Unsettling the Coloniality of Being/Power/Truth/Freedom: Towards the Human, After Man, Its Overrepresentation--An Argument" (2003).

[239] "Historically, ever more precise definitions and measurements of both incompetence and 'racial' difference were central to the burgeoning science and statistics of 'normality.' 'Racial' Otherness was equated or associated with incompetence or inadequacy, as in the typification of Down's Syndrome as 'mongolism,' and in the nineteenth-century ethnic classifications of mental degeneracy and idiocy. In the twentieth-century there has been an even more consequential history of the racialisation of intelligence and competence. Inspired by Galton and the eugenic vision, the pursuit of 'racial' fitness was taken to the point of mass extermination. 'Racial' fitness, entangled with notions about individual incompetence, produced Nazi euthanasia programmes. Less dramatically, in the contemporary world local political economies of (in)competence are… [as in a case study in Belize] located within wider racialised hierarchies of dependency and underdevelopment that have their roots in colonialism and empire. This may result in axiomatic presumptions of 'racial' incompetence" (Jenkins, 1998: 2-3)

chromosomal patterns, test scores, economic development scales, etc[240]--have been mobilized in colonial efforts around the world for centuries to dominate, exploit, and violate norms of political "self-determination" that emerge with/against (ie. in resistance too and as a condition of dehumanizing) processes of colonization[241].

Many colonized peoples around the world have--especially during/after the World Wars and movements to Decolonize Africa--mobilized "self-determination norms" as "human rights" in their efforts to gain political and national independence from their colonizers. Decolonization movements share a rejection of Western- and/or medically-imposed presumptions of incompetence (so often coupled with racism and sexism) by way of socio-political demands for independence and self-determination--which include re/defining local "competencies" via local authorities (Jenkins, 1998). This also means, colonized peoples of the world have been struggling (for centuries now and across different continents) to reject or refuse the internalization of medico-colonial (euro-/US-centric) labels identifying them with collective forms of psychological, intellectual and/or spiritual deficiencies (Fanon, 1952; Benjamin, 2016). I argue that "colonization"—characterized as it is by efforts to dominate, exploit and violate norms (now, UN sanctioned "human rights") of self-determination—is built upon the imposition of culturally-biased (ie. supremacist) presumptions of incompetence (racial, intellectual, spiritual, biological, etc. inferiority) that "function" to medico-legally trans-substantiate political movements

[240] Phrenology, Eugenics, Racism, Environmental Racism, Religious/Spiritual Persecution, DNA-testing, IQ testing and/or adaptive behavioral scales, IMF-regulations, etc.
[241] Processes built upon denying colonized populations due rights of self-determination; let alone, the kinds of self-determination they may have known prior to colonization.

into “personal” (biological, psychological, intellectual, spiritual) deficits; or, disability. The trauma-/responses that become part of the lived experiences of generations of colonized peoples--as a consequence of being “stripped” of their self-determination--are then “white-washed” by colonizers as “evidence,” “positive proof,” or “symptoms” of a “pre-existing condition” of pathology among colonized peoples and mobilized to justify colonial (permanent disciplinary) occupations (Goffman, 1963; Thunder Hawk, 2007).

Self-determination emerged historically as a concept concerned with political “independence” as it pertains to *a group* of people, a nation, or “tribe,” so to speak--it is a concept with far more sociological (groups) than psychological (individuals) valence and critical relevance (Silberman, 2015). Historically speaking, nothing about the concept of “self-determination” is about a single individual’s capacity to exert “control” over others, despite Wehmeyer’s attempt to speak for/against political goals expressed by disabled advocates. Self-determination, as a historically and culturally situated concept, has always referred to a collective who are subject to colonial (non-local) forces. Since at least the 16th Century, colonial forces have mobilized the dominant (Western) science-of-the-times to question the competence of politically marginalized groups (ex. Colonized and/or Enslaved) over whom they seek to exercise a power without local (ie. legitimate) authority; to conduct ”empirical” imperial experiments in “coercive,” “colonial,” “tyrannical,” and/or “totalitarian” forms of power (Weber, 1922; Arendt, 1951). Intellectually and/or developmentally disabled communities--the members of the neurodivergent community “most

impacted" by intersecting "historic systemic oppressions," that particularly converge in "ableism"--are currently (and have been since at least the 1840s in the U.S.) a colonized or occupied people with no homeland outside monolithic institutions. Without roots in what Western authorities recognize as "property" (land), I/DD communities are thus ascribed no human (innate) "rights" to *political* (unappropriated) self-determination (Hartman, 2008). I argue that to understand the historic and systemic oppression of the "most impacted" members of the neurodivergent community, and the political necessity for a neurodivergent model of self-determination, requires a decolonial or anti-colonial perspective.

Neurodivergent Self-Determination: "How We Start"

> "**Self-Determination** is about *empowerment* and *agency*; the right to one's own choices, hopes, dreams and future. Self-Determination practice is infused into the structure of all program activities"
> (ACAT/ACT, "Our Philosophy": 2018; original emphasis).

Excerpt from an Interview with the ACAT/ACT Programs' DNA-Identifying Director, Brent White (BW)

LH: So… One of the first lessons in NEM is that your body is private, personal and self-determined. And that's why you teach "no" and personal space?

BW: *I think wrapping self-determination around the body-centered part is super interesting! I hadn't really thought of it that way before... Well... I*

mean... We talked about ***how we start*** *[teaching self-determination skills], you know:* ***this is your body, this is your space around your body, where teaching self-determination starts with an individual's body.*** *But, I hadn't really thought about putting those two things together.* ***Because it's one body; but, it's also groups of other bodies****. It makes the body...* ***it takes the body and makes it more private, as opposed to the medical model which makes the body public.***

...

BW: *Yeah... I love the way you [Laura] put those things together...* ***I wanted to talk about us being non-touching [too].*** *Which I don't think we ever mentioned in here*[242]*, but I think is also a pretty radical statement. Which could go into that [Self-Determination] part; or, could go into the trauma part.*

Teaching "self-determination skills" to neurodivergent adults "starts" from a conversation about bodies:

Lesson #1 for I/DD student/clients: bodily sovereignty; and

Lesson #1 for CBTIs is: no touching[243].

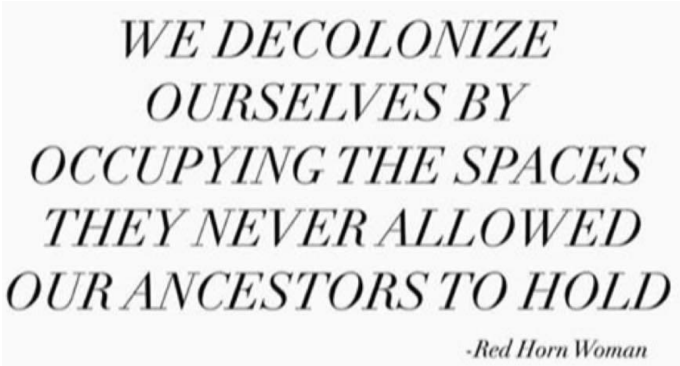
[242] Referring to our Collaborative Document
[243] Exception: fist bumps and/or hand shakes.

These two foundational lessons bring the legitimacy of neurodiversity, trauma-informed perspectives, and self-determination skill training together by drawing attention to the medical model's appropriation of self-determination as a technology of power.

I/DD student/clients attempting to transition out of "special" systems of dependence have spent 18-plus years living under presumptions of incompetence that deny their most basic rights to bodily integrity and sovereignty. Disciplinary behavioral experts train teachers, parents and other authorities (ex. doctors and police) to presume I/DD student/clients are too incompetent to make informed decisions about their bodies or their futures. From youth, I/DD student/clients are taught to believe that they do not possess the independent rights to determine the conditions of their own bodily integrity. Under practically ubiquitous conditions of forced compliance (in group/homes, in hospitals, in schools, in programs, in their local communities, etc), I/DD student/clients enter adulthood more often than not without "rights of refusal," under the guardianship/conservatorship of a non-disabled adult who does have such rights, and with the knowledge that saying "no" is considered a symptom of a "behavioral" issue; and thus, a punishable act of "non-compliance." "Liberty" for adult I/DD student/clients today is utterly conditional and compliance-dependent despite the history of "deinstitutionalization."

The goal of self-determination training is not to teach adult I/DD student/clients that they can "choose" to become independent of systems of dependence—this would be a set-up for failure because I/DD student/clients do not

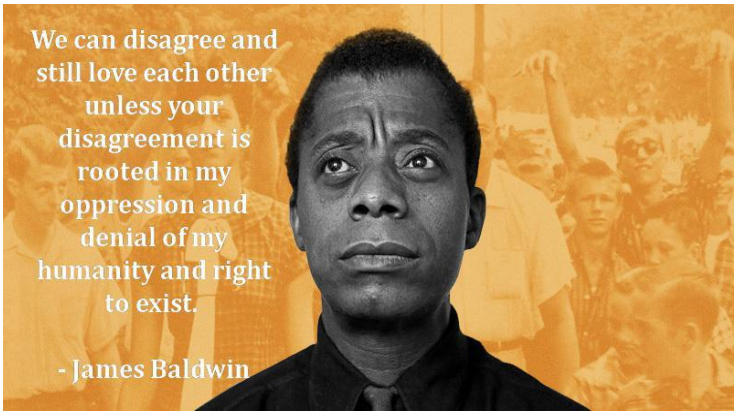
have this "choice" any more than any other politically marginalized community—but that they can interdependently, relationally, and accessibly "disrupt" these systems as they see fit. The goal is to "***occupy***" community spaces where adult I/DD student/clients can practice self-determination skills--choice-making; decision-making; problem-solving; goal setting and attainment; self-regulation; self-advocacy; self-awareness; personal responsibility; and, self-efficacy--and learn about risk and failure without threat of punishment ("positive" or otherwise). This "occupation"[244] makes it possible for adult I/DD student/clients to share *relational* experiences of "empowerment" and "agency" with their peers.



CBTIs are always present, not to dictate behavioral expectations, but to interdependently navigate community-based access barriers with (not for) adult I/DD student/clients. This *interdependence* "makes space" for neurodivergent self-determination practices to "take-up" space where they would otherwise be grounds for exclusion at best, and violence/death at worst. In this practice, CBTIs only act as a barrier between I/DD student/clients, punishment, and/or (re-)traumatization. CBTIs

[244] I use this term in two senses: taking-up space in non-normative ways and a working career. Block, Kasnitz, Nishida, & Pollard, 2016.

"work for" adult I/DD student/clients; but, CBTIs do not "protect" adult I/DD student/clients from risk and/or failure. CBTIs are not "bodyguards." Opportunities to take risks and potentially fail--ie. to try something new (risk) and possibly mess up (fail)--are critical to learning the limits of self-determination in community settings where "it's one body; but, it's also groups of other bodies." Whether situated in communities of their peers or strangers, practicing self-determination is "not a free for all," as Brent would often say to remind everyone that self-determination does not mean you can do whatever you want without any consequences or response from others. Just as NEM opts for relational (group), practice-based learning over a standardized or overly-individualized curriculum; neurodivergent self-determination training under NEM is not conducted in segregated classrooms, but in actual community spaces where "we must live" self-determined lives together, interdependently.[245]



[245] Western political economists would typically reference the "social contract" here--perhaps questioning I/DD student/clients "competence" to make such a "contractual" commitment in organizing their exclusion/segregation from the "commons"/"contract." Given the institutional history of the I/DD community, I would argue that a better model comes from indigenous notions of "sovereignty" and/or critical race theories of "justice" which privilege self-determination only so far as it does not impinge upon the self-determination of others with the same living privilege: "We can disagree and still love each other unless your disagreement is rooted in my oppression and denial of my humanity and right to exist" (Jones, 2015; aka. Son of Baldwin).

