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„ Autism in the US: Employment vs Policy “

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Authors Note

Before I begin, I feel that it is imperative to discuss that for the duration of this thesis, I will use multiple ways to describe those with developmental disabilities. It is in no way my intention to further marginalise, discriminate or “other” any person with a disability by the language I have used. When referring to certain terms which we now know to be politically incorrect, I will first introduce the word with quotations “” and then subsequently for each use I will not. While I do recognise the negative nature of these terms, for the purpose of this paper and to provide an accurate historical and social context, I will not shy away from using them only when appropriately necessary. I would like to further note that when referring to people with intellectual/developmental disabilities I will likely use “them” if a sentences contains ID/DD repeatedly. This is simply a grammatical preference and I do not in any way mean to group people with ID/DD as an “other”. I will largely refer to the phrases “people or persons with disabilities” to keep with a person-first approach.

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List of Abbreviations

ASD	Autism Spectrum Disorder
PDD	NOS Pervasive Developmental Disorder-not Otherwise Specified
AS	Asperger Syndrome
ID	Intellectual Disabilities
DD	Developmental Disabilities
DSP	Direct Support Professional
DSW	Direct Support Worker
SADS	Social Adult Day Services
CDC	Centre for Disease Control
ACLU	American Civil Liberties Union
ICF	Intermediate Care Facility
IRA	Individual Residential Opportunities
US	United States
UN	United Nations
UDHR	Universal Declaration of Human Rights
CRPD	Covenant on Persons with Disabilities
NYC	New York City
NYS	New York State
MFP	Money Follows the Person
NADSA	National Adult Day Services Association
OPWDD	Office for People with Developmental Disabilities
ODEP	Office of Disability Employment Policy
USC	United State Supreme Court
HCBS	Home and Community Services Waivers
ADA	Americans with Disabilities Act
IDEA	Individuals with Disabilities Education Act
WOIA	Workforce Innovation and Opportunity Act

WIA	Workforce Investment Act
NMHA	National Mental Health Act
NIH	National Institute of Health
CMHA	Community Mental Health Act
CMS	Centre for Medicaid Services
LPS	Lanterman-Petris-Short
CRA	Civil Rights Act
EEOC	Equal Employment Opportunity Commission
SI	Self Injurious
NIMH	National Institute of Metal Health
UCP	United Cerebral Palsy
DOJ	Department of Justice
DOeD	Department of Education
DOL	Department of Labor
ECT	Electroconvulsive Therapy
SSA	Social Security Act
ECHR	European Court of Human Rights
JAN	Job Accommodation Network

Abstract

People with various developmental and intellectual disabilities have been portrayed throughout history in ways which still to this day influence how society perceives and treats them. These attitudes and ideas were reflected most significantly via different policy shifts and programs which were designed to treat but ultimately were hindering the capabilities of adults with ASD in the United States. There has been a dramatic change in the disclosure surrounding people with disabilities in the United States but the persistence of an “other-ing” has remained. Different models of disability have evolved with social perceptions which have further advanced the ways for advocates and policy members to approach disability as well as how to ensure the protection of people with disabilities’ rights. This progression has been reflected in employment rates of adults with ASD and this study seeks to find the effects of social care programs on the employment of adults on the autism spectrum. A summary of the historical context of people with developmental and intellectual disabilities provided the necessary framework to understand the complexities of evolution of rights for adults wth ASD in the US. A mixed method approach using both qualitative and quantitative data was used in order to understand the experiences, attitudes and perceptions of adults with ASD, their families and direct support workers have on the employment services. Analysis of data suggested that attitudes, lack of support and job satisfaction had the most prominent effects on the successful employment of adults with ASD.

Key Words: *Autism Spectrum Disorder, Intellectual Disability, Deinstitutionalisation, Employment Rates, Disability rights*

Abstract (German)

Menschen mit unterschiedlichen Lernschwierigkeiten oder Entwicklungsstörungen wurden im Laufe der Geschichte in einer Art und Weise dargestellt, die bis heute Auswirkungen darauf hat, wie die Gesellschaft sie wahrnimmt und behandelt. Diese Einstellungen und Überzeugungen wurden vor allem durch verschiedene Gesetzesänderungen und - Programme deutlich, die dazu dienen sollten, Menschen mit Autismus in den Vereinigten Staaten von Amerika zu fördern, jedoch konträr dazu ihre Fähigkeiten und Möglichkeiten beschränkten. Es fand ein enormer Wandel im Diskurs um Menschen mit Behinderung in den USA statt, jedoch existiert das Phänomen des Other-ings auch weiterhin. Durch unterschiedliche Modelle von Behinderung basierend auf gesellschaftlichen Wahrnehmungen wurden Interessensverbände und Politiker in ihrer Arbeit bestärkt und ein besserer Schutz der Rechte von Menschen mit Behinderungen ermöglicht. Diese Entwicklung spiegelt sich in den Beschäftigungszahlen von Erwachsenen mit Autismus wieder und die vorliegende Studie untersucht die Auswirkungen von sozialen Fürsorgeprogrammen auf die Beschäftigung von Menschen mit Autismus. Eine Zusammenfassung des historischen Konzepts von Menschen mit Lernschwierigkeiten und Entwicklungsstörungen bildet den notwendigen theoretischen Rahmen, um die komplexe Entstehung der Rechte von Erwachsenen mit Autismus in den USA zu verstehen. Es wird eine Mischung sowohl von quantitativen als auch von qualitativen Methoden angewandt, um die Erfahrungen, Einstellungen und Wahrnehmungen von Erwachsenen mit Autismus, ihren Familien und direkten Bezugspersonen im Arbeitsalltag aufzuzeigen. Bisherige Forschungsergebnisse deuten darauf hin, dass Einstellungen, fehlende Unterstützung und Freude an der Arbeit die einschlägigsten Auswirkungen auf die erfolgreiche Beschäftigung von Erwachsenen mit Autismus haben.

Schlagworte: *Autismus, Lernschwierigkeit, Deinstitutionalisierung, Beschäftigungszahlen, Recht von Menschen mit Behinderungen*

LITERATURE REVIEW

To adequately describe, research and analyse the different aspects of this thesis credit must begin to those who have contributed to the work before me and made my current research possible. This section provides a brief overview of the major literary and statistical contributions which I have used throughout this thesis. When discussing the history of disability and the ways in which the concept and policies that shape it have evolved, I decided to take a mixed approach. By doing this I was able to negate the limitations of only using one approach by the strength that comes from having more information, thus giving a better picture. Instead of focusing on one specific idea or piece of legislation, I started with a history which begins with the enlightenment period in order to expose fundamental ideas which have been a part of the United States for over 400 years. These social "norms" have been deeply instilled in society and it is necessary to analyse their origins as well as their criticisms to understand where there ideas that shape disability today have come from. I then chose to use a well known political scientist to ground those perceptions in the hard facts of the different types of policy and movements that have gone on in the US. I paired this with the key paradigms and themes that were produced by scholars such as Foucault and Nussbaum in order to give the most interdisciplinary approach.

John Locke, An Essay Concerning Human Understanding and a Second Treatise of Government, the first essay from Locke was of particular importance for this paper in order to show the beginnings of where the current social perceptions of those with mental illness and developmental disabilities has derived from. His work with developing "the idiot" and "idiocy" is crucial to understanding the fundamentals of personhood and the concept of citizenship as we understand it today. In his later work, he speaks of the social contract that all citizens enter upon choosing to participate within society or are ultimately left out of because of their mental disposition. In *A Second Treatise of Government* Locke defines the social contract which people enter and notably states that

"Men being, as has been said, by nature, all free equal and independent, no one can be put out of this estate, and subjected to the political power of another, without his own consent."[1] This concept is especially notable for this thesis as the idea of consent can only be rationalised with someone (a participating member of society) who is able to consent.

From Asylum to Community: Mental Health Policy in Modern America, Gerald Grob. Gerald Grob, a political scientist and historian gives a detailed overview of the history of mental illness and the social history of what it was like for persons with mental illness and disabilities in 1940-1970s America. He provides a large overview of the policy work that was done for those in the mental health system throughout the forty year span. By doing so, he sheds a light on an unusual group of social advocates for policy changes, the clinicians and psychiatrists who were treating patients at the times.[2] His work follows the head of the National Institute for Mental Health at the time, Robert E. Felix and how he and his supporters were able to overhaul the health care system in such a short span of time. He focuses on those who have obtained services through public assistance programs and provides a backdrop for the development of social policy and the welfare system in the United States. His opinion is definitive that the United States government and its policy members too a grave misstep when they chose to dismantle and subsequently deinstitutionalise state and government run hospitals. The result was a large number of patients severely needing psychiatric services who were cast out into the community with people who were unable to care for them, or worse were left to fend for themselves.

Michel Foucault, gives a timeline of the history of Westernised madness beginning in the Middle Ages to modern day social treatment of those with intellectual disabilities and mental illness. He discussed the key paradigm shifts relating to the which in which

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[1] J. Locke, 'A Second Treatise of Government'

[2] John C Burnham The American Historical Review Vol. 97, No. 4 (Oct., 1992), pp. 1297-1298.

madness and mental disability was perceived throughout different time periods in history. With focuses on delirium and social isolation he analyses the ways in which each society had attempted to create boundaries to separate those who are considered to be what is normal and those who were deemed mad. Foucault introduced the different categorisations of those who were mad, impoverished or insane and the social implications that arise in relation to isolation and confinement from each of them. It would seem that the push for community based care consisted of many wins and losses for the larger group of people with disabilities. Scholars like Foucault surmise that community-based care was not the freedom from institutionalisation that they thought, but merely was a new distribution of power between those with disabilities and those without. He notably acknowledges that "we normals" have ascertained our power through the continuous social isolation and exclusion of people who are different (i.e. disabled, mentally ill and incarcerated).[3] His work on the paradigm between power and knowledge was essential to completely understanding the concept of disability within this thesis.

Martha Nussbaum *Frontiers of Justice: Disability, Nationality and Species Membership 2006* Martha Nussbaum, a prominent figure in American Philosophy writes about social contract theory that has been widely discussed among philosophers such as Locke, Rousseau, Kant and Rawls. She gives a basic overview of the problem with earlier schools of thinking of the contractual agreement. In its most basic form, Social Contract theory itself supposes that all people enter into a social contract because they believe they will get something out of it, and it assumes that any person would not enter into that contract if they did not think they would get something. So who is to say that a rational or "normal" person would enter into the contract if they knew they other person (someone with an intellectual disability) would not be able to give the same type of con-

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[3] C. Drinkwater, "Supported Living and the Production of Individuals" *Foucault and the Government of Disability*, University of Michigan Press, 2006, pp. 229.

tribution?[4] She puts forth a set of ideas, which she deems a capabilities list that seeks to resolve the pitfalls of earlier theory which left out the experiences of those with intellectual disabilities.

UCP Foundation: Case For Inclusion Report, 2019

This report gives a brief background of the history of people with ID/DD and the reasoning describing why the report is relevant today. A Case for Inclusion was created by the United Cerebral Palsy Foundation and the American Network of Community Options and Resources and uses data from various institutions across the 50 states and District of Columbia. The report focuses on the success and failures of implementation of policy in relation to inclusive community services. Since its first report in 2006, it has greatly impacted the ways in which medicaid services are distributed and helped to shape person centred disability policies within the United States.

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[4] M. Nussbaum, ‘Frontiers of Justice: Disability, Nationality, Species Membership’ Cambridge, Harvard University Press, 2006, pp. 15.

CHAPTER 1. INTRODUCTION

1.1 Scope and Approach to Research

In order to fully comprehend the complexities of the evolution of rights for people with Intellectual Disabilities in the labour market, it is important that readers understand and have the relevant social context of people with Autism but also people with ID/DD that comes from history. It is also imperative to recognise, if only on the surface, how the history of ideas that accompanies people with intellectual disabilities gives way to how society continues to perceive them at large. This thesis will provide a full historical context which will give insight on the events leading up to the mass psychiatric policy reform that was the result of institutionalisation and deinstitutionalisation of people with DD/ID which ultimately contributed to the perceived norms of disability today. I will give extensive background information on the different types of policy the United States has adopted in order to protect the rights of people with disabilities so that a common baseline is established. I will then present the findings from my own research which was distributed via a survey evaluation through an undisclosed nonprofit in New York City.

The evaluation given to individuals, family members and support staff was used with the intention of gathering information which would provide an insight to further comprehension of problem areas related to how individuals with Autism procure/maintain employment.

The research question which drove this thesis was:

What are the effects of social care programs on the employment rates of adults with autism?

For this research, “social care programs” was intended to mean government assistance programs such as medicaid which fund adult day programs, vocational programs and supported employment for adults with autism in the United States.

1.2 History of Social Context of People with ID/DD

This chapter will highlight the challenges and stigma that have surrounded people with intellectual disabilities throughout time—specifically autism**.** The evolution of the way in which people with intellectual disabilities have been treated can be best described as consistently poor. There has been a lot of research done on the history of how people with disabilities have been treated from as early as the greek and roman empires. For the sake of time I will begin my historical overview from the late 1600s on.