It is through their bodies that adult I/DD student/clients begin to practice self-determination skills. The first lessons adult I/DD student/clients learn at ACAT/ACT is that their bodies are their own: bodily sovereignty. As they begin the (potentially life-long and/or unending) process of transition--out of segregated systems of forced dependence and compliance, into community-based program activities with their peers and the possibilities of independent living--adult I/DD student/clients are encouraged and prompted (often for the first times in their lives): to say/communicate "no" when desired, to *refuse* what they do not want, and to *practice* self-determining daily activities in *relation* to their neurodivergent peer-group[246], instead of traditional, neurotypical authorities. In addition to learning accessible ways to communicate "no," adult I/DD student/clients learn methods of protecting their "personal space"[247] (often conceptualized as a two-foot circumferential space surrounding their bodies). As you can imagine, learning to protect your body and to refuse unwanted touching is absolutely critical to staying safe while in public community spaces. This is also true in "private" spaces (institutional spaces) for I/DD people who are known to experience significantly higher rates of sexual abuse and violence at the hands of people they know well.[248]

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[246] All group members, by virtue of the program's requirements, share I/D disability experiences. In addition to I/DD, most adult student/clients enrolled in ACAT/ACT have multiple disabilities many of which are non-physical (least privileged in the hierarchy of disabilities).

[247] Recall "E" (pseudonym) teaching me this lesson while I shadowed with her group--See "Introduction"

[248] See BJS and other quoted data demonstrating these statistically underreported facts in the chapter titled "Nothing About Us, Without Us" under the "Trauma-Informed" section.

With some awareness[249] of the rates at which I/DD communities are sexually and otherwise violently traumatized--predominantly by people they know: caregivers, support staff, and family members--CBTIs are first trained in ACAT/ACT's "NO Touching" Rule[250]. I always liked referring to the "No Touching" Rule as ACAT/ACT's "Anti-ABA" Policy. CBTIs are NOT allowed to hug, intimately touch or restrain any adult I/DD student/clients, even if such touching is requested by the student/client or their guardian/conservator. The "no hugging" and "no restraint" aspects of this rule are especially "radical" among service providers; and, oft points of criticism lobbied against ACAT/ACT staff by community members who believe it normal/necessary to literally physically coddle or restrain I/DD adults showing signs of distress[251] or experiencing a "meltdown."

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[249] Some CBTIs learn about these statistics during staff and leadership meetings; other CBTIs learn about this reality from the adult I/DD student/clients whom they serve. As mandated reporters, CBTIs listen carefully when ACAT/ACT student/clients describe their lived experiences with sexual and other violence. Most are sure to ask clarifying questions so as to have as much information as possible before reporting. This is often a difficult decision for CBTIs when they have no control over how that report will affect their adult I/DD student/clients; especially when the reported perpetrator is a guardian/conservator.

[250] This is a rule that applies to CBTIs and those who violate this rule are subject to termination of their employment. This does not mean that I/DD student/clients can't hug people; it only means they cannot hug their CBTIs. This does not mean they cannot express affection and/or appreciation to their CBTIs physically. Again, exceptions are: fist-bumps and/or handshakes. In addition: in the event of imminent danger (ex a car bent on hitting a student crossing the street), CBTIs are expected to move the student out of harm's way by whatever means necessary. If there is time for communication: great; if not (ex. Speed of car): CBTIs are allowed to grab the student and pull them to safety. Without the clear presence of danger and/or bodily harm, however, the NO touching rule stands. This is not a rule to control I/DD student/clients—it is a rule for CBTIs to enforce upon themselves and for I/DD student/clients to observe in the process of learning self-determination skills.

[251] In most programs for I/DD children/adults, staff are trained to practice the methods of ABA which not only promotes things like "positive" hugging; but, also restraining I/DD children/adults with a kind of hug from behind so that the I/DD child/adult cannot move their arms as an acceptable method of "intervention." According to ABAI (2010): "*Restraint* involves physically holding or securing the individual, either: a) for a brief period of time to interrupt and intervene with severe problem behavior, or b) for an extended period of time using mechanical devices to prevent otherwise uncontrollable problem behavior (e.g., self-injurious behavior) that has the potential to produce serious injury. When used in the context of a behavior intervention plan, restraint in some cases serves both a protective and

However, the ACAT/ACT "no touching" rule works to remind CBTIs that they are "working for" adult I/DD student/clients-- hugging is a friendly, not a professional form of contact--and that student/clients transitioning out of "special" systems have been trained to "comply" with hugging. The power differentials between staff and student/clients must be respectfully demonstrated by CBTIs in order to model for I/DD student/clients how to protect themselves from predatory support workers, in particular. This rule models the line between "friends/family" (safety of equals/peers) and "workers/strangers" (potentially unsafe, unequal power) in the lives of I/DD student/clients--a line that is often crossed/blurred when support staff are allowed to indiscriminately hug adult I/DD student/clients; and, especially when ABAI-advocated hugs resemble ABAI-promoted restraint methods (See Illustration of Prone, Basket and Supine ABAI-advocated restraint "Holds").

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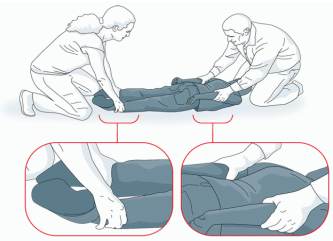
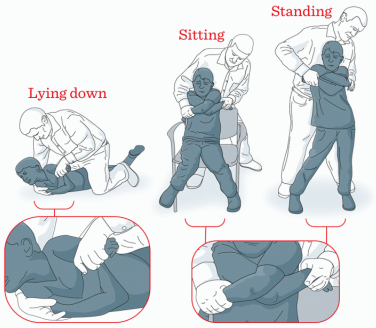
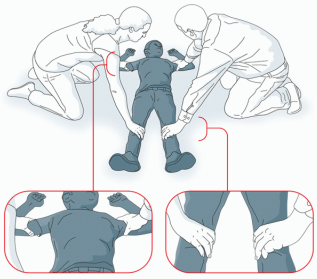
a therapeutic function. These procedures can reduce risks of injury and can facilitate learning opportunities that support appropriate behavior." Again, recall Jen Msumba's testimony in the previous chapter regarding her experience with 4-point restraints. In addition, combinations of restraint, sedation, seclusion, and time-outs from reinforcement are also ABAI advocated practices (Association for Behavior Analysis International, 2010).



Prone Hold



Basket Hold



Supine Hold

When adult I/DD student/clients are taught to "comply" with a hug in place of a hand-shake or a fist-bump, service providers are creating a situation for abuse wherein student/clients do not learn how and/or when to refuse; or, for that matter, that they have any "right to refuse" unwanted touching. Under "ABA-culture," adult I/DD student/clients are taught to believe it is appropriate and "normal" to be touched (ex. Hugged or restrained) by anyone and everyone because they have no right to refuse. In contrast, under the ACAT/ACT "NO Touching" Rule, adult I/DD student/clients learn the difference between, for example: trusted/safe peers, friends and/or family (hugs); their support staff and/or community allies (hand-shake or fist-bump); and, gauging the safety of strangers and/or unsafe acquaintances (personal space).

The goal of self-determination training under NEM--in the combined cases of ACAT/ACT's "No Touching" Rule and community-based lessons in "Bodily Sovereignty," as just one example--is to teach adult I/DD student/clients the self-determination skills necessary to:

1. **Make Choices**: Choose who they might want to hug; and who they "prefer not to."[252]
2. **Make Decisions**: To Decide, based on known information and past experience, to hug someone; or, to refuse a hug.
3. **Problem Solve**: To Recognize when hugging may be problematic/unsafe and know accessible and safe alternatives (ex. fist-bumps, handshakes, personal space, etc.).
4. **Set and Attain Goals**: To create/set personal boundaries they can accessibly hold in place and m/take space for in the moment (ex. Personal space).
5. **Self-Advocate**: To (at minimum) confidently communicate "yes" or "no" to others in accessible and safe ways; even when counter to the wishes of others[253].
6. **Self-Regulate**: To refuse unwanted touching, focus on safety first, and/or to know where to seek access to help/support when needed because controlling others is not possible.
7. **Gain Self-Awareness**: To recognize when they are in un/safe spaces/interactions; and, recognize, avoid, and/or alternatively cope with environmental triggers safely.

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[252] Here, I am intentionally paraphrasing Herman Melville's "Bartleby, the Scrivener" (1853) as an archetype of neurodivergent self-determination and practicing the right to refuse in modern society.
[253] Self-Advocacy is "power"—this example intentionally paraphrases Weber's definition of "power": "Power is the chance to impose your will within a social context, even when opposed and regardless of the integrity of that chance" (1947). As should be clear from this example, this is not an example of control. Self-advocacy is an interactive (always social) form of power/empowerment; it is not the capacity to control yourself or others (recall Wehmeyer's distortion of disability advocates demands).

8. **Take Personal Responsibility**: Taking risks (ex. Interacting with an unfamiliar community member); processing the results of self-determined "risky" choices, decisions or "failures" (positive/negative from their perspective); and, taking action (accept or refuse touch, advocate for personal boundaries, maintain or demand personal space, seek support when needed, etc).
9. **Experience Self-Efficacy**: To actually *believe* they deserve safety, they have the right to be/feel safe, and that saying "no" or "refusing" unwanted touching (hugs are a relatively benign example) does not make them "non-compliant," "incompetent," "deficient," "ungrateful" and/or "undeserving" people.

Despite appearing last on this list, Brent White often emphasized that the ultimate and most important goal in self-determination training for I/DD adults is "Self-Efficacy."

As members of an intergenerationally traumatized community under institutionally advocated presumptions of incompetence and behavioral conditioning norms that routinely deny rights of self-determination, I/DD adults often struggle in moments of opportunity *to believe (or imagine a future where)* others could ever truly respect, honor, or accept their thoughts and feelings about safety; or, that they have any "right" to determine what is un/safe and/or un/abusive to them personally. So often in the experience of I/DD student/clients living under presumptions of incompetence (regardless of age) in the history of the US, abusers are the same people (ex. Institutionally supported "teachers") invested with the authority to

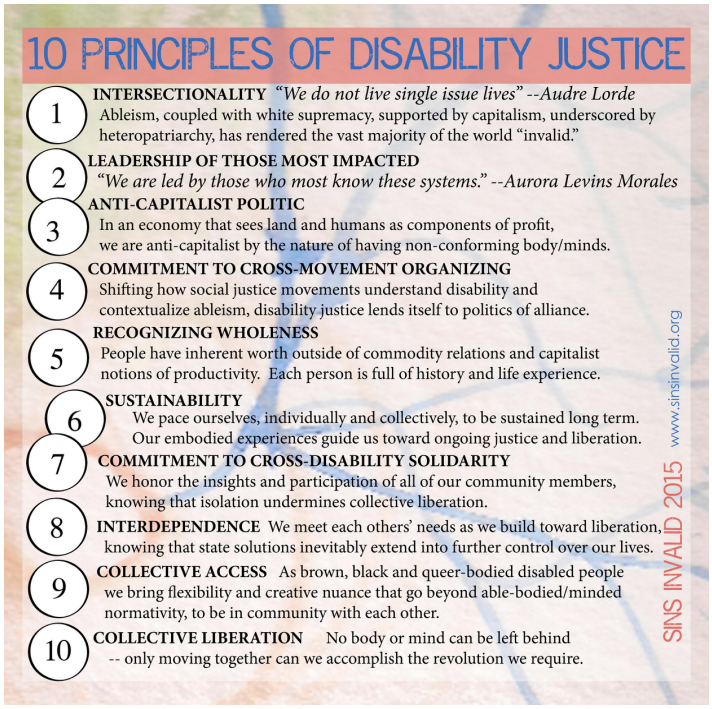
determine for I/DD people what abuse is and is not. I/DD communities are trained via institutional and behavioral conditioning--a lifetime of presumed incompetence under guardians/conservators of various ilks--to believe they cannot make a competent self-determination about safety: their own safety or the safety of others. Without the experience of self-determining personal safety, most adult I/DD student/clients "fail" to recognize when they are in danger or being abused; and, thus, never learn the kinds of self-efficacy skills (belief in "rights" of personal safety) necessary to achieve self-advocacy (power to demand personal/community safety). Everyday abuse/rs become the norm in their lives; and, the kind of future they imagine for themselves is coated in that normalized, lived experience of abuse/rs defining for them the "value/valor" of their "social role" in society (Wolfensberger, 1983).

"The Future is Accessible": "Multiple Possible Futures" Built Upon "Intersectional Interdependence"

Disability Justice Advocate's eighth principle makes political demands for "interdependence:" "We meet each others' needs as we build toward liberation, knowing that state solutions inevitably extend into further control over our lives" (Berne, 2015). This concept of "interdependence" (like "collective access" and "collective liberation") speaks the language of Sociology as a call to imagine a future built upon "social action"--a type of action born from social inter-action ("We meet"); grounded in the historical and material realities of social and community life ("each others' needs"); and, cultivated through relational, shared, lived experiences ("as we

build")--directly opposed to intersecting histories of "social control" ("state solutions"). To begin diverting from the path laid out by "single issue" platforms structured upon colonial legacies of future building, Disability Justice Leaders--distinct from the history of Disability Rights Leaders--demand that "we build" firstly from an "intersectional" politics; and, secondly under the "leadership of those most impacted" (2015).

"Intersectionality"--a concept coined by third-wave feminists to challenge the intersections of race, class, sex and gender as in the works of Audre Lorde, Kimberly Crenshaw, and Patricia Hill Collins--"works for" the decolonization and disentanglement of past-in-present structures of ableism, white supremacy, capitalism, and heteropatriarchy[254]. By augmenting the classic sociological triad--race,



[254] Here, I point to disciplinary leaders who have enjoyed the historic privilege of state sanctioned authority in the denial of the personal/poltical self-determination rights of intersecting disabled, POC, queer and poor populations of the US: Galton, Goddard, Doll, Terman, Skinner, Lovaas, and Wolfensberger are critical examples.
Gibson, Margaret & Douglas, Patty. (2018). Disturbing Behaviours: Ole Ivar Lovaas and the Queer History of Autism Science. Catalyst: Feminism, Theory, Technoscience. 4. 1-28.
https://blogs.uoregon.edu/autismhistoryproject/topics/applied-behavior-analysis/

sex/gender, class--with the addition of disability and neurodiversity, the intersections of white-supremacy, heteropatriarchy, and capitalism can be grounded in a colonial process of ableist "invalidation" (Berne, 2015; Singer, 1999). The personal/political *conflicts* produced by these intersecting processes of invalidation (denials of self-determination) cannot be "functionally" segregated.[255] Nor can these intersecting processes of invalidation be "functionally" ameliorated by medico-legal methods of political assimilation, behavioral control, and/or cultural conformity; for example: applied behavioral analysis (ABA), normalization, social role valorization, and/or "conversion" therapies (Gibson & Douglas, 2018; Lovaas, 1965; Wolfensberger, 1983). Such disciplinary techniques only "work for" a eugenic futurity where the disappearance of difference and the pathologization of personal/political self-determination practices that betray assimilationist agendas produce the conditions for a colonial fantasy of social control and homogeneity. In the past-in-present history of neurodivergent communities of the U.S., institutionalized people who *cannot* conform to the white supremacist, capitalist, and/or heteropatriarchal norm of the free, white, "property"-owning (land, factory, people), heterosexual male have experienced these intersecting processes of invalidation as a barrier to both self-determination and positions of leadership.

Grounded in an "intersectional" political platform, "leaders" of the Disability Justice movement are supposed to be the same people who are "most impacted by

[255] Consider how these intersecting invalidation processes cannot be segregated (can't generally separate racism from sexism or ableism) and how they question "humanness" via "questions of competence," leading anti-colonial abolitionists to ask questions and make statements like: "We are people first!;" "Ain't I a woman?;" "Am I not a man and a brother?;" etc.

these systems" of intersecting invalidation (Berne, 2015; quoting Levins Morales). In the "hierarchy of disability," intellectually and developmentally disabled people unanimously occupy the bottom rungs:

> "Intellectual disability is at the bottom of the disability hierarchy. That is, a great many people who have other types of disabilities actively try to distance themselves from intellectual disability, 'we're not one of them.' People with developmental disabilities might get caught in the overlap as people can have both types of disabilities. The opinions and contributions of people with intellectual disabilities isn't seen as valuable or as important as those of people who have different types of disabilities" (Nichols, 2019).

Some argue that mad/mentally ill communities share this experience of extreme oppression on the bottom rungs[256]. Regardless, Nichols (2019) highlights how the disability hierarchy simultaneously affects both disabled and non-disabled communities: reinforcing ableist privilege within both groups; in addition to "internalized ableism" within disability communities, as well[257].

In the U.S. (and worldwide), intellectually and/or developmentally disabled leaders are incredibly rare--people like Lois Curtis, Elaine Wilson, Tia Nelis, Chester

[256] I would push against this to some extent by pointing to the US cultural imagination of "illness" in "Mental Illness" and the lack of permanence, consistency, and untreatability it implies in comparison to I/D "disability" in the same cultural imagination. I would therefore argue that this variable gives mad communities a "rung" up from I/DD communities in the US.
[257] The more a disabled person can "pass" as able-bodied/minded, the more likely they are to avoid disability oppression and benefit from ableist privilege.

Finn, Betty Williams, Julia Bascom, Cal Montgomery, and a short list of others[258] in the U.S. are the exception, not the norm--and their leadership is relatively unknown (and unknowable[259]) outside their local and/or disability-specific communities. Any record of the long history of I/DD leadership in the US is practically non-existent outside what can be read "between the lines" of institutional superintendent's reports. Sometimes, disabled and/or neurodivergent communities who do not identify as I/DD do "defer" to the authority of I/DD communities whose lived experiences are directly informed by rates of oppression that all other disability and neurodivergent communities are in a privileged position to avoid--as in the case of ACAT/ACT staff. However, I would argue that this "deference" is also a "deferment" that prevents the principles of Disability Justice from mobilizing real cross-disability movement, and diminishes the meaning of "interdependence" in these intersecting movement(s)-making(s).

When "disabled," "neurodivergent," and/or "autistic" leaders (who do not identify as I/DD) "defer" to the lived experiences and expertise of I/DD communities (who are more often "identified" by others than "self-identifying"[260]), the hierarchy of disability remains relatively unchallenged and thus perpetuated, placing "intellectual" (and/or developmental) disability in a perpetual position of leadership deferred. Perhaps this deferment is part of the process of Disability Justice movement-making

[258] Regents of the University of California, Bancroft Library, 2010.
[259] There is a remarkable dearth of information publicly and/or generally recorded and made available about disabled leaders; particularly leaders from I/DD communities. Even when people are interested, the information is often inaccessible. "Word of mouth" is, to this day, the primary locus of information sharing across disability communities.
[260] More on this in the ACAT Case Chapter

and coalition-building; but, this deferral also denies due recognition and respect for the past-in-present value of I/DD communities' labor and leadership. Leaving I/DD people stuck behind barrier-producing questions of "in/competence" in the process of mobilizing Disability Justice--where the "authority" of I/DD community leaders is only "legitimate" when communicated through non-I/DD-identifying, cross-movement leaders who do the "justice" work of "deferring" to I/DD lived experiences--is at minimum a questionable means to an end; and, at worst, a blatantly unjust denial of I/DD communities equitable access to self-determination.

The question remains, then: what is self-determination? The political economist's mistake is to reduce "self-determination" to the political, cultural, and economic "independence" of world nations in processes of state formation. In a similar vein, it is a psychological perversion to reduce "self-determination" to an "individual" personality characteristic or disposition, as Wehmeyer does. What the ACAT/ACT case demonstrates with their radical, yet non-utopic experiment in neurodivergent, trauma-informed leadership is the fundamental meaning of self-determination as an anti-colonial relationship between *bodies/minds* ("self")[261] and inevitably *social actions* ("determination").[262] This "social" world in which the

[261] "Species Being" is fundamentally the place where "the body/mind" and "the self" unite("!") in society (Marx, 1848).
[262] Even in Wehmeyer's discussion of Western definitions of "self-determination" he admits that "Determination" can be both a kind of decision-making that produces a specific action (a determination, n.) and a way of perceiving the quality/quantity of actions in comparison to the actions of others (to be determined, adj.). In both instances, "determination" unites("!") action and power relations in society. (Marx, 1848).

actions of living bodies/minds are situated, is not limited to the "human" as Indigenous, Third and Fourth World scholars have argued for generations.

Immersed in a world of beings invested with equal self-determination ("rights" socially recognized/respected or not) and relational power(s) to impact their environments, body/minds "must live" in a position always in relation to others. It is an ultimately colonial-mentality that leads some to believe that this *relationship of power* can produce the possibility of control[263]. However, to quote one of mine and Tania Coffield's favorite movies, "Jurassic Park" (1993)—a film grappling with scientific ethics and attempts to control and colonize the "self-determination" of living beings (not limited to the "human"):

> "Life will not be contained. Life breaks free, it expands to new territories, and it crashes through barriers painfully, maybe even dangerously, but uh… well, there it is" (Spielberg, 1993).

Living beings struggling for self-determination--like I/DD communities in the US since at least the 1850s--do not aspire to control others; or, for that matter, do they valorize social roles of control as aspirational goals. Communities denied access to "rights" of self-determination only seek the power of equal and/or "legitimate" participation in the world in which "we must live" interdependently. Even "hard" scientists acknowledge that life is an interdependent process in its dependence upon "biodiversity" for its possibility of past, present and future existence--it is hardly surprising then that "social" scientists would call on "neurodiversity" in appeal to "hard" concepts of natural evolution in order to explain the possibilities of social

[263] The colonial fantasy of a one-sided power, above/beyond interdependence and/or relationality

change. What the ACAT/ACT case teaches us about Disability Justice--in its radical, yet non-utopic experiment with a neurodivergent, trauma-informed leadership--is that our social actions within intersecting, and interdependent processes of self-determination are legitimate expressions of where we have been, where we are now, and the multiple possible futures we can build together when we meet each others' needs where we are at now. Where we raise each other on intersectional and interdependent platforms for social change that center our *relationality in self-determination*--the intersections of interdependent "species-being" in social action--we build access to multiple possible futures of power relations that "work for" the foreclose of past-in-present colonial fantasies and institutional dreams of control.