People with mental illness and disability have been called many names over the course of history; countless time periods and cultures one after another, have all helped shape the way in people with disabilities are treated. Throughout recorded history there has been documentation of those deemed "less than" and that have had their worth attributed to their mental state.[5] Progress for people with intellectual disabilities has been continuously halted, with any signs of progression often times being met by ignorance. Language has always played a crucial role in how people with disabilities are treated; words give way to attitudes, perceptions, feelings and judgements about those who are deemed different by society.

In the late 1600's words like mad, idiocy, lunacy, heretic, imbeciles and fool were often the terms used to describe both the ostracised from society and those we know now to have likely suffered a mental illness or disability.[6] It was under these names that countless individuals were persecuted and cast out to rid society of the "oth-

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[5] G. Grob & H. Goldman, *The Dilemma of Federal Mental Health Policy: Radical Reform or Incremental Change?* Rutgers University Press, 2006, pp. 1.

[6] Grob, 2006, pp. 2-3.

er". [7] The difference of characterisation could be essential to solving particular disputes and the words which were used mattered greatly. When it came to legal or estate matters, these words were the differences between inheriting or owning property or not, but more serious offences could be deciding whether someone was accused of being involved in witchcraft, which could ultimately lead to torture or death.[8] The ways in which these individuals were received by each community largely contributed to the social exclusion of persons with DD/ID.[9] By the late 1950s with the advancements of antipsychotics and growing field of psychiatry there was a big push for policymakers to begin the deinstitutionalisation of many state run hospitals. This movement would place patients in less restrictive settings and give them a more inclusive form of treatment within their own communities. The massive changes to how people with ID/DD/Mental Illness were being treated in the community exacerbated already known stigmas and abusive rhetoric. The response to this was a new movement in the 1970s, which saw the reclaiming of some of the words as a way for people with mental illnesses to redefine the term which had for so long been used to define them derogatorily.[10] One of these instances is the reemergence of the term "madness" which at one point deeply signified an "other-ing" which was coupled with abuse and torment, now acts as a synonym for the terms "mental illness or disorder". [11] Because of the nature of the resurfacing of this term a new discipline referred to as "Mad Studies" has come about with the goal of "engaging and transforming oppressive languages, practices, ideas, laws, and systems,

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[7] M. Foucault, *Madness and Civilisation: A History of Insanity in the Age of Reason*, New York, Pantheon Books, 1965, pp. 10.

[8] T. Szasz, *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement*, Syracuse University Press, 1970, pp. 2

[9] Grob, 2006, pp. 1.

[10] P. Beresford, 'Foreword', *Mad Matters: A Critical Reader in Canadian Mad Studies*, Canadian Scholars Press Inc, 2013, pp. 1.

[11] P. Beresford, pp. 10.

along with their human practitioners, in the realms of mental health and the "psy" sciences".[12]

Throughout the Enlightenment period, scholars such as John Locke began a characterisation of "idiocy"[13] that would take hold for hundreds of years to come. The significance of Locke's work is in part due to his career both as an English Philosopher and physician[14], his ideas continue to shape much of the way in which people think today.[15] While Locke references the "idiot" in nearly all of his political writings it is in his one of his most notable works, *An Essay Concerning Human Understanding* that he sets an ideology for those with intellectual disabilities that truly casts them as a sort of second class citizen with limited personhood and political inclusion.[16] The idiot acts as a polar opposite of a "rational" person and because of this causes an exaggerated contrast of what we would consider to be normal. In an *Essay concerning human understanding*, Locke begins writing to understand the origin of human knowledge and experience.[17] This work boldly asserts that our knowledge is gathered from our own individual and collective experiences as people and rejects the existence of innate ideas, this notion became the basis for much of what is now considered westernised empiricism.[18]

In order to establish Locke's own political theory of human understanding and knowledge, the idiot figure is essential to his argument, where he uses it first to counter

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[12] B. LeFrancois, R. Menzies & G. Reaume, 'Introducing Mad Studies', *Mad Matters: A Critical Reader in Canadian Mad Studies*, Canadian Scholars Press Inc, 2013, pp. 13.

[13] Idiocy was defined by Locke as….

[14] His profession as a physician largely relates to why he emphasises a very medical model of disability when describing people with mental illness and disability.

[15] P. Connolly, "John Locke" *Encyclopaedia of Philosophy,* pp. 9.

[16] S. Simplican, *The Capacity Contract: Intellectual Disability and the Question of Citizenship*, University of Minnesota Press, 2015, pp. 2.

[17] J. Locke & P. Nidditch, *An Essay Concerning Human Understanding*, Oxford, Clarendon Press, 1975, pp. 20-25.

[18] Locke & Nidditch, pp. 30.

the existence of innate ideas, second, to clarify what it means to be a human who understands things and third, to remove them from the category of people altogether and classify them somewhere between man and beast.[19] Idiocy is essential to the description of how “normal” humans go through the motions of human understanding and without one he is unable to justify the other. In order to reject the existence of innate ideas, Locke creates a timeline of what he considers to be the evolution of human understanding. Locke first begins with “brutes, idiots and madmen” where he decidedly explains that while a brute is able to observe surroundings and has a slight ability to recall information, they are less than a man because they are unable to form simple ideas.[20] A perception that was widely held by the communities in which people with any mental deviation from the standard norm lived at the time. Locke then goes on to explain how an idiot still cannot think for themselves, nor are they able to truly interact, hold intelligible conversations or “think beyond their instinct”.[21] The differences between Locke’s *brute* and *idiot* are only slight when it comes to mentally, his classification of idiot above brute is only because of the appearance of the body; where an idiot is more closely related to a human than a brute.[22] He does place a large importance on the appearance of a body which is true to sticking with the medical model of disability.[23]

The way in which Locke distinguishes between madman and idiot is unmistakable and socially defining he begins by asserting that idiots have no ability and cannot reason. Whereas mad men do have the capability to be reasonable but they don’t have the correct knowledge of how to understand things or problem solve new ideas for themselves so that they *do* not reason. He makes the conclusion that idiots are less than madmen in any society and pushed forward a set of central ideas that would continue to

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[19] S. Clifford, ‘The capacity contract: Locke, disability, and the political exclusion of “Idiots”’ *Politics, Groups, and Identities*, vo. 2, no. 1, 2014, pp. 90-103

[20] S. Clifford, pp. 92

[21] ibid., pp. 92

[22] ibid., pp. 94.

[23] Foucault, pp. 14.

evolve against people with disabilities through time. This is greatly understood amongst many scholars in the field by crediting him with one of the first differentiations between a mental illness and an intellectual disability.[24] This was a big step forward as the first notable and explicit separation between mental illness and ID which were before considered mutually exclusive.

Moving forward one hundred years, the introduction to S.G Howe's *On the Causes of Idiocy* (1848) begins with "The evils which now infest Society are not inevitable: Idiots, Fools, Simpletons. Circumstances or causes which predispose persons to idiocy".[25] This particular work was a study which was commissioned by the state of Massachusetts in the mid 1800s with the goal of finding out what exactly makes an someone an "idiot". It also was used to determine whether or not there was a way to alleviate them of this "burden".[26] This study was led by S. G. Howe, and he received much criticism from his peers for assuming there was any help to be had for those known as an idiot.[27] He followed behind french physician Edouard Sequin who too believed that those referred to as "mentally retarded" were able to learn and be taught how to participate in society.[28] This was a widely uncommon and often rejected idea for the time period. To find the cause of idiocy, a three-person commission was given a list of known idiots within the state of Massachusetts that they were to go interview and record their findings. The true extent of the labelling of an "otherness" for those with a disability was unparalleled, with them being able to be identified by a list, they were categorised and accounted for by state with little regard to the implications of their person-

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[24] J. Harris, 'Intellectual Disability: Understanding Its Development, Causes, Classification, Evaluation, and Treatment' *Oxford University Press*, 1 September 2005, pp. intro.

[25] S. G. Howe, 'On the Causes of Idiocy' 1858.

[26] S.G. Howe, 'On The Causes of Idiocy' (1858), in C. Northwick, M. Simpson (eds.) *History of Learning Disability,* History of Intellectual and Developmental Disability, 2001, pp. 1-10.

[27] G. Grob 'From Asylum to Community: Mental Health Policy in Modern America' Princeton University Press, New Jersey, 1991, pp. 3.

[28] Edouard Seguin, *New World Encyclopedia, 2007,* Retrieved 30 May 2019 from //www.newworldencyclopedia.org/p/index.php?title=Edouard_Seguin&oldid=997727.

hood. It just so happened that for many of the individuals who were seen by this commission it was reported that it was "difficult to say whether the person should be called an idiot".[29] For these individuals commonly described by the reporter as persons who were often severely limited in language and social skills, had trouble connecting with family or neighbours, and sometimes had perfect skills in music or art.[30] With what is known today, these people would be classified as somewhere on the Austin Spectrum.

It was around this same time in the mid 1850s that activist Dorothea Dix fought for those with mental illness and intellectual disability. She toured many hospitals which housed those being cared for by the state, and advocated for politicians and states to do better because of what she saw.[31] Throughout the course of her life time she helped open 32 state psychiatric hospitals dedicated to caring for these individuals. While her actions were for the benefit of those held in institutions, the state hospitals simply were not prepared for the amount of work that resulted.[32] All though inpatient care provided people with disabilities access to more services, the hospitals themselves were largely underfunded and understaffed. With the emergence of the psychiatric field, asylums would prove to be the centrepiece of the legal and practical framework that comprised the discipline.[33] By the 1940s nearly 90% of all of the institutionalised people in the country were under the care of public run hospitals.[34] The living conditions where many of these people with ID/mental illness lived were harsh and in certain cases cruel. Institutions

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[29] C. Northwick, M. Simpson, pp. 2.

[30] J. Donavan, C. Zucker, 'The Early History of Autism in America: A surprising new historical analysis suggests that a pioneering doctor was examining people with autism before the Civil War' *Smithsonian Magazine,* January, 2016.

[31] Norwood, Arlisha. "Dorothea Dix." National Women's History Museum. National Women's History Museum, 2017. Date accessed.

[32] Unite For Sight, Module 2: A Brief History of Mental Illness and the Us Mental Health Care System, New Haven, CT, 2003, accused via: https://www.uniteforsight.org/mental-health/module2

[33] E. Novella, 'Mental Health Care and the Politics of Inclusion: A social Systems account of Psychiatric Deinstitutionalisation' *Journal for Theoretical Medicine and* Bioethics, vol. 31:6, pp. 414.

[34] ibid., pp. 414.

which were originally designed to segregate/cure the mentally ill and intellectually disabled were ultimately found to be in violations of human rights and closed down. Hundreds of stories came out in newspapers and books which showed the true ways in which institutions were "caring" for their disabled population. Most notably the exposé *The Shame of the States* was released by Albert Deutsch which fully detailed the extent of the issues that were plaguing many of the hospitals within the mental healthcare system.[35] Examples of these institutions can be found in all of the fifty states, however I will later focus specifically on two in both New York and Chicago. Where the Willowbrook State School in Staten Island, New York and the Cook County Infirmary later referred to as "Dunning" in Chicago would be homes to some of the poorest living conditions of people in state care in history.[36]

With institutionalisation on the rise from the later part of the 18th century there were almost 560,000 individuals who were committed to institutions all across the US by the early 1960s.[37] In order to combat the rise of people being labeled as crazy or lunatics, states began to take steps in order to ensure these "undesirable" traits would not be passed forward. Many states were introduced to the concept of Eugenics, which is defined as "the science of improving a human population by *controlled* breeding to increase the occurrence of desirable heritable characteristics" and was a popular belief among those who sought to "preserve" what were considered *right* Americans.[38] In 1907, Indiana became the first of many states to enact a compulsory sterilisation law. The Indiana Eugenics Law of 1907 sterilised the "undesirables, defectives, and mentally retarded" who were institutionalised and thought to be unfit to procreate and pass along

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[35] Grob, 2006, pp. 16.

[36] D. Ferguson, 'Historian unearths IDs of thousands buried in Dunning mass grave' *Chicago Tribune,* 21 October, 2014.

[37] Unite For Site, Module 2.

[38] Dyck, E. 'Institutionalisation', *Eugenics Archive,* 5 December, 2014, Retrieved May 30, 2019, from http://eugenicsarchive.ca/discover/tree/54823635bf64660000000001

their genes to the rest of society.[39] More than 29 states followed this example and came up with their own eugenics laws which again sought to "preserve" pure races thus leaving no room for another group which was already socially excluded.[40]

Henry Goddard, a well know eugenist and the Director of Research at a training school for the feeble-minded in New Jersey was largely responsible for the projection of these now proven false narratives. He also is accredited with the invention of the word *moron*, from a greek word which typically meant dull or stupid.[41] He used the word in order to characterised those who were *criminally* stupid and used this as a basis for many deportations during the flux of immigration in the early 1900s.[42] He authored a book "The Kallikak family" which would soon become a major tool for those in favour of the eugenics movement. The book, claimed to be a case study by Goddard, followed a young girl who was feeble-minded and in the care of his school, he traced back her family history to an affair three generations ago between a grandfather and woman who was considered "feeble and degenerate".[43] This, according to Goddard, led to almost all of the descendants within the family being in some way tainted and warned that this this particular type of trait could easily be passed on from generation to generation and stated that these types of families were multiplying and contributing to the "rising tide of feeble-mindedness".[44]

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[39] P. Reilly, "Involuntary Sterilisation in the United States: A Surgical Solution", *The Quarterly Review of Biology,* vol. 62, no. 2, June 1987, pp. 153-170.