… The truth about Rabbit Holes is that they usually end where a family must live ...

CHAPTER 6:

a *CONCLUSION*

In my near-two years conducting participant observations and volunteer work on the ground with the Ala Costa Adult Transition and Community Training (ACAT/ACT) programs I gained a tremendously new perspective on social movement and social change. In terms of what I now like to call radical, but non-utopic transition-making, ACAT/ACT have offered me the perspective to imagine multiple possible futures for social movement. Multiple possible futures potentially beyond any current sociological imagination, which are not rooted in any single political issue or teleological philosophy, and that could be legitimately "neuro-divergent" in practice. "Neuro," in this instance, represents *what is beyond what we already know*—like the brain itself, presently both tangible (matter) and beyond comprehension and/or (in)competence; or, like tomorrow: built upon the material realities of the present/today, but through variable interactions we cannot predict or control. "Divergent" is not synonymous with "diversity." The practice of "divergence" is less about composition (the state of a thing) than it is about turning off-course, taking a different route, or *turning the history of the present on its head* (to paraphrase Marx and Foucault). The present moment is an intersection where we must live, but also from where we must interdependently imagine making transitional movements toward tomorrow.

The Disability Justice Movement (Berne, 2015) is dedicated to taking this turn under the leadership of disabled, POC, and queer people so as to protect the potentialities of a future built interdependently and intersectionally—bringing traditionally segregated communities together to gather perspective on where we are, how we got here, where we want to go, and what we need to get there. Under the leadership of those "most impacted" by where we are now and how we got here,[264] traditionally multiply-marginalized communities "set the bar" for where and how we start to make divergent (multiple possible) transitions into tomorrow. This bar is not "low" because it is "accessible" to all—it is historically unprecedented and unimaginably "high" for that reason!

To imagine and build toward multiple possible, accessible futures will demand cross-disability, cross-movement, cross-cultural and cross-continental solidarity never before known in the history of our "species' being"—futures of solidarity never before given the possibility of existence and that cannot exist within a colonial mentality built upon the denial and historical appropriation of the self-determination of our future leaders. Building an accessible future starts, as in the case of ACAT/ACT, with what I am calling *intersectional interdependence*: training each other in self-determination skills so that we learn how to recognize the differences between empowering relationships and internalized-/oppression as cultivated within historically-situated hierarchies of control. But/and—most importantly(!) as Brent

[264] Here: I ask you to imagine the I/DD student/clients at ACAT/ACT occupying such positions of leadership as some of the people "most impacted" by where they are positioned within social institutions today and by the socio-structural/institutional practices that situate (and, often control in order to harness) their positionalities.

White pointed out to me—so that we can teach each other how to practice trauma-informed self-advocacy, self-efficacy, and personal responsibility in *the process* of transition-/movement-making.

As Tania Coffield said in reference to self-determination skills themselves, transition-/movement-making is not a "product" that we can "truck, barter, and trade" (Smith, 1776/2014). The ACAT/ACT case demonstrates how transition-/movement-making is a practice without end, a future that will never be "determined" once and for all—it is a practice in process, it is a practice of living in process, it is a practice for which limits cannot be set because they are forever "yet to be determined." ACAT/ACT's NEM[265] offers a starting place, but not a finish line.

The intersectional interdependence built into the (Brent) "White Method" (puns-aside, but also intended) is an attempt *to turn the history of the present on its head.* It is not about controlling outcomes, it is about ensuring access to a place to start so that self-determined transition-/movement-making is accessible to all. That starting place is "an intersection"[266] where self-determination skills can be learned through interdependent commitments to a leadership whose lived experience includes intergenerational immersion within the systems that led everyone to that intersection in the first place. Intersectional interdependence, as a starting place, becomes a

[265] Legitimizing Neurodiversity, Trauma-Informed Perspective, and Self-Determination Skill Training.
[266] Note that I am using the word "intersection" to reference both the geographic meeting of roads/streets as well as the concept of "intersectionality" which refuses single-issue platforms for an understanding of how our lived experiences are defined by divergent personal/political identities that are never singular.

"moment of opportunity" for *divergences* to take their course, and for multiple possible futures to materialize in the environments in which we all must live.

Neurodivergent transition/movement-making is not "one-size fits all." STEPS[267] can be taken when and where access conflicts[268] present "moments of opportunity"[269] for interdependent bridge building across/between intersections.[270] ACAT/ACT are built upon a "vision" of multiple possible futures that can exist in simultaneous sovereignty *and* solidarity.

Brent White managed to find a place to start pursuing his "vision" under the umbrella of Ala Costa Centers in 2009. The ACAT/ACT programs celebrate ten-years of Autistic-led transition programming in 2019. In Chapter 2, "**The Rabbit Hole**," I historically situate the space in which ACAT/ACT materialized into the programs they are today: Berkeley, CA. This brief historical review is accompanied by a discussion of how a disabled and neurodivergent graduate student like me came to design a co-participatory ethnographic research project with Brent White, the Disabled, Neurodivergent, and Autistic (DNA) Director of both programs. Woven together, these three threads—Disability Movements in Berkeley (1970s-1990s), Brent White's ACAT/ACT "vision" (2009-2019), and a disabled/neurodivergent ethnographer (2016-2018)—are like three acts in a historical play about deinstitutionalization movements, "transition-making" post-deinstitutionalization

[267] Legitimizing Neurodiversity, Trauma-Informed Perspective, and Self-Determination Skill Training.
[268] Ex. Environmental triggers that unavoidably lead to "meltdown"
[269] Quoting "Joan" (pseudonym)
[270] Ex. Between "passing" staff, I/DD-identified student/clients, and community members when environmental trigger-induced "meltdowns" take place in community spaces like the grocery store.

within the non-profit industrial complex, and the present moment where they intersect, even in this work.

This history prefaces my analysis of "**Neurodivergent Leadership: The ACAT/ACT Case**" in Chapter 3. I situate the ACAT/ACT Programs within the formation of a "neurodivergent leadership" that only became possible as a practice in the U.S. around the turn of the 21st century and at the intersection of decades of movements toward the deinstitutionalization of divergent, intergenerational traumas unevenly experienced across marginalized communities of the US; and, particularly intersecting in the lived experiences of Mad, Intellectually and/or Developmentally Disabled Women of Color. In the case of the ACAT/ACT programs, I argue that the majority neurodivergent staff are more likely to identify as "neurodivergent" than "disabled" as a way to acknowledge their ableist (and other forms of) privilege over their I/DD student/clients. In witnessing the everyday ableism (often intersecting with racism, sexism and classism) that I/DD students/clients experience in their community-based program, CBTIs interdependently learn to "check their privilege" and literally "follow the lead" of their I/DD student/clients. In so doing, CBTIs respect the self-determination of their I/DD student/clients and honor their leadership as "those most impacted" by their shared, community-based environments. I also consider the ways that Community-Based Teacher/Instructors (CBTIs) at ACAT/ACT represent a cross-section of larger populations. Many CBTIs openly identified with lived experiences of trauma, anxiety, and depression but did not identify as "disabled" or "neurodivergent"—they were "TAD-Only." This was most

common among POC CBTIs. In light of these findings, I consider how traumas passed between generations of BIPOC are not necessarily self-identified as forms of neurodivergence and/or disability; but/and, why intersectionally lived experiences of/with intergenerational trauma could make multiple de-medicalized and decolonized futures of cross-movement and cross-disability organizing possible.

In Chapter 4, "***Nothing About Us, Without Us*: A Neurodivergent Education Model (NEM)**," I begin to unpack the *practice* of neurodivergent transition-making. The disabled, neurodivergent, and autistic (DNA) leaders of ACAT/ACT designed NEM over years of working with I/DD adults transitioning out of Special Education systems. ACAT/ACT's DNA leaders and I collaborated to document how NEM can be put to practice. In this chapter I unpack the first two out of three (what I call) "STEPS" of NEM: Legitimizing the Practice of Neurodiversity and A Trauma-Informed Perspective on Education. Legitimizing the practice of neurodiversity involves decolonizing medicalized models of disability and recognizing neurodivergent practices as everyday acts of resistance against forced assimilation and dependence. I unpack ACAT/ACT's explanation for "why" and "how" to practice a trauma-informed perspective in education when trauma is a strong unifier under the umbrella of neurodiversity, across/between disability communities, and even outside these two broadly identified communities.

Finally, in Chapter 5, "**Self-Determination Training: Trauma-Informed Practices, Interdependent Transitions and Multiple Possible Futures**," I complete my analysis of NEM with perhaps the most important "STEP": Training in Self-

Determination Skills and Personal Responsibility." Before I unpack ACAT/ACT's methods of self-determination skill training as described in the same collaborative document containing "STEPS" 1 & 2, I offer a deep analysis (or deconstruction) of Michael Wehmeyer's definition, functionalist model, and historical analysis of "self-determination" particularly as he presents them in a lecture sponsored by the *National Gateway to Self-Determination* (1999, 2005, 2007, 2011). In my attempt to decolonize the history of self-determination as outlined by Wehmeyer (2011), I work to legitimize neurodivergent practices throughout that same history and to demonstrate a trauma-informed perspective that focuses on the lived experiences of generations of I/DD people. In the process, my analysis comes to represent a history of the Western appropriation of "self-determination," particularly in terms of how this appropriation "functions" as a primary tactic in past-in-present, on-going processes of colonization and intergenerational trauma—the medicalization of which is but a more recent manifestation within a much longer history. With a critique of this appropriation firmly situated in a decolonized history, I then present ACAT/ACT's work toward training I/DD adults in self-determination skills and personal responsibility—particularly through the example of their controversial "no hugging" rule.

In this way, my work attempts to build a *bridge* at the intersection of movements for Third & Fourth World sovereignty, Global Black independence, and Neurodivergent self-determination. This "bridge"—built on the backs of generations and at the intersection of divergent, collective and intergenerational traumas—is an

intersectional platform upon which we can work *interdependently* to "uplift," not a "talented tenth," but a generation of leaders "most impacted" from across/between our desegregated communities (Washington, 1901; DuBois, 1903; Fanon, 1963; Moraga & Anzaldua, 1983; Shiva & Mies, 1993; Hartman, 1997; Thunder Hawk, 2007; Berne, 2015). While we gather under the newfound shade of our *intersectional interdependence* to train each other in trauma-informed self-determination practices under the leadership of those "most impacted" (this often means: "traumatized" and/or "neurodivergent") along the roads we took to get here, "we build" in new directions, toward "visions" of accessible paths into multiple possible futures that have the potential to turn the history of the present on its head.

BIBLIOGRAPHY

ABC Law Centers (2018). "Involuntary Sterilization of Disabled Americans: A Historical Overview." *American Baby & Child Law Centers.* Retrieved August 23rd, 2019 (https://www.abclawcenters.com/blog/2018/11/06/involuntary-sterilization-of-disabled-americans-an-historical-overview/).