[40] Ibid., pp. 156.

[41] M. Dambeck & T. Reynolds, *History of Stigmatising Names For Intellectual Disabilities,* Mentalhelp.net: An American Addiction Centres Resource, accessed at: https://www.mentalhelp.net/articles/history-of-stigmatizing-names-for-intellectual-disabilities-continued/

[42] J. Straley, 'It Took a Eugenicist To Come Up With "Moron"' *National Public Radio,* 14 February, 2014, accessible at: https://www.npr.org/sections/codeswitch/2014/02/10/267561895/it-took-a-eugenicist-to-come-up-with-moron

[43] I. Grenon, J. Merrick, "Intellectual and Developmental Disabilities: Eugenics" *Frontiers in Public Health,* vol. 2, no. 201, 20 October, 2014.

[44] ibid.,

These ideas were quickly picked up by vocal eugenists of the time; for in their view, the United States needed to be the strongest it could be during wartime, and those with intellectual disability or mental illness simply would bring down the quality of people within the system.[45] In 1911, would-be president and then governor of New Jersey signed into law a bill which again called for the compulsory sterilisation of criminals and the mentally retarded.[46] California was one of the most offending states with records showing that at least 20,000 people were sterilised over a thirty year period. These procedures were preformed quickly, and without the knowledge of the individual; often times they were told they were receiving a general procedure rather than the truth. The highest court in the United States Supreme Court would hear a case *Buck v. Bell* (1927) which would allow for the continuation of forced sterilisation.[47] The stigma and beliefs that led to these types of actions were a direct result of the words which have been used to describe people with intellectual/developmental disabilities and mental illnesses throughout history. The stereotypes and dramatised narratives that accompanied them were largely influenced by scholars such as John Locke who continue to be widely respected in the philosophical field while simultaneously still pushing these narratives.

1.3 The Push for Deinstitutionalisation

Other treatment doctors in the early to mid 1900s used to try to eradicate the symptoms of those with intellectual disability, mental illness and behavioural issues were more invasive than the initial treatments used (isolation/restraint). These ranged from shock therapy to psycho surgery (lobotomies) to the uses of newly discovered psy-

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[45] ‘Involuntary Sterilisation of Disabled Americans: An Historical Overview’, *ABC Law Centre,* 6 November, 2018, accessible at: https://www.abclawcenters.com/blog/2018/11/06/involuntary-sterilization-of-disabled-americans-an-historical-overview/

[46] P. Rahe, “Woodrow Wilson: This So-called Progressive was a dedicated Racist”, *Foundation for Economic Education,* 17 September 2016.

[47] Nourse, V. (2011). Buck v. Bell: A Constitutional Tragedy from a Lost World. Pepp. L. Rev., 39, 101.

chotropics.[48] In the 1930s, insulin therapy and electroshock therapy or also known as electroconvulsive therapy (ECT) was used as a means to treat violent convulsive and seizure behaviour.[49] ECT still to this day remains controversial in whether or not it should be used as a forefront to fight mental illnesses and severe behavioural symptoms or as a last resort which is heavily regulated due to its extreme side effects i.e. to those surviving the high death rate but being rendered particularly indifferent and "child-like".[50] It was through these invasive and reportedly damaging practices that physicians relied upon to treat disorders until psychotropic drugs made their appearance. Doctors then began to opt for a lesser invasive form of treatment, before long term studies were concluded to show the potential side effects of these mind altering drugs.[51]

With emergence of medication to treat symptoms and patients vocalisation/condemnation of the isolating environments that had been used for treatment, were begins a shift from "asylum based" to community based care. This movement was on there rise in many countries and the United States undertook the massive overhaul to the health care system in a short amount of time which see the release of patients from state run institutions. Although there was no formal set of international standards for the treatment of persons with disabilities, the US began to move toward a more inclusive way of treating its disabled population. As referenced in Section 1.2 deinstitutionalisation was the response to patients dissatisfaction and the community based model of taking care of the ID/DD/Mentally Ill population. These new attitudes furthered the push for anti-discrimination advocacy that was happening in the country at the time with the civil rights movements already fully underway. The limited personhood of people with disabilities and mental illnesses played a key role in why people with ID were being so

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[48] D. Healy & E. Shorter, 'Shock Therapy: A History of Electroconvulsive Treatment in Mental Illness' New Jersey/London, *Rutgers University Press*, 2007, pp. 1.

[49] A.M. Foerschner, "The History of Mental Illness: From Skull Drills to Happy Pills" *Inquiries Journal: Social Sciences, Arts and Humanities,* vol. 2, no. 9, 2010, pp. 2.

[50] Healy, pp. 3.

[51] Grob, 1991, pp. 135.

outwardly discriminated against for so long. Equality was dictated by a set amount standards and disability was not one of them. The United States constitution entrusted the welfare of the people (all people) to the states, which enabled the idea of localised government. This meant that the federal government at the time did not recognise the obligation to push for policy which would have had far reaching effects across the entire country.[52] Local communities and their attitudes had a direct correlation with what was going to be pushed for policy of that state, which led to inconsistencies with the way in which deinstitutionalisation was carried out. The original goal of the movement from asylum based care was meant to centralise around the reforms of psychiatry as a whole after the second World War.[53] Common belief among psychiatrists at the time was that people would better benefit from being in their own communities receiving care, rather than segregated in an institution.[54] This was a major shift from the central ideas which first began with the concept of asylums, where individuals were meant to be kept away from the outside world in order to receive treatment which would make them better.

With the creation of the Social Security Act, the United States federal government was taking a collectively more involved approach to caring for its citizens. This landmark act in policy was a clear precursor to the emergence of new policy ideas that would begin to shape disability policy in the United States.[55] It was the statement from two exceptional researchers that further advanced the true evolution of ideas for the time which was that “the worst home is better than the best mental hospital”[56]. This highlighted the ideological shift that showed human needs and social values were essential to the quality of care for those within institutions, and it was simply an aspect of

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[52] Grob, 2006, pp. 15.

[53] Novella, pp. 412.

[54] Novella, pp. 411.

[55] Grob, 2006, pp. 7.

[56] Novella,pp. 410.

care which they would not receive within the hospitals.[57] Eventually, with the amount of people participating in mental hospital census' paired with a decrease in amount time spent within hospitals, many considered the wave of deinstitutionalisation to be largely successful while this was not exactly the case.[58] While the idea for deinstitutionalisation was well intended it was also extreme in that it was a total restructuring of systems originally designed to manage instead of treat, because of this the side effects of that reconstruction were equally as extreme. Many people who required full time care were sent to their homes or put in to residential care where they were often cared for by family members or people who were significantly under-qualified.[59] In many state governments, more specifically local communities, people were simply unwilling to denounce their own social prejudices that allowed for the underfunding of patients being brought back into the community.[60] Consequently the communities then did not have necessary preparations for the amount of people who would be released from institutions. Because of this, often times there was not enough staff available for community based care to run the way which it was intended.

As referenced earlier in section 1.2 the time right after deinstitutionalisation was the pivotal moment where foundations for the new field of *Mad Studies* first began to emerge. The late 1960s, 70s and 80s began civil rights movements for people with an ID/DD and mental illnesses which were soon also refereed to as the "mental patients liberation movement" or "psychiatric survivors movement". There is still ongoing debate within the psychiatric community about where these movements are separate entities or whether the "mad movement" is a mere expansion upon earlier advocacy.[61] Judi

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[57] Novella, pp. 415.

[58] A. Scull *'Social Order/Mental Disorder: Anglo-American Psychiatry in Historical Perspective*' Rutledge Library Editions: Psychiatry, University of California Press, 1989, pp. 43.

[59] Novella, pp. 411.

[60] B. Lefrancois, R. Menzies, G. Reaume, pp. 7.

[61] J. M. Poole ET AL. 'Sanism, "Mental Health", and Social Work/Education: A Review and Call to Action', *Intersectionalities: A Global Journal of Social Work Analysis, Research, Policy and Practice,* vol. 1, 2012, pp. 4.

Chamberlin, an advocate for the Ex-Patients' Movement and use of "Mental patients" terminology argues that the terms are not to be used synonymously.[62] When patients began to recognise the institutionalised oppression they formed coalitions which would question the foundations and validity of medical interventions, treatment, human rights violations and the involuntary commitment of people to institutions.[63] These coalitions turned into the creation of several organisations whom were dedicated to supporting people that were part of the patient/survivor movement and brought awareness to socially constructed binaries and ideas like ableism, sanism, mentalism etc.[64]

1.4 ***Models and Theories of Disability***

There are many ways in which disability can be described depending on the discipline and way in which one perceives the *concept* of disability. The Americans with Disabilities Act is clear in its *legal* definition of what a disability is and defines it "with respect to an individual as: a physical or mental impairment that substantially limits one or more major life activities" [65] Many people have contributed to the impact social policy has had on people with disabilities but failed to take into consideration any type of capacity for learning or inclusion that people with ID/DD could have or acquire. Social theories have shaped in many ways, the nature in which people with intellectual disabilities are still treated and thought of today. An example of this is the evolution of social contract theory—which dictates that in order to be a member of society, every person willingly gives up some of their own rights and will participate in society for a presup-

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[62] J. Chamberlin, "The Ex-Patients' Movement: Where We've Been and Where We're Going' *The Journal of Mind and Behaviour Special Issue, Challenging the Therapeutic State*, Vol. 11, no. 3, 1990, pp. 324.

[63] J. M. Poole ET AL, pp. 5.

[64] ibid., pp. 5.

[65] Americans With Disabilities Act, 1990

posed, mutually beneficial social order.[66] This theory has been widely discussed amongst prominent philosophers but operates on the premise of exclusion, meaning that the theory assumes the people who are able to enter into a social contract are “normal” i.e. without an intellectual disability.[67] While people are no longer able to simply lock away individuals and deem them mentally incompetent or mad, many of the attitudes and stereotypes against people with ID remain and social exclusion is just one of the ways in which society still treats people who deviate from the status quo. People with disabilities are especially vulnerable to these types of mistreatment, because the socio-cultural models that are available still lack the basis of equality that would bring people with ID into a fair social contract.

The lack of an equal contract is a fundamental basis for why people with disabilities will almost always have unequal citizenship experiences.[68] The very notion of including people with disabilities is only an afterthought, because it was not until our social structures and institutions were *already* designed that people then realised that these needed to be adjusted to include those who had never been intended for their use.[69] It is questionable to assume that society can right such a large mistake, however Martha Nussbaum, proposes a way in which to counteract the significantly lack of attention that is given to people with intellectual disabilities as it relates to the social contract. She proposes a “capabilities approach” which focuses on ten characteristics or “freedoms” that all participating members of society should be able to experience.[70]

The term disability can be broken down even further to categories such as physical, intellectual and developmental disabilities. The approaches in which psychiatrists

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[66] M. Nussbaum, pp. 5.

[67] M. Nussbaum, pp. 20.

[68] M. Nussbaum, pp. 99.

[69] M. Nussbaum, pp. 98.

[70] M. Nussbaum, pp. 70.

and sociologists began to treat patients with noticeable[71] intellectual disabilities is explained most accurately by the different models of looking at disability. By first examining the medical model, which is also often referred to as the individual model, the focus was mainly on the medical “problems” within an individual, it assumed that a person is “defected” or some kind of deviation from what is considered to be “normal”.[72] This deviation of normal was reinforced via Locke’s original description of a person with an intellectual disability. The medical model continuously focuses on the “personal tragedy” aspect of the disability; categorising a person with a disability a someone with “bad luck” or that needs to be “fixed” or otherwise “cured” by medicine. It does not take into account a persons environment but rather chooses to focus on the things a person is unable to do solely because of their disability and places the responsibility of adaptation entirely on the individual.[73] This model was what lead the scientific community before the emergence of other models which came to be a rebuttal to this theory. The medical model has been largely though of as being an impairment of on the body, where as individuals can not physically do things, however over time that has evolved to include mental health problems and impairments as well.[74] Two “debilitating assumptions” of this model, as described by lawyer and disability expert Theresia Degener, are that people with disabilities *need* “shelter and welfare” which allows for their own isolation via segregation and that their own “impairment can foreclose legal capacity” which

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[71] Noticeable in the sense that the person in question displayed behavioural tendencies as well as psychological symptoms, varying in degree and severity but with which were other wise considered to be abnormal.

[72] M. Retief & R. Letšosa., *‘Models of disability: A brief overview’,* Faculty of Theology, North-West University South Africa, HTS Teologiese Studies/ Theological Studies 74(1), AOSIS, 2018, pp. 1-10.

[73] Pushing the Boundaries of Inclusive Travel, Design and Living: An Economic Model of Disability, *Travability*, 2011pp. 1-14.

[74] M. Berghs, Atkin K, Graham H, Hatton C, Thomas C. Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. Public Health Res 2016;4(8). pp. 25.

legitimised states' preemptive laws taking away basic consenting rights from the individual.[75]

The social model of disability is considered to be one of the foundations that Disability Studies is built on. The social model is a complete rejection of this medical model in that it does not define disability as something which restricts the persons affected. Instead, it focuses on society and its hesitations to make the changes that are necessary to accommodate persons with a disability thus creating the barriers which impede a person to be "abled" in the first place.[76] The social model and activism arose out of the national movement of deinstitutionalisation where individuals fought to take back their care.[77] An important aspect of this model is the implications that it has in regards to being able to participate within the workforce. Social theorists argue that a functional body is essential to capitalism as a contract, being able to work/get paid for that work is part of the functionality of a capitalist society. However, if your body is not "functional" in the way that meets the demand of being able to be employed, then you will be socially excluded or isolated which is why having complete access to job opportunities is a central feature of the inclusive social model.[78] Many scholars including Foucault, argued that what truly drives the social model is the lack of separation of what constitutes an impairment and what constitutes a disability.[79] Critical Disability Theory, which is also closely related to the social model is particularly useful when used to get to the underlying and fundamental differences of words such as "impairment" and "disability".[80]

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[75] T. Degener, "Disability in a Human Rights Context" *Disability Human Rights Law,* vol. 5, no. 35, 2016, pp. 3.

[76] M. Rioux, and F. Valentine in 'Critical Disability Theory' R. Devlin and D. Pothier (eds.) *Does Theory Matter? Exploring the Nexus between Disability, Human Rights and Public Policy*, UBC Press, Vancouver/ Toronto, 2006, pp. 47.

[77] M. Berghs, pp. 36.

[78] ibid., pp. 36.

[79] S. Tramain, "Foucault and the Government of Disability" *University of Michigan Press,* Ann Arbor, 2015, pp. 9

[80] M. Berghs, pp. 39.

Critical Disability Theories main goal is to present people with disabilities in a way which highlights their potential, capability, relate ability and diverseness while simultaneously opening the door for the origins that surround those who are also participating in other categories (sexuality, identity, race etc).[81] In this respect, the model recognises an impairment as the absence or defect of a body part or bodily function, and sees disability as something which is added to a persons "impairment" but then focuses on the disability that is placed upon them within a social context, failing to take into consideration the person with the "impairment" themselves.[82] It presents these two concepts as entirely different entities, with one having little to no effect on the other despite the first being a necessary condition for the second.[83]

When understanding the social model of disability, it is useful to conceptualise it through a Foucauldian lens which allows one to more fully understand the different power dynamics and their effects. For example, when recognising social inclusiveness from the perspective of community-based supported housing, we are able to see a new and clear power relationship.[84] Both staff and the individuals have pre-supposed identities and "roles" which they respectively belong align with the "contract-oppressor schema" Foucault describes.[85] Staff members who work in housing are expected to fulfil a certain role, they are paid to help fulfil the needs of the individual to the acceptable extent that the employer has set. They are there to support actions such as mastering everyday skills but mitigate and prevent others (self injurious behaviour, inappropriate behaviours.. Staff are hired because they are considered to be more able than the per-

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[81] ibid., pp. 39.

[82] S. Tremain, pp. 9

[83] ibid., pp. 9.

[84] C. Drinkwater, pp. 232.

[85] M. Foucault, *'Power/Knowledge Selected Interviews and Other Writings 1972-1997'* ed. Colin Gordon, Pantheon Books, New York, 1976, pp. 92.

sons they serve, and because of that they are entrusted to teach and guide.[86] The very foundation of this socially inclusive hierarchy is based on the idea that those which are being served are going to be made better in some way, meaning that in someway society at large has the responsibility to “fix”.[87] Just as when thinking of the term “impairment” and how it interacts within a social context, one has to acknowledge that an impairment, which is most simply defined as having something missing, has been defined that way by larger powers at be. The term has been constructed in a way which has the potential to further advance already unequal power relations.[88]

Another model which is closely related to this is the human rights model. The human rights model is the newest model to be added to analysing disability.This model agrees with the social model’s explanation of the barriers people with disabilities face that are created by a respective society, and then provides a theoretical framework for policies that will highlight the importance of human dignity.[89] The human rights model goes a step further by acknowledging civil, political, economic and social rights into its approach.[90] The human rights model of disability goes beyond the social model in that it explicitly acknowledges the overwhelming adversity and difficulties that some people with disabilities have experienced throughout their life and moves to include this perspective in the creation of new social justice theories.[91] The Universal Declaration of Human Rights (UDHR) provides the legal framework for the human rights model. Given the history of people with ID/DD there is a tendency to focuses on restrictions of major and inalienable rights and often times the right to work is overlooked. Employment is a major feature of every persons life and enshrined within Article 23 of the UDHR is

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[86] C. Drinkwater, pp. 236.

[87] C. Drinkwater, pp. 233.

[88] S. Tremain, pp. 11.

[89] T. Degener, pp. 4.

[90] M. Retief & R. Letšosa, pp. 4.

[91] Rioux, M. and F. Valentine, pp. 48.

the right to work. It states “Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment” it goes to say that “Everyone, without discrimination, has the right to equal pay for equal work”[92] it was presupposed that all persons were to be included under this article, however later more protections would be added specifically for people with ID/DD.

The Convention on the Rights of Persons with Disabilities (2007) (CRPD) was one of the first to address the rights of people with disabilities on a global scale and was largely modelled after the Americans with Disabilities Act, closely resembling the original document. The United States however, has not ratified the CRPD. Many US lawmakers and policy analysts argue that there is no need for the ratification of CRPD because US law already has the ADA and its ratification would interfere with existing laws such as IDEA and change some fundamental titles within the ADA. Many other lawmakers disagree with this noting that any major discrepancies would be addressed within the reservations, understandings and declarations (RUDs). One of the largest criticisms of the CRPD is that is is difficult for countries which have signed on to enforce. There are very little sanctions which would arise from a direct violation of the CRPD. There is also no clear connection between the CRPD and other bodies which carry out legislation such as the European Court of Human Rights.[93] Article 25 of the CRPD The CRPD was essential to solidifying the human rights model as a was in which we now look at disability because it introduced a new paradigm of how we can understand rights.[94] The CRPD has been regarded as a rights-based approach, that champions for the complete inclusions and dismemberment of social barriers and discrimination so that people with disabilities are able to have their best quality of life.[95]

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[92] Universal Declaration of Human Rights (adopted 10 December 1948, entered into force 10 December 1948) Article 23.

[93] M. Berghs, pp. 35.

[94] ibid., pp. 32.

[95] ibid., pp. 34.

Finally, the last model of disability that is important to note is the economic model which addresses the effects of persons disability and thereby classifies that person based on their capabilities.[96] This model however can be split into two different trains of thought, the first being that people with disabilities participating in the economy will ultimately boost the economy.[97] This creates an incentive to hire more people it ID/DD into the workforce, because they will stimulate more growth. The second thought, proposed by Nussbaum is that while one of the main goals for people with disabilities is to participate fully in society by being employed, its important to recognise that the government never be able to recoup the expenses it will incur in order to educate and train them to enter into the work force. This however does not mean that we should not provide these services, it just means that we have a moral obligation to do so rather than a financial one.[98] Both of these versions of the economic model are highly criticised because neither of them promote inclusivity without the underlying stigma that we are supposed to be working on eradicating.

Since Autism Spectrum Disorder is typically defined via a medical model[99] of disability the American Psychiatric Association explains it as 'a disability characterised by impairments in communication and social interaction, repetitive behaviours, and limited areas of interest".[100] People who are on the autism spectrum are typically diagnosed within the first two years of life and symptoms can be severe to moderate depending on the individual.[101] ASD disorders comprise of autism, Asperger Syndrome and pervasive

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[96] Pushing the Boundaries of Inclusive Travel, Design and Living: An Economic Model of Disability, *Travability*, 2011, pp. 6.

[97] Novella, pp. 417.

[98] M. Nussbaum , 'Frontiers of Justice: Disability, Nationality, Species Membership' Cambridge, Harvard University Press, 2006, pp. 58.

[99] Defined previously

[100] Novella, pp. 412.

[101] National Institute of Mental Health, Autism Spectrum Disorder

developmental disorder-not otherwise specified (PDD-NOS) the latter simply meaning that it is a disorder on the autism spectrum which falls into one of 4 categories.[102] This broad spectrum means that people with autism can have high or low IQs; it is not uncommon for those with ASD to also have a psychiatric diagnosis (depression, anxiety, bipolar etc).[103] The symptoms that an individual on the spectrum may face almost always affect social interaction which can be manifested as problems with eye contact, being able to participate/reciprocate conversation, engaging in self injurious behaviour, talking to oneself, or not picking up on simple social cues.[104] Symptoms may also manifest with behavioural tendencies including aggression, self-injurious behaviour, screaming/yelling, suicidal ideation, propter destruction, PICA[105] or inappropriate sexual behaviour.[106] There are currently more than 3.5 million people in the United States that are considered to be on the Autism Spectrum with data as seen below, suggesting it is becoming more prevalent each year.[107]

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[102] D. Hendricks, “Employment and adults with autism spectrum disorders: Challenges and strategies for success” *Journal of Vocational Rehabilitation,* vol. 32, no. 2, 2010, pp. 126.

[103] Henricks, pp. 131.

[104] R. Rosales, H. Whitlow, ‘A component analysis of job interview training for young adults with autism spectrum disorder” *Behavioural Interventions*, April 2019, Vol.34(2), pp.148.

[105] PICA is a term for a type of behaviour where an individual will focus on a particular object and immediately ingest it, whether it is edible or not.

[106] Hendricks, pp. 135.

[107] Autism Speaks

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children	This is 1 in x Children..
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59

Table 1: Source: Centre for Disease Control https://www.cdc.gov/ncbddd/autism/data.html

Today many people will go to great lengths in order to try and figure out the causes of some intellectual disabilities, most notably autism. Anti Vaccination movements have become increasingly popular in recent times largely in part to the now discredited researcher and former doctor Andrew Wakefield.[108] His research was found to have used both unethical and flawed methodology, but the effects of that have been profound. He claimed to have found a connection that related the vaccine for measles, mumps and rubella or MMR and Autism thus insinuating that it was those vaccines solely responsible for children being diagnosed with autism.[109] The damage from false data like this however was utterly incomprehensible and before it was able to be corrected, rates for vaccinations dropped more than 12% in just six years.[110] Once a stigma or a "reason" for this difference was introduced, it took on a life of its own. People today still believe this false narrative and believe that autism is something which was caused by life saving vaccines. Ignoring published and accredited doctors and researcher who have debunked this faulty research, they believe that risking diseases that once burdened society is more important than the possibility of their child of having an intellectual disability.

Although Autism is most often a life-long condition, vast improvements to the nature of care for these individuals has greatly enhanced the quality/length of life for adults. Through early intervention programs, individualised treatment plans and services can have highly impactful effects on quality of life and ability to function independently.[111] Through evolving legislation, advocacy and social awareness the United States has taken great leaps forward in safeguarding the rights of persons with disabilities specifically with legislation such as the Rehabilitation Act 1973, the Americans with Disabilities Act 1990 and Individuals with Disabilities Education Act 1990[112]. History has not always treated those with differences such as intellectual disability kindly and there is

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[108] A. Hussain, S. Ali, M. Ahmed ET. AL. "The Anti-vaccination Movement: A Regression in Modern Medicine", *US National Library of Medicine National Institutes of Health,* vol. 10, no. 7, 3 July, 2018, pp. 2.

[109] ibid., pp. 2.

[110] ibid., pp. 3

[111] National Institute of Mental Health

[112] The Individuals with Disabilities Education Act (IDEA) was originally the Education for All Handicapped Children Act 1975.

still much to be done when it comes to achieving adequate equal rights specifically in the employment sector—to the comparative “normal” population.

Employment is only one of the ways in which everyday people are able to fully participate within their own communities. Adults with disabilities who are trying to fully integrate within the community should be able to have that chance to work amongst their peers in order to reach the highest quality of life available to them. It has been shown that adults with autism who are employed have a much greater quality of life than those who do not.[113] It is not only for the benefit of the individual that adults with autism should hope for full employment, when more people with autism are fully employed then they will be using less government assistance and are now contributing to taxes.[114] In order to be fully participating members of society and engage in the proper social capacity, employment is a central feature of their inclusivity. The deviation in normal social behaviours which are associated with autism can greatly impact an individuals ability to successfully function in a working environment, and because of this it places those with autism with a greater potential to remain unemployed.[115] Recently, there has been a pushed for customised employment specifically for adults who are on the autism spectrum. It is important to note the significance of increases or decreases of persons with ID/DD with respect to the percentage of people with disabilities who are or are not employed. The population of people with disabilities increased between 2010 to 2017 from 12.5 to 13.2 percent with 2010 being its lowest year, further studies showed that between 2016 and 2017 the percentage of people with disabilities in the United States then dropped from 13.3 to 13.2 percent.[116] The data shows that the population of people with disabilities considerably rose from 2010 to 2017, with the employment data as well. However as of 2017, employment of persons with disabilities

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[113] Eggleton, Robertson, Ryan and Kober, 1999.

[114] Hendricks, pp. 126.

[115] R. Rosales, pp. 148.