ACAT. (2015). "Bay Area Day of Mourning 2015." *Facebook*. Retrieved November 26, 2019 (https://www.facebook.com/events/1527993604147783/?active_tab=about).

Adams, Rachel. (2017). "Michel Foucault: Biopolitics and Biopower." *Critical Legal Thinking: Law and the Political*. Retrieved November 20, 2019 (http://criticallegalthinking.com/2017/05/10/michel-foucault-biopolitics-biopower/#fn-22546-26)

Administration for Community Living. (2017). "History of the DD Act." *U.S. Department of Health and Human Services, Administration for Community Living (ACL)*. Retrieved November 17, 2019 (https://acl.gov/about-acl/history-dd-act#ftn2)

Adorno, Theodor W., Else Frankel-Brunswick, Daniel Levinson, & Nevitt Sanford. (1950). *The Authoritarian Personality*. Harper & Brothers.

Ala Costa Centers. (2019) "What is the ACAT Program." *Ala Costa Centers*. Retrieved November 15, 2019 (https://www.alacostacenters.org/transition-program/).

Ala Costa Centers. (2019) "Adult Community Training Program (ACT)." *Ala Costa Centers*. Retrieved November 15, 2019 (https://www.alacostacenters.org/adult-community-program/).

Alameda County Social Services Agency. (2012). "Elders & Disabled Adults: Alameda County Public Guardian-Conservator, Probate Conservatorships, & LPS Mental Health Conservatorships." *ACgov*. Retrieved November 19, 2019 (https://www.alamedasocialservices.org/public/services/elders_and_disabled_adults/public_guardian.cfm)

Alexander, Michelle. (2010). *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*. The New Press.

American Association on Intellectual and Developmental Disabilities. (2019). "What

is Intellectual Disability?" *AAIDD*. Retrieved November 19, 2019: (https://www.aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability)

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC.

American Psychological Association. (2017). "125th Anniversary APA Timeline." *American Psychological Association Archives*. Retrieved November 26, 2019 (https://www.apa.org/about/apa/archives/timeline).

American Psychological Association. (2018a). "Instrumental Conditioning." *APA Dictionary of Psychology*. Retrieved November 26, 2019 (https://dictionary.apa.org/instrumental-conditioning).

American Psychological Association. (2018b). "Operant Conditioning." *APA Dictionary of Psychology*. Retrieved November 26, 2019 (https://dictionary.apa.org/operant-conditioning).

APSE. (n.d.). "Employment First Works." *APSE*: Employment First, Employment For All. Retrieved November 17, 2019 (https://apse.org/employment-first/)

ARC, The. (2019a). "Position Statements: Employment." *The Arc*. Retrieved November 17, 2019 (https://thearc.org/position-statements/employment/).

Arendt, Hannah. (1951). *The Origins of Totalitarianism*. A Harvest Book: Orlando.

Asperger, Hans. (1944). Die ''autistischen Psychopathen'' im Kindes- und Jugendalter. *Arch Psychiatr Nervenkrankh* 117: 76–136.

Association for Behavior Analysis International. (2010). "Statement on Restraint and Seclusion." *ABAI*. Retrieved November 26, 2019 (https://www.abainternational.org/about-us/policies-and-positions/restraint-and-seclusion,-2010.aspx).

Author Unknown. (1977). "Disabled In San Francisco Vow to Continue Sit-In." *New York Times* (1977 Archives). Retrieved September 8, 2018 (https://www.nytimes.com/1977/04/17/archives/disabled-in-san-francisco-vow-to-continue-sitin.html).

Author Unknown. (2012). "Judge Rotenberg Center Trial: Tape Shows Teen Being Shocked 31 Times (GRAPHIC VIDEO)." *HuffPost*. Retrieved November 20, 2019 (https://www.huffpost.com/entry/judge-rotenberg-center-trial_n_1420633).

Author Unknown. (2016). "Syracuse State School." *Asylum Projects*. Retrieved November 15, 2019 (http://www.asylumprojects.org/index.php/Syracuse_State_School).

Autistic Self Advocacy Network. (2009). "'The A Word' from ASAN Australia." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/2009/04/the-a-word-from-asan-australia/).

Autistic Self Advocacy Network. (2019a). "Leadership: Members of ASAN's Board of Trustees." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/about-asan/leadership/).

Autistic Self Advocacy Network. (2019b). "Empowering Leadership: A Systems Change Guide for Autistic College Students and Those with Other Disabilities." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/resources/books/empowering-leadership-a-systems-change-guide-for-autistic-college-students-and-those-with-other-disabilities/).

Autistic Self Advocacy Network. (2019c). "Association for Behavior Analysis International Endorses Torture." *ASAN: Autistic Self Advocacy Network*. Retrieved November 24, 2019 (https://autisticadvocacy.org/2019/05/association-for-behavior-analysis-international-endorses-torture/).

Autistic Self Advocacy Network (2019d). "Autism & Safety Toolkit." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/policy/toolkits/safety/).

Autistic Self Advocacy Network. (2019e). "Autism & Safety Toolkit: Research Overview on Autism and Safety." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/wp-content/uploads/2017/11/Autism-and-Safety-Pt-1.pdf).

Autistic Self Advocacy Network. (2019f). "2019 Anti-Filicide Toolkit." *ASAN: Autistic Self Advocacy Network*. Retrieved November 20, 2019 (https://autisticadvocacy.org/projects/community/mourning/anti-filicide/).

Barnow, Burt S. (2008). "The Employment Rate of People with Disabilities." United States Department of Labor, *Bureau of Labor Statistics Monthly Labor Review.* Retrieved November 17, 2019 (https://www.bls.gov/opub/mlr/2008/article/employment-rate-of-people-with-disabilities.htm)

Bascom, Julia. (2012). *Loud Hands: Autistic People, Speaking*. Autistic Self Advocacy Network.

Beach Center on Disability. (n.d.). "Michael Wehmeyer." *University of Kansas*. Retrieved November 20, 2019 (https://beachcenter.lsi.ku.edu/people/wehmeyer-michael).

Beckwith, Ruthie-Marie. (2016). *Disability Servitude: From Peonage to Poverty*. Palgrave Macmillan.

Benjamin, Ruha. (2013). *People's Science: Bodies and Rights on the Stem Cell Frontier*. Stanford University Press.

Benjamin, Ruha. (2016). "Informed Refusal: Toward a Justice-Based Bioethics." *Science, Technology & Human Values*, 1-24.

Berne, Patty. (2015). "Disability Justice ~ A Working Draft by Patty Berne." *Sins Invalid*. Retrieved November 19, 2019 (https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne)

Biestek & Gehrig. (1978). *Client Self-Determination in Social Work: 50 Year History*. Loyola University: Chicago.

Biklen, Douglas. (1995). "Facilitated Communication." *American Journal of Speech-Language Pathology*, 1.2: 21-2.

Block, P., D. Kasnitz, A. Nishida, & N. Pollard. (2016). *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. Springer: New York.

Blume, Harvey. (1998). "Neurodiversity: On the Neurological Underpinnings of Geekdom." *The Atlantic*. Retrieved November 20, 2019 (https://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/305909/).

Bortz, Abe. (1970). "Historical Development of the Social Security Act." *Social Security Administration*. Retrieved August 14th, 2019 (https://www.ssa.gov/history/bortz.html).

Brown v. Board of Education of Topeka. (1954) 347 U.S. 483. *Justia*. Retrieved November 17, 2019 (https://supreme.justia.com/cases/federal/us/347/483/).

Brown, H. and H. Smith (1992) "Assertion, Not Assimilation: A Feminist Perspective on the Normalisation Principle", in H. Brown and H. Smith (Eds) *Normalisation: A Reader for the Nineties*, London: Routledge**:** 149-171.

Brown, Lydia. (2011). "The Significance of Semantics: Person-First Language: Why It Matters." *AutisticHoya*. Retrieved November 20, 2019 (https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html).

Bureau of Justice Statistics. (2017). "Crime Against Persons with Disabilities, 2009-2015 – Statistical Tables." *U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics, Erika Harrell, BJS Statistician*. Retrieved November 19th, 2019 (https://www.bjs.gov/content/pub/pdf/capd0915st.pdf)

Bureau of Justice Statistics. (2019). "Disabilities: Publications & Products." *U.S. Office of Justice Programs, Bureau of Justice Statistics, The National Crime Victimization Survey*. Retrieved November 19, 2019 (https://www.bjs.gov/index.cfm?ty=tp&tid=924)

California Department of Education. (2018). "Employment First Policy." *California Department of Education*. Retrieved November 17, 2019 (https://www.cde.ca.gov/sp/se/st/employmentfirstpolicy.asp)

California Department of Education. (2018). "Reauthorization of the IDEA 2004." *California Department of Education*. Retrieved November 17th, 2019 (https://www.cde.ca.gov/sp/se/lr/ideareathztn.asp)

California State Council on Developmental Disabilities. (2019). "How does the Council define developmental disability?" *State of California*. Retrieved November 19, 2019 (https://scdd.ca.gov/aboutdevelopmentaldisabilities/)

California State Council on Developmental Disabilities (2013). "Employment First Policy." *California SCDD*. Retrieved November 17, 2019 (https://scdd.ca.gov/wp-content/uploads/sites/33/2016/10/Employment-First-Policy-Summary-SCDD-CECY.pdf)

California State Council on Developmental Disabilities. (2011). "Employment First Report: A Vision of Californians with Developmental Disabilities Working in Competitive Integrated Employment." *California SCDD*. Retrieved November 17, 2019 (https://scdd.ca.gov/wp-content/uploads/sites/33/2016/10/2011-Employment_First_Report-12.18.13.pdf)

Carey, Allison. (2010). *On the Margins of Citizenship: Intellectual Disability and*

Civil Rights in Twentieth-Century America. Temple University Press.

Carlson, Licia. (2009). *The Faces of Intellectual Disability: Philosophical Reflections*. Indiana University Press.

Charlton, James I. (2000). *Nothing About Us Without Us: Disability Oppression and Empowerment*. University of California Press: Berkeley.

Churchill, Ward. (2004). *Kill the Indian, Save the Man: The Genocidal Impact of American Indian Residential Schools*. City Lights Publishers.

Clark, Robert. (2004). "The Classical Origins of Pavlov's Conditioning." *Integrative Physiological and Behavioral Science*, 39.4: 279-94.

Collins, Patricia Hill & Sirma Bilge. (2016). *Key Concepts: Intersectionality*. Polity: Cambridge.

Cone, Kitty. (Unknown). "Short History of the 504 Sit In." *Disability Rights Education &Defense Fund.* Retrieved November 15, 2019 (https://dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/).

Crenshaw, Kimberle. (1997). "Intersectionality and Identity Politics: Learning from Violence Against Women of Color" in Mary Lyndon Shanley & Uma Narayan (Eds.), *Reconstructing Political Theory: Feminist Perspectives*. Pennsylvania State University Press. 178-93.

Culham, Andrew & Melanie Nind. (2003). "Deconstructing Normalization: Clearing the Way for Inclusion." *Journal of Intellectual and Developmental Disability*, 28.1: 65-78.