[116] Houtenville, A. and Boege, S. (2019). Annual Report on People with Disabilities in America: 2018. Durham, NH: University of New Hampshire, Institute on Disability.

held at 35.5% with that percentage of individuals 18-65, however when compared to the population of people employed without disabilities the percentage doubled.[117] The majority type of these employments are through supported employment and vocational rehabilitation programs and with only 12-14% of those individuals in competitive integrated employment.[118]

Because the ASD can vary largely in severity and symptoms, it comes as no surprise that when entering the labor force they would have different types of needs.[119] Everyday social interactions can be exceedingly difficult with roadblocks to communication (taking things to literally, not understanding tone, facial expressions, inappropriate responses) constantly hindering the worker-employer relationship and may even lead to termination.[120] Those examples presuppose that the applicant was able to successful complete the job application process, which can pose its own set of difficulties to those with ASD. Understanding social order and rules, recognising cause and effect, being able to work independently, maintaining healthy hygiene practices and understanding appropriate conversation topics with the opposite gender are all situations a person with ASD can potentially have trouble completing.[121] While much has been written about the importance of including people with autism in the workforce, more attention recently has been given to the importance of job satisfaction in the workplace.[122] Job satisfaction is measured by companies in order to gauge how conducive their working environment is for those whom they employ. This applies not only to people with disabilities but people who do not have any as well, most people who find no enjoyment

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[117] ibid,.

[118] UCP, *The Case For Inclusion Report 2019,* United Cerebral Palsy Foundation/American Network of Community Options and Resources, 2019, pp. 1.

[119] Hendricks, pp. 127.

[120] ibid., pp. 127.

[121] Hendricks, pp. 128.

[122] B. Pfeiffer ET AL. “Impact of person-environment fit on job satisfaction for working adults with autism spectrum disorders” *Journal of Vocational Rehabilitation,* vol. 48 issue 49, 2018, pp. 50.

in their job or working environment generally do not last very long there. The working environment for adults with Autism has been shown to impact their overall job performance. While the push for community integrated employment has been largely effective for some it can pose potential barriers they otherwise would have avoided.[123]

How states go about including people with DD/ID into the workforce varies greatly on the state and the policies that that state has enacted in order to facilitate an inclusive environment. The Case for Inclusion Report, is a tool crafted by the United Cerebral Palsy Foundation in order to measure how well states are implementing inclusive disability policy. While all 50 states within the US are required to provide employment services and comply with all federal laws regarding employment, some states are better at implementing policy that works than others. The report focuses on the states who both excel and need to dramatically improve their disability policy standing and does so by ranking them. The foundations responsible have created a system which focuses on key areas to measure the success of policy within the state. The rankings are divided via 5 categories: promoting independence, tracking health, safety and quality of life, keeping families together, promoting productivity, and reaching those who are in need.[124] The way in which each score is broken down is as follows:

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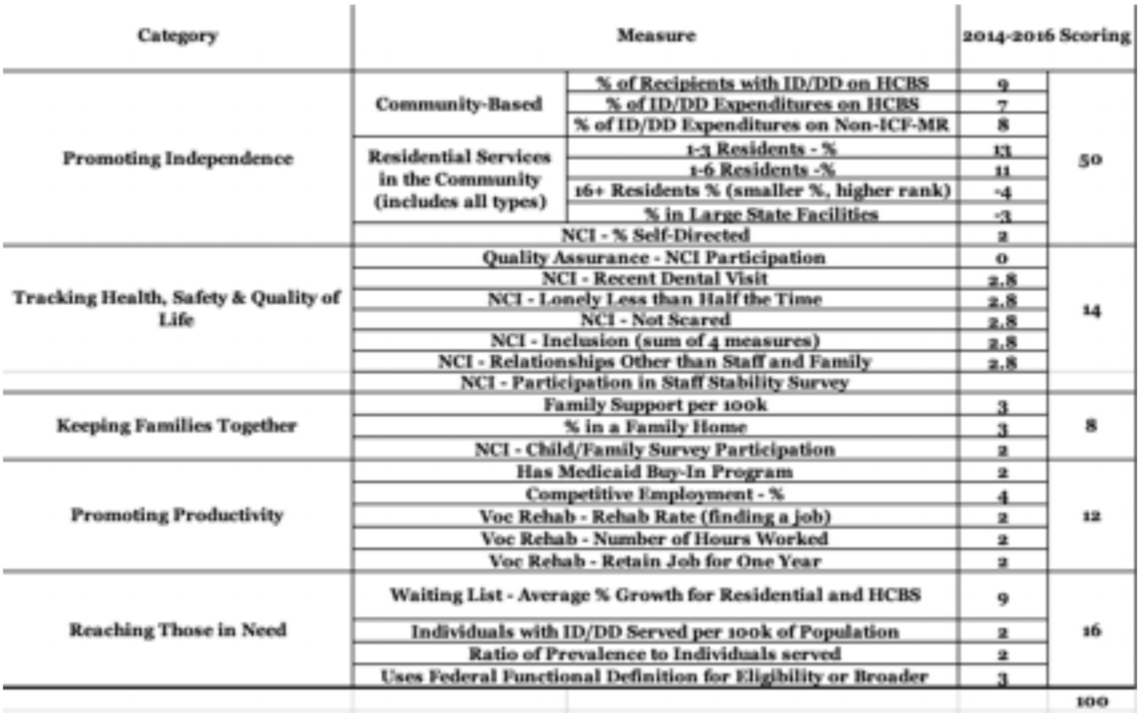
[123] B. Pfeifer, pp. 3

[124] UCP, pp. 23.



Category	Measure		2014-2016 Scoring	
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	50
		% of ID/DD Expenditures on HCBS	7	
		% of ID/DD Expenditures on Non-ICF-MR	8	
	Residential Services in the Community (includes all types)	1-3 Residents - %	13	
		1-6 Residents -%	11	
		16+ Residents % (smaller %, higher rank)	-4	
		% in Large State Facilities	-3	
	NCI - % Self-Directed		2	
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		0	14
	NCI - Recent Dental Visit		2.8	
	NCI - Lonely Less than Half the Time		2.8	
	NCI - Not Scared		2.8	
	NCI - Inclusion (sum of 4 measures)		2.8	
	NCI - Relationships Other than Staff and Family		2.8	
	NCI - Participation in Staff Stability Survey			
Keeping Families Together	Family Support per 100k		3	8
	% in a Family Home		3	
	NCI - Child/Family Survey Participation		2	
Promoting Productivity	Has Medicaid Buy-In Program		2	12
	Competitive Employment - %		4	
	Voc Rehab - Rehab Rate (finding a job)		2	
	Voc Rehab - Number of Hours Worked		2	
	Voc Rehab - Retain Job for One Year		2	
Reaching Those in Need	Waiting List - Average % Growth for Residential and HCBS		9	16
	Individuals with ID/DD Served per 100k of Population		2	
	Ratio of Prevalence to Individuals served		2	
	Uses Federal Functional Definition for Eligibility or Broader		3	
				100

Table 2: Source, A Case For Inclusion, United Cerebral Palsy Foundation

The report also pays special attention to the current direct support professional (DSP) crisis that is currently plaguing so many states.[125] The reason for the acknowledgement of this crisis is because the turnover ratio of staff is becoming detrimental to the success of adults with autism who are using medicaid services. DSPs are fundamental in the success of adults with autism, whether in residential homes, day programs or vocational workshops. While DSPs and staff who work closely with people with DD are there first to preform a job, they often develop relationships with the individuals and give them a sense of stability in their lives, which produces positive results their own daily lives. High turn over rates are detrimental to the relationship building that comes with working with adults with autism, with the cause for most people leaving being low

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[125] ibid., pp. 5.

pay and burnout.[126] Lack of job training and preparedness is another reason why many DSPs, respite workers and caregivers eventually leave the field or government agencies. Staff are required in some states to complete state regulated trainings and in others there is little to no federal oversight.

The history of the way in which people with DD/ID have been treated directly relates to the way which they are treated now. Many different theories and approaches have contributed to the commonly held beliefs which still dictate policy that effects people with disabilities everyday lives. The evolution of social norms such as those proposed by Locke, have in some ways evolved and also remained the same. This can best be seen through the evolution of terms that was used to described people with disabilities and how those terms which were meant to demean and degrade, were reclaimed and taken back. It is by no coincidence that particular words such as "mad" were reclaimed and further turned into a new way to look at disability identity. The perceptions of people with ID/DD have shifted dramatically but only in the last 50 years in the United states, with tangible changes to ideologies being noticed through different initiative designed to put the person first. Deinstitutionalisation was a difficult but necessary movement in order for person centred, community based care to really become the new standard. This change did not happen overnight, and it took many years an presidencies in order for the US to see real results with the closings of many state run institutions. These landmark achievements in the care of people with disabilities was largely possible due to the evolution of different models of disability and how each model has brought something new to disability identity. Movements have also helped shift the way in which people with disabilities have been treated, with the civil rights, patient liberation and "mad studies" movements all contributing to the fight for equality and equal personhood. While fighting for the equal employment rights of persons with disabilities

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[126] Brody, D. 'The Job Most People Don't Know about but is Crucial to People with Disabilities', Forbes- 10 January 2019. https://www.forbes.com/sites/denisebrodey/2019/01/10/the-job-most-americans-dont-know-about-but-is-crucial-to-the-success-of-people-with-disabilities/#726c5ea96105 (accessed 2 February 2019).

may not seem that important to some, it is a crucial part to everyday life. Having the ability and the right to work, regardless of what afflicts a person is imperative to the overall life experience of people. Having a job amongst peers in the community is what individuals strive for so that they can have some sense of “normal” when they have been told all their life they aren’t.

CHAPTER 2. POLICY ANALYSIS

2.1 Policy Introduction

While many people in the United States considered the Social Security Act of 1930 to be when the federal government first began to intervene with disability policy, The National Mental Health Act of 1946 is what gave many healthcare providers in the field of psychiatry access to completely change the national institutionalised system. [127] The political climate at the time in the United States under president FDR meant that there was momentum for change that was centralised around those who were unable to adequately care for themselves.[128] One of the many reasons that local governments had been so unsuccessful in the caring for persons with disabilities was largely due to budgeting and expenses. States had little incentivised reasoning to undertake the care of these people with little to no means to pay for it. The National Mental Health Act, addressed this issue by providing states with the opportunity to receive grant funding that would be provided by the federal government.[129] This funding would be used for the creation of new hospitals, clinics and treatment centres that would aid the mission of finding the cause, diagnosis and treatment of mental disorders and impairments.[130] Robert Felix lead the development of mental health policy in the United States by advocating for policy changes through organising information panels that policy and law-makers could use to directly translate into services to be provided, which would be mandated by the federal government.[131] The effects of this Act were seen within the next two years of its implementation to law, with every state in compliance, and the cre-

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[127] Grob, 1991, pp. 45.

[128] ibid., pp. 50.

[129] ibid., pp. 53.

[130] ibid., pp. 53.

[131] ibid., pp. 56.

ation of mental health departments within them.[132] A new governing body was created by the NIMH and sent out representatives who were able to track compliance and counsel state governments on approached to mental health that steered away from state run hospitals.[133]

Robert Felix was instrumental in creating a new way to look at public health policy which included those who were suffering form some type of mental health disorder. He was able, alongside policy makers, to completely shift the narrative that mental illness and disability was solely an individualised problem.[134] He stated the conversation for inclusion, asserting that these issues were not just a problem for one person but instead was a public and community problem that needed to be addressed for the betterment of that community. The creation of the Mental Health Act also allowed for the creating of the National Institute for Mental Health (NIMH) which was a research body that was left to be led by Felix. He was able to link his organisation with other respected research organisations at the time under the National Institute of Health (NIH) which had a significant impact on the organisations ability to receive funding from congress that would be put towards community oriented services.[135]

By the mid 1950s with the recurring national governors conference[136] were rooted around the emergent and long term needs of the mental hospitals within each state. Surveys sent out to each state revealed that nearly 750 millions dollars was being spent by states on the complete remodelling of state run institutions and direct patient care services.[137] In accordance with his idea of a New Frontier in 1963, President John F

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[132] L. Joni Maria, "A State-Level Analysis of Deinstitutionalization and the Impact of Chlorpromazine" (2015). LSU Doctoral Dissertations. pp. 1357. hps://digitalcommons.lsu.edu/gradschool_dissertations/1357

[133] Grob, 1991, pp. 54

[134] ibid., pp. 55.

[135] ibid, pp. 56.

[136] event which takes places every year where governors from all 50 states come together in order to talk about collective resolutions and policy implementation

[137] Grob, 1991,pp. 163.

Kennedy signed into law the Mental Retardation Facilities and Community Health Centres Construction Act (1963) or Community Mental Health Act of 1963 (CMHA) which was intended to provide states with grants that would create mental health clinics within communities under the NIMH.[138] The idea of the creation of these clinics was that consumers would be able to live at home but still receive treatment. However, the CMHA never allocated money for the long-term operative costs of running these facilities and because of this many were never built or finished completely.[139] The resulting effects of this were that many patients were discharged form state hospitals and received by communities and families that were unable to properly care for them, thus creating a paradoxical effect regarding the "success" of the act.[140]

It wasn't until 30 July, 1965 that President LBJ signed the first bill for Medicaid and later medicare services into law in the United States. This first bill provided insurance to people already getting social security assistance and it consisted of two separate parts which were hospital and medical insurance.[141] It gave states the option to receive money from the federal government for providing healthcare services to low-income people, children, the blind and people with disabilities.[142] However, it wasn't until 1973 when Medicaid was amended to include people under 65 with long-term disabilities that those with ID really began to see a change in the treatment they were receiving, with new benefits like drug coverage to improve treatment outcomes.[143] The government

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[138] S. 1576 (88th): An Act to Provide Assistance in Combating Mental Retardation Through Grants for Construction of Research Centres and Grants for Facilities for the Mentally Retarded and Assistance in Improving Mental Health Through Grants for Construction and Initial Staffing found at https://www.govtrack.us/congress/bills/88/s1576/summary

[139] ibid.

[140] S. Eide, "*Systems Under Strain: Deinstitutionalisation in New York State and City*", Report from: Manhattan Institute, November 2018.

[141] "CMS Program History" *History of Centres for Medicare and Medicaid Services*, United States Federal Government, June 2018, accessible at: https://www.cms.gov/About-CMS/Agency-information/History/

[142] ibid.

[143] ibid.

controls how much it matches states by per capita income, and they largely vary depending on the state.[144] Up until 1982 Medicare was being used to reimburse hospitals providing psychiatric car based on allowed costs, however due to the fear of patients been treated poorly and the risk of fraud the system was changed so that medicare would reimburse states in two separate ways.[145]

In 1967, the state of California passed the Lanterman-Petris-Short (LPS) Act which ended forced and indefinite commitment of people with mental illness and disabilities.[146] This Act was essential in safeguarding individuals rights while simultaneously protecting public safety. The LPS Act gave psychiatrist more time and power to evaluate patients in order to make sure they were not wrongly or involuntarily committed, it also introduced the concept of informed consent for the use of psychotropic medications during these holds.[147] This progress was essential to the development of persons with disabilities actually being considered during the process of involuntary commitments in psychiatric wards and hospitals by emphasising a need for the "imminent dangerousness" a patient must display.[148]

The Rehabilitation Act of 1973 was one of the first pieces of legislation in the United States that explicitly prohibited the discrimination of a person on the basis of their disability, intellectual or physical in any federally funded agency or program.[149] Although the Act had much support from the senate, then President Richard Nixon ve-

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[144] W. Cohen, "Reflections on the enactment of Medicare and Medicaid" *Journal of Health Care Finance Review,* vol. 3, no. 11, December 1985, pp. 5

[145] ibid.

[146] "Understanding the Lanterman-Petris-Short (LPS) Act" *Disability Rights of California,* 8 January, 2018, accessible at: https://www.disabilityrightsca.org/publications/understanding-the-lanterman-petris-short-lps-act

[147] ibid.

[148] A. Stone, D. Rogers, S. Kruckenberg, & A. Lieser. (2012). Impact of the mental healthcare delivery system on california emergency departments. *The western journal of emergency medicine*, *13*(1), 51–56. doi:10.5811/westjem.2011.6.6732

[149] 'A Guide to Disability Rights Laws', US Department of Justice, Civil Rights Division: Disability Rights Section, https://www.ada.gov/cguide.htm

toed it twice before it was eventually signed into law and it wasn’t until 1977 that it was fully enacted.[150] The Act is divided into many sections, each focusing on a specific aspect of discrimination someone with a disability may encounter throughout their lifetime and seeks to address Under the Rehabilitation Act, private employers were awarded the same level of shielding as they were in title VII of the Civil Rights Act, as most of the definitions used are referenced directly.[151] Section 501 of the Rehabilitation Act focuses specifically on employment opportunity and established a federal committee who would work in partner with the Equal Employment Opportunity Commission in order to further the advancement of people with disabilities in the workforce.[152] This provision meant that federal agencies were mandated to submit their own plans for the implementation of affirmative action policies and plans (i.e. from hiring to matching to job growth opportunities).[153] Section 503(a) added affirmative action requirements for any contracted employer of the US government of over $10,000USD, however unlike section 501, this did not mean that employers are explicitly required to hire persons with disabilities, just that contracts are made which contain language relating to affirmative action.[154]

Section 504 of the Rehabilitation Act is arguably the most important, as it would later become the basis for the Americans with Disabilities Act 1990 (ADA).[155] The language used in section 504 would come to be considered “a law that preceded the movement” as it contained explicitly anti-discrimination language that went largely unnoticed during the drafting sessions as the senate at the time was seemingly more occu-

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[150] B. Chamusco, ’Revitalising the Law That ‘Preceded the Movement’: Associational Discrimination and the Rehabilitation Act of 1973’ *The University of Chicago Law Review*, vol 84, 2017, pp. 1286.

[151] K. D. Henry, “Civil rights and the disabled: comparison of the rehabilitation act of 1973 and the americans with disabilities act of 1990 in the employment setting.” *Albany Law Review, 54(1),* pp. 126.

[152] B. Chqmusco, pp. 1291.

[153] K.D. Henry, pp. 127.

[154] ibid., pp. 127

[155] ibid., pp. 125.

pied with budget concerns.[156] After the Rehabilitation Act was amended in 1978, it allowed for persons with complaints to sue in order to enforce the law, this was done by adding Title VI of the Civil Rights Act to the Act.[157] The next few years were part of a conservative presidential administration and disability policy was slow. The enforcement of the Rehabilitation act was not what original policy makers had been hoping for, and the lack of discussion about section 504 meant that many individuals who would bring their suits to court were met with judges who struggled with the true meaning of how policy makers had intended the language to be interpreted.[158] While there are many mixed reviews on the practical success of the Rehabilitation Act, it is clear that the Act set up the framework for future disability policy that would prove to reshape how people with disabilities were treated.

In 1990 President George H. W. Bush signed the Americans with Disabilities Act (ADA) into law. The act was meant to be observed with the Rehabilitation Act of 1973, as congress stated that additionally provisions were needed in order to further protect the American disabled population as well as provide them with a way in which to seek redress. The policy makers of the Rehabilitation Act and ADA took into consideration that the first only applied to those who were receiving federal funding at people working at places which did not could still be subject to discrimination.[159] Because of this they decided a new law was needed which would emulate the same sentiment as the first but would also consist of a larger means of protection.[160] The ADA itself does not specefaillly define what types of disabilities are covered but the DOJ describes it as a document which "protects the rights of people with substantial impairments (either physical or intellectual) that severely hinders their ability to preform one or more major

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[156] B. Chamusco, pp. 1293.

[157] ibid., pp. 1292.

[158] ibid., pp. 1294.

[159] K.D. Henry, pp. 125.

[160] B. Chamusco, pp. 1295.

life activities such as breathing, walking, reading, thinking, seeing or hearing etc.”[161] Others have approached the lack of definition of handicapped is done individually in a multi faceted approach where a total of three qualifications need to be established. The first follows the standard set by the DOJ but goes on to add the person must have a documented record of this impairment (and to have been known to have had it) and finally, the person must be found to be “otherwise qualified”[162] to preform the job and job functions.[163] Within the interpretation of “otherwise qualified” the Supreme Court often refers to the case *School Board v. Arline* (1987). It was through this ruling that it was decided when someone is officially considered “handicapped” and an employer has the intention to fire that person, they must provide tangible reasoning based on fact that does not amount to discrimination.[164] The only way in which a person can be denied employment or fired immediately is if that person also poses an immediate and significant threat to the health, safety and well being of those they would encounter during employment and there is absolutely no way to “accommodate” or eliminate the potential threat.[165]

The ADA was a major step forward with regards to employment because it created regulations for any company or business with 15 or more employees and the idea was that it would eradicate discrimination based on disability. The ADA consists of five titles which were created in order to facilitate increased access to services and opportunity in both public and private spheres.[166] Under the ADA all public and private educa-

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[161] US Department of Justice, “Americans with Disabilities Act, ADA Update: A Primer for State and Local Governments” *Civil Rights Division: Disability Rights Section,* 2010, pp. 2.

[162] *Southeastern Community College v. Davis.* 442 US 397 (1979).

[163] K.D. Henry, pp. 127.

[164] ibid., pp. 131.

[165] ibid., 131.

[166] C. Schall, ‘The Americans with Disabilities Act— are we keeping our promise? An analysis of the effect of the ADA on the employment of persons with disabilities’ *Journal of Vocational Rehabilitation*, vol. 10, 1998, pp. 192.

tion institutions must meet requirements outlined within Titles II and III. [167] The enforcement of the ADA falls to the Department of Justice (DOJ), Equal Employment Opportunity Commission (EEOC), Department of Education (DOEd) and Department of Labor (DOL). However all of the employment provisions is the sole responsibility of the EEOC.[168] Title II explicitly prohibits the discrimination of any individual on the basis of their disability in any service, program, or activity which is provided by public, state or local governments.[169] Title III prohibits the discrimination on the basis of disability in public accommodations which fall into 12 categories that activities can take place. [170] The crucial purpose of the ADA is to make the inclusion of persons with disabilities into "normal" life as simple as possible. The use of integrated settings with as little restrictions or ostentatious accommodations is essential to that fundamental idea. Within the ADA lies the terms "reasonable modification" which has been a topic of contention amongst sociologists and policy makers since its original drafting. Because so many institutions think about policies, practices and designs with the "normal" person in mind, people with disabilities are an after thought, and therefore certain services must be modified so that they are able to participate amongst their peers.[171] The ADA national networks defines a reasonable accommodation as reasonable "if they do not create an undue hardship or a direct threat" however even that wording is vague, for it leaves opening the next line of questioning for what is considered an "undue hardship".[172]

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[167] K. Walker, 'Comparing American Disability Laws to the Convention on the rights of Persons with Disabilities with Respect to Post Secondary Education for Persons with Intellectual Disabilities' *Northwestern Journal of International Human Rights*, vol. 12;1, 2014, pp. 117.

[168] The U.S. Equal Employment Opportunity Commission, "The ADA: Your Employment Rights as an Individual with a Disability" *Equal Employment Opportunity Commission Government Facts.*

[169] Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990). Title II.

[170] Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).

[171] Department of Justice, *Civil rights Union Policies and Procedures*, pp. 3.

[172] ADA National Network "Reasonable Accommodations in the Workplace" *ADA National Network information, Guidance and Training on the ADA* accessible at: https://adata.org/factsheet/reasonable-accommodations-workplace

There had been some concern in years after the ADA came into force that supreme court decisions would narrow the definition of the word disability and so in 2008 the ADA Amendments Act (ADAAA) came into force.[173]

Even with all of these provisions in United States law one of the most defining pieces of legislation didn't come until later, with Olmstead v. L.C. (1999). Where two women, Lois Curtis and Elaine Wilson were both diagnosed with multiple mental illnesses/DD and consented to their placement in a state run psychiatric institution to receive treatment. Both were eventually cleared by doctors there to return to their respective community programs but instead were both held within the institution involuntarily. Both women filed suit against the state of Georgia under the ADA to be released.[174] The case was brought before the supreme court where it was decided within the same year. The decision by the court helped to finally provide clarification on the classification of mental illness and its coverage under the ADA. The court found that persons with disabilities have the right to have services provided to them in the least restive environment possible and that the "unjustified isolation" of any person that has a disability qualifies as discrimination under Title II of the ADA.[175] Justice Ruth Bader Ginsburg delivered the majority opinion and reaffirmed that placement in community-based services is required when the individual does not express any immediate objections to returning to their community program, state professionals have deemed it appropriate and the transfer form institutionalised care can be reasonably accommodated.[176] Anything

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[173] U.S. Department of Labor, Office of Disability Employment Policy, "The Americans with Disabilities Act" 2 May 2019. accessible at: https://www.dol.gov/odep/topics/ADA.htm

[174] "Olmstead: Community integration for everyone" United States Department of Justice Civil Rights Division, 2 May 2019, accessible at: https://www.ada.gov/olmstead/olmstead_about.htm

[175] Olmstead v. L. C., 527 U.S. 581, 587 (1999).

[176] ibid.

less would be discrimination under Title II of the Americans with Disabilities act and also a violation of the 14th Amendment of the US Constitution[177].

Individuals with Disabilities Education Act (IDEA) was designed to provided educational opportunities to children and adults with disabilities which would give them the necessary tool for a life of future education, employment opportunities and independent living.[178] IDEA mandated states to focus on the transitional services that would be needed in order for people with disabilities to smoothly transition from their original programs to employment.[179] The Workforce Innovation and opportunity Act of 2014 amended the Workforce Investment Act (WOI) and the Rehabilitation Act, under which people with ID/DD were exceedingly under-employed.[180] WOIA provides services that are aimed at increasing positive outcomes of competitive integrated employment and transitional services for youth moving from one type of program to another. [181] It works in conjunction with laws and regulations that have already been set up under federal law. Under this law every state is mandated to comply with federal law that directs "15% of federal grants to pre-employment transition services and 50% to provisional services to young people with significant disabilities".[182] Under WOIA there should be a greater increase in people successfully entering into the workforce, with relevant job training and job readiness.

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[177] All persons born or naturalised in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the state wherein they reside. No state shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any state deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.