Davis, Leigh Ann. (2011). "People with Intellectual Disabilities and Sexual Violence." *The ARC*. Retrieved November 25, 2019 (http://thearc.org/wp-content/uploads/2019/07/Sexual%20Violence.pdf).

DD Coalition. (2014). "Voices from Fairview." YouTube. Retrieved November 19, 2019(https://www.youtube.com/watch?v=GP85pIcBQQ8)

Dean, Mitchell M. (2009). *Governmentality: Power and Rule in Modern Society*. SAGE Publications.

DeAngelis, T. (2012). "Was 'Little Albert' Ill During the Famed Conditioning Study?" *American Psychological Association*, 43.3: 12.

Disability Rights International. (2014). "The United Nations calls again for

investigation of JRC's shock treatment." *Disability Rights International*. Retrieved November 20, 2019 (https://www.driadvocacy.org/the-united-nations-calls-again-for-investigation-of-jrcs-shock-treatments/).

Doll, Edgar A. (1935)."A Genetic Scale of Social Maturity." *American Journal of Orthopsychiatry*, 5.2: 180-90.

DuBois, W.E.B. (1903). *The Talented Tenth*. Create Space Independent Publishing Platform.

Durkheim, Emile. (1895). *The Rules of Sociological Method*. Free Press: New York.

Durkheim, Emile. (1897). *Suicide: A Study in Sociology*. Free Press: New York.

Ed Roberts Campus. (2018). "About." *Ed Roberts Campus* Retrieved September 8, 2018 (https://www.edrobertscampus.org/about/).

Education of All Handicapped Children Act. (1975). S. 6 – 94th Congress. *GovTrack*. Retrieved November 17, 2019 (https://www.govtrack.us/congress/bills/94/s6/summary#libraryofcongress)

Fanon, Frantz. (1952). *Black Skin, White Masks*. Pluto Press.

Fanon, Frantz. (1963). *The Wretched of the Earth*. R. Philcox (trans.) Grove Press: New York.

Federal Register. (2013). "Change in Terminology: 'Mental Retardation' to 'Intellectual Disability'." *Social Security Administration, National Archives, Federal Register: The Daily Journal of the United States Government*. Retrieved November 20, 2019 (https://www.federalregister.gov/documents/2013/08/01/2013-18552/change-in-terminology-mental-retardation-to-intellectual-disability).

Federici, Silvia. (2004). *Caliban and the Witch: Women, the Body, and Primitive Accumulation*. Autonomedia.

Ferguson, Philip M. (1994). *Abandoned to Their Fate: Social Policy and Practice Toward Severely Retarded People in America, 1820-1920*. Temple University Press.

Ferguson, Philip M. (2014). "Creating the Back Ward: The Triumph of Custodialism and the Uses of Therapeutic Failure in Nineteenth-Century Idiot Asylums" in L. Ben Moshe, C. Chapman, & A. Carey (Ed) *Disability Incarcerated:*

Imprisonment and Disability in the United States and Canada. Palgrave MacMillan.

FindLaw. (2019). "Compulsory Education Laws: Background." FindLaw. Retrieved November 15, 2019 (https://education.findlaw.com/education-options/compulsory-education-laws-background.html).

Foucault, Michel. (1978). *The History of Sexuality (Volume 1): An Introduction.* Hurley (trans.) Vintage Books Edition, 1990.

Foucault, Michel. (1995). *Discipline & Punish: The Birth of the Prison*. Vintage Books.

Foucault, Michel (2004). *Security, Territory, Population: Lectures at the College De France, 1977-1978*. Palgrave: New York.

Found SF. (Unknown). "Patient No More: 1977 Occupation of Federal Offices in San Francisco—Historical Essay." *Paul K. Longmore Institute at San Francisco State University*. Retrieved November 15, 2019 (http://www.foundsf.org/index.php?title=Patient_No_More:_1977_Occupation_of_Federal_Offices_in_San_Francisco).

Frith, Uta. (1991). *Autism and Asperger Syndrome*. Cambridge University Press.

Fromm, Erich. (1957). "The Authoritarian Personality." *Deutsche Universitatszeitung*, Band 12.9: 3-4.

Garen, Josef. (2011). "The Trouble with Neurodiversity: Etiologies, Normativity, and the Autistic Struggle for Identity." University of British Columbia, Vancouver. Master's Thesis. Retrieved November 20, 2019 (https://pdfs.semanticscholar.org/9916/89916b54435da8cb31a7c6cc74b46b5d7d2a.pdf).

Garfinkel, Harold. (1967). *Studies in Ethnomethodology*. Prentice Hall Inc.

Gibson, Margaret & Patty Douglas. (2018). "Disturbing Behaviors: Ole Ivar Lovaas and the Queer History of Autism Science." *Catalyst: Feminism, Theory, Technoscience*, 4.2: 1/28

Gill, Michael. (2015). *Already Doing It: Intellectual Disability and Sexual Agency*. University of Minnesota Press.

Goddard, H. (1912). *The Kallikak Family: A Study in the Heredity of Feeblemindedness*. MacMillan Co.: New York.

Goffman, Erving. (1961). *Asylums: Essays on the Social Situation of Mental Patients*. First Anchor Books.

Goffman, Erving. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Prentice Hall: New Jersey.

Gonnerman, Jennifer. (2007). "The School of Shock." Mother Jones. Retrieved November 20, 2019 (https://www.motherjones.com/politics/2007/08/school-shock/).

Gorr, Karen. (2019). "Karen Gorr." *The Minnesota Governor's Council on Developmental Disabilities, Parallels in Time: A History of Developmental Disabilities*. Retrieved November 19, 2019 (https://mn.gov/mnddc/parallels/six/6d3/karen-gore-personal-story.html)

Gramsci, Antonio. (2000). *Selections from The Prison Notebooks*. Hoare & Smith (Eds). International Publishers Co.: Milan.

Grim, Andrew. (2015). "Sitting-In for Disability Rights: The Section 504 Protests of The 1970s." *Smithsonian: National Museum of American History*. Retrieved September 8, 2018 (http://americanhistory.si.edu/blog/sitting-disability-rights-section-504-protests-1970s).

Haraway, Donna. (1988). "Situated Knowledges The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies*, 14.3: 575-99.

Harrell, Erika. (2017). "Crime Against Persons with Disabilities 2009-2015 – Statistical Tables." *U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics*. Retrieved November 26, 2019 (https://www.bjs.gov/content/pub/pdf/capd0915st.pdf#page=4).

Harris, James C. (1998). *Developmental Neuropsychiatry: Assessment, Diagnosis, and Treatment of Developmental Disorders*. Oxford University Press: 92.

Hartman, Saidiya. (1997). *Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America*. Oxford University Press: London.

Hartman, Saidiya. (2008). *Lose Your Mother: A Journey Along the Atlantic Slave Route*. Farrar, Straus and Giroux.

Harvey, David. (2005). *The New Imperialism*. Oxford University Press: Oxford.

Harvey, David. (2007). *A Brief History of Neoliberalism*. Oxford University Press:

Oxford.

Hershey, Laura. (1991). "You Get Proud By Practicing." (Poem). Retrieved November 22, 2019 (http://www.thenthdegree.com/proudpoem.asp).

Heumann, Judith E. & Hehir, Thomas. (1994). "Questions and Answers on the Least Restrictive Environment Requirements of the Individuals with Disabilities Education Act." *United States Department of Education, Office of Special Education and Rehabilitative Services*. (https://www.wrightslaw.com/law/osep/lre.osep.memo.1994.1123.pdf).

Human Rights Campaign. (2019) "The Lies and Dangers of Efforts to Change Sexual Orientation or Gender Identity." *Human Rights Campaign: Health & Aging*. Retrieved November 20, 2019 (https://www.hrc.org/resources/the-lies-and-dangers-of-reparative-therapy).

Hunsaker, Michael Ryan. (2018). "On Restraint… and How it is Used Incorrectly." Why Haven't They Done That Yet. *Wordpress*. Retreived November 28, 2019. (https://whyhaventtheydonethatyet.wordpress.com/2018/06/13/on-restraint-and-how-it-is-used-incorrectly/).

Incite! (2007). *The Revolution Will Not Be Funded: Beyond the Non-Profit Industrial Complex*. South End Press: Cambridge.

Independence Northwest. (2011). "Memorial for Judy Cunio: June 30th in Salem." *Independence NW*. Retrieved November 20, 2019 (http://independencenw.org/2011/06/23/memorial-for-judy-cunio-june-30th-in-salem/)

IDEA, "20 US Code, Section 1400 - Short Title, Findings, Purposes." *Cornell Law School, Legal Information Institute: Open Access to Law*. Retrieved November 17, 2019 (https://www.law.cornell.edu/uscode/text/20/1400).

Individuals with Disabilities Education Act. (2004). "Section 1401 (34) Transition Services." Retrieved November 17, 2019 (https://sites.ed.gov/idea/statute-chapter-33/subchapter-i/1401/34)

Individuals with Disabilities Education Amendments Act (2004). *20 U.S.C. § 1400*. Retrieved November 17, 2019: (https://www.law.cornell.edu/uscode/text/20/1400)

Jenkins, Richard. (1998). *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge: Cambridge University Press.

Jones Jr. Robert (Son of Baldwin). (2015). Twitter Post. *Twitter*. Retrieved November 26, 2015 (https://twitter.com/SonofBaldwin).

Judge Rotenberg Center. (n.d.). "Judge Rotenberg Educational Center: A Day and Residential School." *JUDGERC.org*. Retrieved November 22, 2019 (https://www.judgerc.org/).

Kafer, Alison. (2013). *Feminist, Queer, Crip*. Indiana University Press.

Kaplan, Sharyn. (2011). "Memories: Judy Cunio." *Last Memories*. Retrieved November 20, 2019 (http://judy-cunio.last-memories.com/memories/poz/10).

King, John B., Sue Swenson, Janet L. LaBreck, Ruth Ryder. (2017). "A Transition Guide: To Postsecondary Education and Employment for Students and Youth with Disabilities" *Office of Special Education and Rehabilitative Services, United States Department of Education*. Retrieved November 15, 2019 (http://www.wrightslaw.com/law/osers/transition.postsecondary.guide.2017.pdf).

Kivel, Paul. (2007). "Social Service or Social Change?" In Incite's *The Revolution Will Not Be Funded: Beyond the Non-Profit Industrial Complex*. South End Press: Cambridge. 129-50.

Kleinfield, Sonny. (1992). "Declaring Independence in Berkeley." *Independent LivingInstitute.* Retrieved September 8, 2018 (https://www.independentliving.org/toolsforpower/tools2.html).

Kronstein, Alex. (2018). "Treating Autism as a Problem: The Connection Between Gay Conversion Therapy and ABA." *The Nova Scotia Advocate*. Retrieved November 20, 2019 (https://nsadvocate.org/2018/07/11/treating-autism-as-a-problem-the-connection-between-gay-conversion-therapy-and-aba/).

Kudlick, Catherine. (2018). "The 'Patient No More' Mural." *Paul K. Longmore Institute on Disability*. Retrieved November 15, 2019 (http://longmoreinstitute.sfsu.edu/patient-no-more-mural).

Kuti, Fela. (1977). "Colonial Mentality" [Recorded by Fela Kuti]. On *Sorrow Tears and Blood*. Nigerian Kalakuta.

Larsson, Eric V. & Scott Wright. (2011). "O. Ivar Lovaas (1927-2010)." *The Behavior Analyst*, Spring 34.1: 111-14.

Laties, Victor. (1987). "Society for the Experimental Analysis of Behavior: The First

30 Years (1957-1987)." *Journal of the Experimental Analysis of Behavior*, 48:3, 495-512.

Laurence, Bethany. (2019). "Social Security and SSI Disability Benefit Amounts and COLA for 2018." *NOLO*. Retrieved November 22, 2019 (https://www.nolo.com/legal-updates/social-security-and-ssi-disability-benefit-amounts-for-2018.html).

Lewis, Sharon. (2011). "Statement of Sharon Lewis Commissioner Administration of Developmental Disabilities Administration for Children and Families, Department of Health and Human Services Before the Committee on Health, Education, Labor and Pensions, United States Senate." *U.S. Department of Health and Human Services, Administration for Community Living (ACL).* Retrieved November 17, 2019 (https://acl.gov/sites/default/files/news%202017-03/2011-03-02-SenateTestimony_of_SharonLewis.pdf)

Library of Congress Congressional Research Service. (1975). "S. 6 (94th): Education for All Handicapped Children Act." *GovTrack*. Retrieved November 17, 2019 (https://www.govtrack.us/congress/bills/94/s6/summary#libraryofcongress)

Lovaas, Ovar I., Schaeffer, B. & Simmons, J. (1965). "Building social behavior in autistic children by use of electric shock." *Journal of Experimental Research in Personality*,1, 99-109.

Lovaas, Ovar I. & Simmons, J. (1969). "Manipulation of self-destruction in three retarded children." *Journal of Applied Behavior Analysis*, 2.3, 143-157.

Lovaas, Ovar I., Koegel, R., Simmons, J. & Long, J. (1973). "Some generalization and follow-up measures on autistic children in behavior therapy." *Journal of Applied Behavior Analysis*, 6.1, 131-166.

Manning, Philip. (2017). "Erving Goffman and Dramaturgical Sociology." *Cleveland State University. ResearchGate*. Retrieved November 26, 2019 (https://www.researchgate.net/publication/314405702_Goffman_and_Dramaturgical_Sociology).

Marx, Karl. (1844). *The Economic and Philosophic Manuscripts of 1844*. Milligan, Martin (Trans.) Prometheus Books: Amherst (1988).

Marx, Karl. (1845). "Theses On Feuerbach." In In *Marx/Engels Selected Works, Vol. One*. Progress Publishers, Moscow, 1969, pp. 13-5. Retrieved November 20, 2019 (https://www.marxists.org/archive/marx/works/1845/theses/theses.htm).

Marx, Karl. (1848). "Manifesto of the Communist Party." In *Marx/Engels Selected Works, Vol. One*. Progress Publishers, Moscow, 1969, pp. 98-137. Retrieved November 20, 2019 (https://www.marxists.org/archive/marx/works/1848/communist-manifesto/).

McGuire, Anne. (2016). *War on Autism: On the Cultural Logic of Normative Violence (Corporealities: Discourses of Disability)*. University of Michigan Press.

Melville, Herman. (1853). "Bartleby, The Scrivener: A Story of Wall-Street." *The Piazza Tales* in *Putnam's Magazine*.

Minnesota Governor's Council on Developmental Disabilities. (2019). "We Are People First."*Parallels in Time: A History of Developmental Disabilities*. Retrieved November 20, 2019 (https://mn.gov/mnddc/parallels/seven/7b/5.html).

Miserandino, Christine. (2003). "The Spoon Theory." *But You Don't Look Sick*. Retrieved November 19, 2019. (https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/).

Moraga, Cherrie & Gloria Anzaldua. (1983). *This Bridge Called My Back: Writings by Radical Women of Color*. Kitchen Table/Women of Color Press.

Morin, Amanda. (2014). "The Difference Between IEPs and Service Plans." *Understood USA LLC*. Retrieved November 17, 2019 (https://www.understood.org/en/school-learning/special-services/special-education-basics/the-difference-between-ieps-and-service-plans).

Msumba, Jen. (2016). "My Life Inside the Judge Rotenberg Center--Skin Shock, Aversives, What It Was Like." *YouTube.com*. Published December, 2016. Retrieved November 22, 2019 (https://www.youtube.com/watch?v=6B_ej5zyWp0).

Msumba, Jen. (2019). "The Super Fantastic Autism Show" (Vlog). *Youtube.com*. Retrieved November 22, 2019 (https://www.youtube.com/channel/UCkrQAGJxuxInf5jNSRfrsyw).

National Association for Down Syndrome. (2018). "Background Information: The Origins of the Term Down Syndrome." *NADS*. Retrieved November 20, 2019 (https://www.nads.org/about-us/history-of-nads/).

National Center for Victims of Crime. (2018). "Crimes Against People with

Disabilities." *National Crime Victims Week: Fact Sheet*. Retrieved November 20, 2019 (https://ovc.ncjrs.gov/ncvrw2018/info_flyers/fact_sheets/2018NCVRW_VictimsWithDisabilities_508_QC.pdf).

National Center on Secondary Education and Transition. (2004). "Parent Brief: Promoting Effective Parent Involvement in Secondary Education and Transition, Person Centered Planning: A Tool For Transition." *NCSET, Institute on Community Integration*. Retrieved November 17, 2019 (http://ncset.org/publications/viewdesc.asp?id=1431).

National Council on Disability. (2008). "The Rehabilitation Act: Outcomes for Transition-Age Youth." *NCD*. Retrieved November 17, 2019 (https://ncd.gov/publications/2008/rehabilitation-act-outcomes-transition-age-youth-doc).

National Council on Disability. (2018). "Beyond Guardianship: Toward Alternatives ThatPromote Greater Self-Determination for People with Disabilities." *NCD*. Retrieved November 19, 2019 https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Interior.docx).

National Institutes of Health. (2010). "Fact Sheet: Intellectual and Developmental Disabilities."*U.S. Department of Health & Human Services, NIH: Research Portfolio Online Reporting Tools (RePORT) Archive*. Retrieved November 19, 2019 (https://archives.nih.gov/asites/report/09-09-2019/report.nih.gov/nihfactsheets/ViewFactSheet34ef.html?csid=100&key=I#I).

Neuman, Ken & Shirley. (2019). "Fairview Survivors: A Short Film By Geri Newton" *The Minnesota Governor's Council on Developmental Disabilities, Parallels in Time: A History of Developmental Disabilities*. Retrieved November 19, 2019 (https://mn.gov/mnddc/parallels2/one/fairview/fairview.html).

Nichols, Meriah. (2019). "Disability Hierarchy is Real and It's Holding Us Back." *Meriah Nichols*. (Blog). Retrieved November 26, 2019 (https://www.meriahnichols.com/disability-hierarchy/).

Nirje, Bengt (1969). "*The Normalization Principle and its Human Management Implications*." In R. B. Kugel & W. Wolfensberger (Eds.) *Changing Patterns in Residential Services for the Mentally Retarded.* Washington DC: President's Committee on Mental Retardation. 179-95

Oliver, Mike. (1981). "A New Model of the Social Work Role in Relation to

Disability" in J.Campling (ed.) *The Handicapped Person: A New Perspective for Social Workers?* London: RADAR. Retrieved November 22, 2019 (https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Campling-handicppaed.pdf).

Oliver, Mike. (1990). "The Individual and Social Models of Disability." A Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, July 23, 1990. Retrieved November 26, 2019 (https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-in-soc-dis.pdf).

Osgood, Robert L. (2008). *The History of Special Education: A Struggle for Equality in American Public Schools*. Praeger: Westport, Connecticut.

O'Toole, Corbett Joan. (2015). *Fading Scars: My Queer Disability History*. Reclamation Press: Richmond, CA.

PACER's National Parent Center on Transition and Employment. (2019). "The Rehabilitation Act of 1973." *PACER*. Retrieved November 15, 2019 (http://www.pacer.org/transition/learning-center/laws/rehab.asp).

Paul K. Longmore Institute on Disability (2017). "Protesting Across the US: 'The Nation's Disabled Have Declared War' – The Berkeley Barb, April 22-28, 1977." *Patient No More*. Retrieved November 15, 2019 (http://longmoreinstitute.sfsu.edu/patient-no-more/protesting-across-us).

Paul K. Longmore Institute on Disability. (2018). "Virtual Tour." *Patient No More.* Retrieved September 8, 2018 (http://longmoreinstitute.sfsu.edu/patient-no-more/introduction).

Pavlov, I. P. (1897). *The work of the digestive glands* (W.H. Thompson, English translation, London, 1902). London: Griffin.

Pelka, Fred. (2004). "The Disability Rights and Independent Living Movements: Timeline." *University of California, Berkeley*. Retrieved November 15, 2019 (https://bancroft.berkeley.edu/collections/drilm/resources/timeline.html).

People First of Oregon. (n.d.). "People First of Oregon Photo Album." *People First*. Retrieved November 20, 2019 (http://www.people1.org/photos.htm).

People First of West Virginia. (n.d.) "History of People First." *People First.* Retrieved November 20, 2019 (https://peoplefirstwv.org/old-front/history-of-people-first/).

Piaget, J. (1963). *The origins of intelligence in children*. New York: Norton. (Original work published in 1936).

Pilkington, Ed. (2018). "Human Rights Body Calls on US School to Ban Electric Shocks on Children." *The Guardian*. Retrieved November 22, 2019 (https://www.theguardian.com/us-news/2018/dec/18/judge-rotenberg-center-electric-shocks-ban-inter-american-commission-human-rights).

Puar, Jasbir. (2009). "Prognosis Time: Towards a Geopolitics of Affect, Debility, and Capacity." *Women & Performance: A Journal of Feminist Theory*, 19.2: 161-72.

Puar, Jasbir. (2011). "The Cost of Getting Better: Suicide, Sensation, Switchpoints." *GLQ: Journal of Lesbian and Gay Studies*, 18.1: 149-58.

Red Horn Woman (Hay Shaw Wiya). (n.d.). "Poetry." *Red Horn Woman*. Retrieved November 26, 2019 (https://www.redhornwoman.com/poetry?lightbox=dataItem-ji3zovbn6).

Regents of the University of California, Bancroft Library. (2010). "Leaders with Developmental Disabilities in the Self-Advocacy Movement." *UC Berkeley Library*. Retrieved November 26, 2019 (https://bancroft.berkeley.edu/ROHO/collections/subjectarea/ics_movements/self_advocacy.html).

Regional Center of the East Bay. (2019). "About Us." *RCEB*. Retrieved November 19, 2019 (https://rceb.org/about-us)

Roberts, Ed. (1977). "Worth Repeating: Ed Roberts' 504 Sit In Victory Rally Speech." *OlliBEAN*. Retrieved November 15, 2019 (https://ollibean.com/ed/).

Rose. (2005). "Species Being, Social Being and Class Consciousness." *Internationalist Perspective*, 43 (Winter/Spring 2005). Retrieved November 20, 2019 (http://internationalist-perspective.org/IP/ip-archive/ip_43_species-being.html).

Roy, Audrey Jane. (1998). "Sovereignty and Decolonization: Realizing Indigenous Self-Determination at the United Nations and in Canada." Master's Thesis, University of Victoria. Retrieved September 9th, 2019 (http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.473.1475&rep=rep1&type=pdf).