[178] K. Bush & M. Tassé, 'Employment and Choice Making for Adults with Intellectual Disability, Autism and Down Syndrome', *Research in Developmental Disabilities* vol. 65, pp. 23-25.

[179] ibid., pp. 26.

[180] *WIOA: What it means for people with intellectual and/or developmental disabilities (I/DD),* National Policy Matters, The Arc, 2015, pp. 2.

[181] ibid., pp. 5.

[182] ibid., pp. 5.

ASD traditionally requires long term treatment and because of this the associated costs of service are higher. Most private insurance plans do not cover the majority of ASD treatments and as such most people are left to use medicaid to avoid out of pocket costs.[183] The Home and Community-Services Waivers or (HCBS Waivers) were created under Section 1915 of the Social Security Act as a Medicaid Waiver. The waivers are a way for adults with disabilities to continuously receive long term care from states in their homes or community settings.[184] The HCBS waiver program was designed to expand the original provisions of medicaid to people who would otherwise not qualify, through the HCBS certain program requirements are abled to be waived so that people who truly need them are still able to revise services they otherwise could not be able to afford.[185] HCBS waivers can either be autism specific or through ID/DD programs with some families being eligible for coverage regardless of income bracket.[186] The centres for Medicare and Medicaid Services released guides on how states were able to comply with Olmstead. The amount of people receiving HCBS waivers has increased by 86% between 2005 to 2016 with a total of 807,000 individuals receiving home and community based services. This is directly proportionate to the investment in HCBS programs doubling to almost $35.5 billion dollars coupled with a significant decreased in institutionalised spending.[187]

The employment first initiative was created by a subdivision of the US Department of labor, the Office of Disability Employment Policy and it was created “to invest in systems change efforts that result in increased community-based, integrated employ-

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[183] L. Wang, D. Mandell, L. Lawer, ET, AL., “Healthcare Service Use and Costs for Autism Spectrum Disorder: A comparison Between Medicaid and Private Insurance”, *Journal for Autism and Developmental Disorders,* vol. 43, no. 5, May 2013, pp. 1057-64.

[184] CMS Program History” *History of Centres for Medicare and Medicaid Services*, United States Federal Government, June 2018, accessible at: https://www.cms.gov/About-CMS/Agency-information/History/

[185] ibid.

[186] L. Wang, pp. 1058.

[187] UCP, pp. 9.

ment opportunities for individuals with significant disabilities…it centres on the premise that **all** citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life."[188] Of the 30 states that have employment first policies the majority of them are focused specifically on people with DD.[189] Segregated employment workshops typically are the product of day programs that use funds from medicaid to build vocational skills, however these programs ultimately further contribute to the "other-ing" of people with DD/ID by keeping them separated from their peers and paying them well below minimum wage for their work.[190] Other agencies, such as the Job Accommodation Network (JAN) were created in order to help employers provide the best accommodations possible for people with specific types of disabilities. For Autism specifically, it touches on what to consider for people who are on the autism spectrum. It focuses first on social skills and lets employers now why certain individuals may have trouble showing correct social skills while in working environment.[191] It presents full descriptions on the different levels of interaction and possible areas for improvement such as behaviour, socialising/communication, coworker interaction and effectiveness in the job place.[192] JAN also breaks down the different functional levels required for successful job completion by both limitation and work related function and finally offers potential situations and problem solving solutions for related scenarios.[193] There are many resources available through this agency for over 25 types of disabilities that are seen under the ADA. Once employment first

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[188] U.S. Department of Labor, Office of Disability Employment Policy, "Employment First Policy" 2 May 2019. accessible at: https://www.dol.gov/odep/topics/employmentfirst.htm

[189] APSE, Employment First Employment For All "Fact Sheet", www.apse.org

[190] C. Jansen, M. Picciola, B. Taylor, "Equip for Equality: Illinois Employment First BluePrint",*US Department of Health and Human Services: The Administration on Intellectual and Developmental Disabilities,* October 2014, pp. 5.

[191] Job Accommodation Network, "Accommodation and Compliance: Autism Spectrum" 22 June 2019. Available at: https://askjan.org/disabilities/Autism-Spectrum.cfm?

[192] ibid.

[193] ibid.

initiatives were organised in most states, more attention was pushed toward job satisfaction and job retention.

With all of the changes in federal policy over the last few decades, it is practical that one would assume these changes translate directly into each state and local government thus creating tangible results. However, for the majority of states, the progression of employment for people with disabilities has been slow. In the following two sections, I will focus on the employment policies/rates of employment for people with ID/DD in New York and Illinois. These two particular states have been selected because they represent the lower and higher end of states which were ranked by the UCP Foundation and the 2018 Annual Report on people with a disability in America. The have also been selected because they were states that made longstanding policy changes after they were found to be home to some of the worst conditions within psychiatric institutions.

2.2 New York Policy

As referenced in chapter 1, New York was home to one of the worst instances of human rights abuses for people with DD/ID in a institutionalised setting. The Willipowbrook State School was located in Staten Island, NY and it at one point housed over 6,000 people at once.[194] A case was brought before the NY District court as the New York State Association for Retarded Children v. Carey (1972). The suit cited the violations of the patients rights under the due process and equal protection clauses of the 14th amendment.[195] There were several atrocities cited as violations of rights including over crowding, unlawful or unreasonable restriction, poor living conditions etc. The cases outcome was crucial in setting ethical standards which would be federally regulated and enforced for the care of people with DD in state run institutions. It also expedited

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[194] “The Closing of Willowbrook” *Disability Justice,* 10 April 2019, accessible at: *https://disabilityjustice.org/the-closing-of-willowbrook/*

[195] U.S. Const. amend. XIV.

the push for community reintegration and renamed all “state schools” as Developmental Centres”.[196] The Willowbrook Consent Judgement outlined specifically how to humanely treat residents, but the implementation took nearly ten years with it remaining open until 1987.[197] This decree had major influences on disability policy within the state with the enactments of the Protection and Advocacy System in the DD Assistance and BOR Act, the Education for all Handicapped Children Act and the Civil Rights of Institutionalised Persons Act. These would later lead to the drafting of the ADA. [198]

In the state of New York, the Office for People with Development Disabilities (OPWDD) is the leading body responsible for the state regulations regarding services provided to individuals with Autism Spectrum Disorders, DD/ID, cerebral palsy, down syndrome and other cognitive impairments. [199] The office was originally named the Office of Mental Retardation and Developmental Disabilities and was created in 1979 in order to ensure the implementation of the Willow-brook Consent decree.[200] In 2010 the President Barack Obama signed into law legislation that formally struck the phrase “mental retardation” from all federal health, education and labor policy to be replaced with ‘Intellectual disability”.[201] In October of 2013 New York States’ (NYS) Olmstead cabinet issue a state wide plan that addressed the responsibility for serving all New York residents in a community based setting. The plan demanded that all state run agencies take the appropriate actions and steps in order to support the transition from institutionalised to community based settings, to further the involvement of all individuals within

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[196] “Milestones in OMRDD’s History Related to Willowbrook” *Department of Administration Council on Developmental Disabilities,* http://mn.gov/mnddc/extra/wbrook/wbrook-timeline.htm

[197] S. Kristen, "HOW THE WILLOWBROOK CONSENT DECREE HAS INFLUENCED CONTEMPORY ADVOCACY OF INDIVIDUALS WITH DISABILITIES" (2017). CUNY Academic Works.

[198] OMRDD., pp. 2

[199] New York State Government, Office for People with Development Disabilities “Agency Overview” accessible at: https://opwdd.ny.gov/opwdd_about/overview_of_agency

[200] ibid.

[201] M. Diament, *“Obama Signs Bill Replacing Mental Retardation with Intellectual Disability”* Disability Scoop, The Premier Source for Disability News, 5 October, 2010.

their community and to uphold the accountability to all aspects mandated by the Olmstead decision.[202] OPWDD committed to an ICF transition plan within its Transformation Agreement which stated that over the next few years programs would being to shift from the old model of ICF living to more Supervised Individual Residential Opportunities (IRAs).[203] OPWDD also committed to federal programs attempting to fix the gap from medicaid funds to services, the "Money follows the person" (MFP) Demonstration is an example of this.[204] MFP seeks to increase community based services while eliminating restrictions to services that exist within state laws, budgets and medicaid plans, since it began over 1500 individuals in NYS have transitioned successfully.[205]

The National Adult Day Services Association (NADSA) provides services through state agencies and non profits via a social and medical model approach. Social adult day services (SADS) are crucial to the community based care initiatives in that they help to prevent the institutionalisation of older adults with ID/DD into nursing homes.[206] SADS programs are typically supervised programs that promotes adults with DD/ID to socialise amongst their peers and work to be included in their own personal care in a well structured and observable environment.[207] The program functions as a supportive service to try and limit the burnout of family members who care for their individuals at home while dually serving as a means for the socialisation and inclusion of people with DD/ID thus improving quality of life.[208] These programs are imperative to

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[202] Office of People with Developmental Disabilities, "OPWDD, ICF Transition Plan Implementation Strategy" *New York State Government,* September 2014, pp. 1

[203] ibid., pp. 2.

[204] United States Department of Health "New York State: Money Follows the Person" Factsheet, *New York State Government,* 2015.

[205] ibid.

[206] NYS Office of the Aging, " Social Adult Day Services Programs (SADS)" *New York State Government,* 2015.

[207] ibid.

[208] ibid.

the functional ability of the individuals which they serve, with out them many would be kept in isolating environments which would not be conducive to achieving the highest attainable standard of living in the least restrictive setting which they are entitled to.

According to the CDC, the estimated yearly costs for caring for someone with autism is between $17,000 to $21,000 USD per year depending on the severity of the diagnosis.[209] Early intervention programs for children and regular behaviour intervention specialists are crucial to the management and ongoing treatment of Autism Spectrum Disorders. Recently, Governor Andrew Cuomo and the New York Senate passed Bill S8953, which amended social services law and included medically necessary services, such as the use of ABA Therapists to be fully covered under Medicaid funding.[210]

The Case For Inclusion Report has recently placed New York as one of sixteen states in the country which has a main focus of familial supports with the majority of their families receiving services through supported home environments (200 families per 100,000 people).[211] New York is currently ranked at number eighteen out of all fifty states. They came in with 38.5% (promoting independence) which includes community based services and residential services that are received within the community, 13.2% (tracking healthy, safety and quality of life) which includes quality assurance, inclusions, and other NCI indicators. Followed by 4.2 % (keeping families together), 6.4% (promoting productivity) including competitive employment and tracking vocational rehabilitation rates,hours worked, and job retention, and finally 15.0% (reaching those in need) or the population served, with the total ranking coming to 77.3% (#18). [212]

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[209] “Autism and Insurance Coverage, State Laws”, *National Conference of State Legislatures,* 8 August 2018, accessible at: http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx

[210] Senate Bill S8953

[211] UCP, pp. 12.

[212] ibid., pp. 19.

2.3 Illinois Social Care Policy/Programs

In Illinois, Chicago State Hospital also referred to as "Dunning" had a documented history of housing patients in buildings described as "a tomb for the living" CITE. When the Olmstead decision was enacted in the summer of 1999 many states immediately began to rework their national laws in order to been compliance. Illinois moved far slower than most states with 80% of its long-term care budge still being spent on institutionalised care up until as late as 2003.[213] According to the United States Bureau of Labor, there were approximately six million people who were employed in 2017.[214] Of those, 37% were employed in some type of job.[215] The Illinois Human Rights Act explicitly rejects any employment practice which discriminates on the basis of a person's mental or physical disability if that disability in no way hinders their ability to preform essential job functions.[216] In 2009, the Employment and Economic Opportunity for Persons with Disabilities Task Force Act was signed into law by then Governor Quinn.[217] The task force was mandated by the governor to identify the extent of the pitfalls of the employment system for those with disabilities. The task force put forth a number of recommendations that it believed should be addressed within the subsequent employment first legislation. These recommendations included but were not limited to:

> "1. Issuing policy that was intersectional and would be able to be picked up by different states and agencies.

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[213] M. Minkler, J. Hammel, S. Magasi, V. Vasquez, M. Bristol, D. Coleman, "Community-Based Participatory Research in Disability and Long-Term Care Policy" *Journal of Disability Policy Studies,* vol. 19, no. 2, September 2008, pp. 1.

[214] United States Bureau of Labor, accessed by https://www.bls.gov/eag/eag.il.htm

[215] Erickson, W., Lee, C., & von Schrader, S. (2014). 2013 Disability Status Report: Illinois. Ithaca, NY: Cornell University Employment and Disability Institute(EDI).

[216] 75 IL Comp. Stat. Sec. 5/1-103), accessed via https://www.blr.com/HR-Employment/Discrimination/Disabilities-ADA-in-Illinois 10 June 2018.

[217] C. Jansen, pp. 3.

> 2. Developing knowledge management systems which would be able to track the progress of the state and hold the right agencies accountable for any discrepancies.
> 3. Drastically improving the quality of care from staff members by creating new compliance standards and developing trainings with employment first goals in mind.
> 4. Creating a budget capable of providing the necessary resources and incentivising care.
> 5. Strengthening the development and smooth transition of students with disabilities so that they are ready for the workforce when it is time for them to enter it." (Equip for Equality, 3).