Self-Advocates Becoming Empowered. (2019). "About SABE." *SABE: Self-*

Advocates Becoming Empowered. Retrieved November 20, 2019 (https://www.sabeusa.org/meet-sabe/).

Schweik, Susan. (2009). *The Ugly Laws: Disability in Public*. New York University Press.

Schweik, Susan. (2011). "Lomax's Matrix: Disability, Solidarity, and the Black Power of 504." *Disability Studies Quarterly*, 31.1.

Sessions, George. (1995). "Postmodernism and Environmental Justice: The Demise of The Ecology Movement?" *Trumpeter*. Retrieved November 20, 2019 (http://trumpeter.athabascau.ca/index.php/trumpet/article/view/305/456).

Sequenzia, Amy. (2019). "Autistic Conversion Therapy." *Autistic Women & Nonbinary Network (AWN): Neurodiversity is for Everyone*. Retrieved November 25, 2019 (https://awnnetwork.org/autistic-conversion-therapy/).

Shakespeare, Tom. (2010). "The Social Model of Disability." In L. Davis (Ed) *The Disability Studies Reader*. Routledge: New York: 266-73.

Shakespeare, Tom. (2013). *Disability Rights and Wrongs Revisited*. Routledge: London.

Shapiro, Joseph. (2018). "The Sexual Assault Epidemic No One Talks About." *NPR*. Retrieved November 20, 2019 (https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about).

Shiva, Vandana & Maria Mies. (1993). *Ecofeminism*. Zed Books: London.

Shiva, Vandana. (2005). *Earth Democracy: Justice, Sustainability and Peace*. South End Press.

Silberman, Steve. (2015). *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. Avery: New York

Silberman, Steve & Mark Leviton. (2017). "Misunderstood and Misdiagnosed: Steve Silberman on the Mysteries of Autism. [Interview]" *The Sun Magazine*, March 2017. Retrieved November 20, 2019 (https://www.thesunmagazine.org/issues/495/misdiagnosed-and-misunderstood).

Singer, Judy. (1998). *Odd People In: The Birth of Community Amongst People on the*

Autism Spectrum: *A personal exploration of a New Social Movement based on Neurological Diversity*. An Honours Thesis presented to the Faculty of Humanities and Social Science, the University of Technology, Sydney, Australia.

Singer, Judy. (1999). "'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference." In Mairian Corker & Sally French's (Eds) *Disability Discourse*. Open University Press: Buckingham. 59-67.

Skinner, B. F. (1938). *Behavior of Organisms*. Copely Publishing Group.

Smith, Adam. (2014). *The Wealth of Nations*. Shine Classics.

Snyder, Sharon L. & David T. Mitchell. (2006). *Cultural Locations of Disability*. University of Chicago Press.

Spielberg, Steven. (1993). *Jurassic Park*. Universal Pictures Studios.

Stuhler, Linda S. (2011). "Syracuse State Institution For Feeble-Minded Children: (1916)." *VCU Libraries Social Welfare History Project*. Retrieved November 15, 2019 (https://socialwelfare.library.vcu.edu/issues/syracuse-state-institution-feeble-minded-children-1916/).

Superior Court of California. (2019). "Conservatorships of Adults." The Superior Court of California, County of San Francisco. Retrieved November 19, 2019 (https://www.sfsuperiorcourt.org/divisions/probate/conservatorships-of-adults)

Thunder Hawk, Madonna. (2007). "Native Organizing Before the Non-Profit Industrial Complex." In Incite's *The Revolution Will Not Be Funded: Beyond the Non-Profit Industrial Complex*. South End Press: Cambridge: 101-7.

Trent, James W. (1994). *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. University of California Press, Berkeley.

U.S. Census Bureau. (2018). "Quick Facts: Alameda County, California." *U.S. Census Bureau*. Retrieved November 22, 2019 (https://www.census.gov/quickfacts/fact/table/alamedacountycalifornia/INC110217#INC110217).

U.S. Congress. Senate. Committee on Health, Education, Labor, and Pensions. (2010) "Rosa's Law : Report (to Accompany S. 2781)." Washington, D.C.: U.S. G.P.O. Retrieved November 17, 2019

(https://www.federalregister.gov/documents/2017/07/11/2017-14343/rosas-law)

U.S. Department of Education, Individuals with Disabilities Education Act. (2019). "Statute and Regulations." US Department of Education IDEA Website. Retrieved November 17, 2019 (https://sites.ed.gov/idea/statuteregulations/)

U.S. Department of Education. (2015). "The Rehabilitation Act of 1973: As amended through PL 114-95, enacted December 10, 2015." *US Department of Education*. Retrieved November 17, 2019 (https://www2.ed.gov/policy/speced/leg/rehab/rehabilitation-act-of-1973-amended-by-wioa.pdf)

U.S. Department of Labor, Office of Disability Employment Policy. (n.d.). "ODEP Employment First." Department of Labor. Retrieved November 17, 2019 (https://www.dol.gov/odep/topics/employmentfirst.htm)

U.S. Department of State. (2010). "Judith Heumann." *U.S. Department of State Archive: Senior Officials Biographies.* Retrieved November 17, 2019 (https://2009-2017.state.gov/r/pa/ei/biog/144458.htm)

U.S. Food and Drug Administration. (2016). "FDA News Release: FDA proposes ban on electrical stimulation devices intended to treat self-injurious or aggressive behavior." *FDA*. Retrieved November 20, 2019 (https://www.fda.gov/news-events/press-announcements/fda-proposes-ban-electrical-stimulation-devices-intended-treat-self-injurious-or-aggressive-behavior).

Walker, Nick. (2013a). "Throwing Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm." *Neurocosmopolitanism: Notes on Neurodiversity, Autism, and Cognitive Liberty* (blog). Retrieved November 20, 2019 (https://neurocosmopolitanism.com/throw-away-the-masters-tools-liberating-ourselves-from-the-pathology-paradigm/).

Walker, Nick. (2013b). "Neuro-what?" *Neurocosmopolitanism: Notes on Neurodiversity, Autism, and Cognitive Liberty* (blog). Retrieved November 20, 2019 (https://neurocosmopolitanism.com/neuro-what/).

Walker, Nick. (2014a). "Neurodiversity: Some Basic Terms & Definitions." *Neurocosmopolitanism: Notes on Neurodiversity, Autism, and Cognitive Liberty* (blog). Retrieved November 20, 2019 (https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/).

Walker, Nick. (2014b). "Toward a Neurocosmopolitan Society."

Neurocosmopolitanism: Notes on Neurodiversity, Autism, and Cognitive Liberty (blog). Retrieved November 20, 2019 (https://neurocosmopolitanism.com/toward-a-neurocosmopolitan-society/).

Walt Disney Productions, Samuel Armstrong, and Lewis Carroll. (1951). *Walt Disney's Alice in Wonderland*. Racine, Wis: Whitman.

Washington, Booker T. (1901). *Up From Slavery: An Autobiography*. Value Classic Reprints.

Watson, John B. (1913). "Psychology as the Behaviorist Views It." *Psychological Review*, 20, 158-177.

Watson, John B. & Rayner, R. (1920). "Conditioned Emotional Reactions." *Journal of Experimental Psychology*, 3.1: 1-14.

Weber, Max. (1922). *Economy and Society*. University of California Press: Berkeley.

Weber, Max. (1947). *Theory of Social and Economic Organization*. Oxford University Press.

Weber, Max, Hans Gerth & C. Wright Mills. (1958). *From Max Weber: Essays in Sociology*. Oxford University Press: New York.

Wehmeyer, Michael. (1999). "A Functional Model of Self-Determination: Describing Development and Implementing Instruction." *Focus On Autism and Other Developmental Disabilities*, 14.1: 53-62.

Wehmeyer, Michael. (2005). "Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations" *Research and Practice in Severe Disabilities*, 30.3: 117.

Wehmeyer, Michael & Sharon L Field. (2007). *Self-Determination: Instructional and Assessment Strategies*. Corwin Press, Sage Publications: Thousand Oaks, CA.: 3-5.

Wehmeyer, Michael. (2011). "Section 2: Defining Self-Determination: Second Section of A Presentation Entitled 'What is Self-Determination and Why is it Important?" *National Gateway to Self-Determination. Youtube.* Retrieved November 26, 2019 (https://www.youtube.com/watch?v=VC2SLLHMsHo).

White, Brent. (2016). "ACAT: Ala Costa Adult Transition Program." *WordPress*.

Retrieved November 15, 2019 (https://alacosta-acat.org/?fbclid=IwAR3l8BL_HjEd7jsvk3mtRzvlTsRexVk9oV74Esq7Edl6widXMoeaAhQ7pKs).

White, Brent. (2016). "Little Spiel." *ACAT/ACT Programs of Ala Costa Centers*. (Unpublished).

Whitfield, Norman & Barrett Strong. (1970). "War." [Recorded by Edwin Starr]. On *War & Peace*. Motown Records.

Wilder, G., Albertson, J., Stuart, M., Dahl, R., & Warner Home Video (Film). (1971). *Willy Wonka & The Chocolate Factory*. United States: Warner Home Video.

Wing, Lorna. (1981). "Language, Social, and Cognitive Impairments in Autism and Severe Mental Retardation." *Journal of Autism and Developmental Disorders*, 11.1: 31-44.

Wing, Lorna. (1988). "The Continuum of Autistic Characteristics." In E. Schopler & G. Mesibov (Ed.) *Diagnosis and Assessment in Autism*. Springer. 91-110

Wolfensberger, Wolf. (1972). *The Principle of Normalization in Human Services*. National Institute on Mental Retardation: Toronto.

Wolfensberger, Wolf. (1983). Social Role Valorization: A Proposed New Term for the Principle of Normalization. *Mental Retardation*, 21.6: 234-9.

Wolfensberger, Wolf. (1999). "A Contribution to the History of Normalization, with Primary Emphasis on the Establishment of Normalization in North America between 1967-1975." In Flynn and Lemay's (Ed). *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. University of Ottawa Press: Ottawa. 51-116.

Wolfensberger, Wolf. (2017a). "PASS/PASSING." *Wolf Wolfensberger*. Retrieved November 19, 2019 (https://wolfwolfensberger.com/life-s-work/pass-passing).

Wolfensberger, Wolf. (2017b). "Wolf Wolfensberger." *Wolf Wolfensberger*. Retrieved November 19, 2019 (https://wolfwolfensberger.com/wolf-wolfensberger).

Wright, Peter W. D. & Pamela Darr Wright. (2019). "Transition, Transition Services, Transition Planning." *WrightsLaw*. Retrieved November 17, 2019 (https://www.wrightslaw.com/info/trans.index.htm).

Wynter, Sylvia. (2003). "Unsettling the Coloniality of Being/Power/Truth/Freedom: Towards the Human, After Man, Its Overrepresentation—An Argument." *The New Centennial Review*, 3.3: 257-337.

Wynter, Sylvia. (2015). *On Being Human As Praxis*. McKittrick (Ed.). Duke University Press.

Zukas, H. (1975). "The History of the Berkeley Center for Independent Living" *Independent Living Institute*. Retrieved September 8, 2018 (https://www.independentliving.org/docs3/zukas.html).