In order to begin to fix the disability system in Illinois, employment first legislation was crucial in order to ensure compliance with federal policy. Under the ADA and supreme court decisions such as *Olmstead v L.C.* segregation of people with disabilities to institutions or non community setting was found to be grounds for discrimination based on disability. The Illinois Employment First Act was enacted in 2013 and gave state policy makers, stakeholders and non profit agencies the tools needed in order to prioritise competitive and integrated employment for those with DD/ID within the state.[218] The challenge for Illinois was to completely overhaul the state's disability policy and mechanisms in regards to the barriers to both competitive and integrated employment, funding issues with each and transition services.[219] Despite the progress that came from the ADA and movement of people with DD/ID from institutionalised to community based settings, segregation is still evident in the employment sphere.[220] Many employers believe that the physical inclusion of people with DD/ID in the work-

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[218] ibid., pp. 5

[219] ibid., pp. 5

[220] ibid., pp. 6-7.

force is sufficient. However, working and participating in the community does not only mean showing up. Segregated workforce settings can be just as detrimental to the progression of jobs skills of people with disabilities as not including them at all. Studies show that most people who are participating in integrated employment are actually part of a “work crew” of other individuals with disabilities and are often paid minimum or sub minimum wage calculated for people with DD/ID.[221] Full employment means dismantling the systems which allows segregation so that those with disabilities are able to be treated equally as their peers, including the wage that they are receiving. Individuals with ID/DD in Illinois have two options when they are trying to secure the funds that come through the Illinois Department of Human Services. This department is a US government agency that helps to provide immediate access to integration services that will strengthen the community by empowering individuals. [222] The first option that individuals have is to go through the Vocational Rehabilitation Office while the second is to go through the HCBW programs through medicaid.[223]

Within the last few years organisations such as Equip for Equality and the American Civil Liberties Union of Illinois have brought forth several cases that challenge the compliance of the ADA for people with ID/DD/Mental illnesses. One notable case regarding people with ID/DD is *Ligas v Hamos* (2005) later known as the Ligas Consent Decree. The suit was filed by nine people with different developmental disabilities who were living in large state funded institutions that wanted to transition to receiving community based services but were denied by the state of Illinois.[224] A consent decree was issued for this suit which allowed over 6,000 individuals seeking community integration an evaluation and placement into the appropriate community setting over a 6 year peri-

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[221] ibid., pp. 4.

[222] Illinois Department of Human Services, accessible at: http://www.dhs.state.il.us/page.aspx?

[223] C. Jansen, pp. 8.

[224] Access Living, “Annual Report: Ligas v Hamos Fact Sheet” Access Living, 11 January, 2011. Accessible at https://www.accessliving.org/v30

od, it also allowed current residents who wished to remain within state institutionalised care to stay where they were with adequate funding and resources.[225]

According the UCP and ANCOR Foundations Report, Illinois has consistently ranked as one of the worst states at number forty four of fifty when it comes to supporting their disabled population. At promoting independence they received 28.5%, 13.5% at tracking health, safety and quality of life, 1.8% of keeping families together, 5.7% Promoting productivity, 14.1% of reaching those in need for a combined 63.6%. [226] There have been several attempts by the state to reconfigure disability policies however budgeting seems to be the overall reason for why progress has ceased. Illinois continue to be ranked low in national reports complied from various monitoring agencies tracking states progression across the United States.

2.4 Conclusion

The enactment of policy reforms in the United States solidified the changes in ideology that came from the respective social movements and awakenings for people with disabilities. Federal proponents of disability policy such as Robert Felix dedicated their lives to the evolution and inclusion of disability rights as a comprehensive part of federal law. The emergence of new governmental agencies specifically designed in order to look after those with developmental and intellectual disabilities were crucial to setting new normative standards for how to treat those who were considered “different”. Legislation such as the Rehabilitation Act and later the Americans with Disabilities Act were defining moments for disability policy in the United States. The federal enactment of these document meant that states were monitored and forced to comply. This was done by ensuring the new policy was being enforced or they would be met with consequences from the federal government. While it took a while for many states to be able to effectively initiate new policy, once it was done there was an increase in employment

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[225] ibid.

[226] UPC pp, 16.

opportunities for those with disabilities across the country. Although many considered these policies to be largely successful, arguments are still made for the areas of the documents which continue to remain vague amongst legal theorists.

As mentioned within this chapter Social Security and Medicare services remain crucial to the success and daily living of people with ID/DD. Individuals are able to be provided basic needs whether that be transportation services, day services, respite, employment training, workshops, in home support etc all through comprehensive benefits which medicare provides. HSBC waivers allow for millions of Americans to receive community based care largely covered by the federal government. However these services do sometimes have large wait lists, and because of this there can be individuals left waiting with no service for extended periods of time.

Other key pieces of legislation which directly effected the day to day life of adults with disabilities are supreme court decisions such as Olmstead v. L.C. 1999. This legislation ended the use of excessive restriction, calling for care to be given in the least restrictive setting possible as well as encouraging state hospitals to integrate those with ID/DD back into community based settings whenever feasibly possible. With these advancements in legal precedent as well as national policies, states began to take appropriate steps in order to create Employment First policies which would make the employment of adults with developmental disabilities a priority. The decision to prioritise competitive integrated employment and vocational skills was long awaited. With full employment opportunities being one of the defining steps for true community integration and inclusion, these policies across the US were a necessary initiative to further advance employment opportunity.

Many state-specific disability policies have been exclusively shaped by experiences of individuals within that state. This is noticeably seen in the evolution of policy work that has happened in both New York and Illinois where each state recognised the horrible atrocities going on in state run hospitals and took the necessary steps in order to either a) close those hospitals or b) set new policies and standards so that those abuses would never be repeated. These states also enacted new policies which would push employment first initiatives to serve a greater percentage of their disabled population. National organisations and foundations have created several reports which were useful in tracking the development of a states employment policy as well as other policies which seek to provide individuals with the highest quality of life.

CHAPTER 3 - METHODOLOGY

3.1 Research Design

The approach that I took to this research was mixed methods. I decided early on that I would combine both qualitative and quantitative data in order to yield the best results for this thesis. The basis for this decision came from the understanding that each method is founded on a specific paradigm; with quantitative research being based on positivism and empirical findings which provide the researcher with an objective view of the respondents lived in experience.[227] The nature of this paradigm allows for the mass surveying of a particularly high number of respondents so that the researcher is able to produce an analysis with little to no influence.[228]

The quantitative paradigm is rooted in both interpretivism and constructivism, meaning that a persons perceived reality has a large number of possibilities based on their own lived experiences and truths.[229] It operates on the notion of a socially constructed reality which is always changing. Sample sizes for this type of research are generally smaller, and usually consist of small focus groups and interviews where the researcher is directly involved with those participating. While there are many arguments as to why a mixed-methods approach does not work, a shared world view links these too methods; the notion that at their fundamental cores each has the goal of "understanding and improving the human condition".[230] When analysing my qualitative data, I relied largely on grounded theory in order to draw parallels between it and the historical

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[227] J. E. M. Sale ET AL, Revisiting the Quantitative-Qualitative Debate: Implications for Mixed-Method Research, *Kluwer Academic Publishers,* Netherlands, 2002.

[228] P. Burnard, P. Gill, K. Stewart, E. Treasure and B. Chadwick, "Analysing and presenting qualitative data" *British Dental Journal*, vol. 2014, no. 8, 2008, pp. 429.

[229] UPC, pp. 16.

[230] C. Reichardt, S. Rallis, "The Relationship Between the Qualitative and Quantitative Research Traditions, 2004

research I had previously done. I used open coding in order to uncover and categorise major themes within the interviews. My interviews were semi structured so that I began my research with the first set of questions and immediately began analysis after so that I would be observant to recurring themes/know if I need to obtain another aspect of the topic.[231]

With the knowledge of how both of the qualitative and quantitative paradigms contribute to the understanding of research, it became obvious to me that they would serve as tools to gather information to help answer my research question. For this thesis, I set out with wanting to understand *What are the effects that social care programs have on the low employment rates of adults with Autism Spectrum Disorders?* I decided on using quantitative of data so that I would be able to gather a large amount of responses to give a more factual and evidence-based amount of data. I wanted to be able to get an objective view of the experience of adults with autism and the experience of their care-givers/family members. I insisted on using a mixed-methods approach largely because I believe that the limitations from one type of data would be balanced by the contributions of the other. An example of this being, the surveys which were sent out to adults with autism would be limited to those who are extremely high functioning (i.e. They can read/understand/ navigate the types of question within the survey). This limitation would immediately negate those with a lesser academic intelligence[232] but who are otherwise qualified to give their perception of their employment experience.

In order to evaluate the perceived effectiveness of a specific program or service, I knew that having multiple perspectives would be essential to being able to get a clear picture of how that service is preforming. With this in mind, I decided to collect data from the individuals themselves, to measure how they believe these programs are working for them. I also decided to give a survey to the parents/guardians and people who

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[231] J. Corbin, A. Strauss, “Grounded Theory Research: Procedure, Canons, and Evaluative Criteria” *Quantitative Sociology,* vol. 13, no. 1, 1990, pp. 6.

[232] Meaning, those who are not able to read or fully understand the types of questions being asked via a survey, but who are still able to preform certain job functions and communicate fully.

work directly with adults with autism to get their perspectives as well. Each of the surveys had the same basic questions with a slight delineation to their respective roles.

3.2 Procedures

For my research I decided to survey two groups of people to measure the effects of social care programs such as medicaid on adults with autism. The two groups were split between the individuals themselves, where I received 32 surveys back of 100 sent out. The time frame to complete the survey was over three consecutive months from April 2019 to the end of June 2019. The group of individuals was further categorised by age group, 18-35 and 35 and over. The second group of surveys was sent to both parents/guardians of adults with autism(32) as well as immediate care workers (56) (i.e. direct support workers, respite workers etc). In total I received 32 Individual Surveys and 88 from Parents/DSPs. The surveys for the parents/Guardians were distributed using the software Qualtrics, Here I was able to create the survey and cumulate the results until I was able to put them into an excel sheet. I chose to use an internet survey for the parents/DSPs because it was the least time consuming, with the survey being accessible and user friendly from any mobile device with internet. Due to the nature of my job, I come into contact with the parents and workers of people with Autism daily and was able to distribute the survey to participants via word of mouth. I was able to do this by informing them this was for my own research project, and was completely independent of the agency which I work for. I informed them that the survey was completely anonymous and voluntary, and that they were able to quit or stop answering at any time. For the individuals survey, I decided to use hard copy paper surveys. I made this choice because I felt that an internet survey may be too overstimulating/participants may become distracted.

3.2.1 Ethics/Informed Consent

Due to the sensitive nature of the topic/group of persons which I sought to receive my data from I had to be sure that all ethical standards as set out by the University of Vienna were followed and ensured. Ethical approval was gained from the University Committee where all research methods where extensively described before being approved by the University. The gathering of informed consent from all participants who are able to give it, and if not, receiving that consent from the appropriate person (i.e. parent or guardian). In order to ensure the compliance of informed consent for the surveys which were distributed by hand, each was also assigned a number. They were asked to remember this number as the survey would be handed back to them. The respondents were instructed to read and answer the the first question and stop. It asked “are you 18 years or older, can you consent to participate in this survey?” Of the 100 surveys received, only 32 were usable. 10 responded “no” and 5 responded “I’m not sure” to the first question. After receiving a “yes” each survey was collected, I checked with necessary management that the person was able to give their own consent. Upon the appropriate receipt of approval, surveys were placed on the table where respondents were able to come and take the survey with their corresponding number. Next each respondent was handed an informed consent waiver (as submitted to the ethics committee). They were informed that participation was completely voluntary, and they could stop answering any questions at any time. Each survey was created so that it would produce no foreseeable negative effects or outcomes on the individuals who decided to participate. The individuals were then told that they would be able to request the results for up to 1 year following completion, and that I was the only person who had access to the results of each survey.

The qualitative data that I collected was in the form of 5 concise, semi structured interviews which lasted for a total of 10 minutes each. Each of the respondents from this data were selected randomly from those who were unable to complete the survey due to misunderstanding/misreading of the questions. The inclusion of those who were unable to complete the survey was essential to being able to produce well-rounded results about the effects of these programs. This type of data collection also gave respondents a chance to give a more personalised perceptive of their opinion of employment programs. Because of this I chose to do a semi structured interview consisting of only three open ended questions as to be sure not to lose the audience.

3.2.2 Recording and Storage of Data

Each Respondent was given a number that would serve as their identifier for the duration of the survey and interview. Each record of informed consent was scanned and uploaded into an encrypted USB file for which only I have the password. All hard copies of informed consent were secured in a locked filing cabinet under an ambiguous heading for further identity protection. Due to the haute of the interviews and understanding of all ethical concerns none of the semi structured interviews were recorded with any type of listening device. Instead, I was given permission to take notes during the interview, these notes were also linked to each persons specific number they were given. Any specific quotes were marked by the use of direct (“”) quotation marks, any paraphrasing was recorded with single (‘’) quotation marks.

3.2.3 Interview Environment

Upon the beginning of the interview, the respondents were again informed that at any time throughout the interview, they could leave or stop answering questions if they wanted. They were also informed that if at any time they wanted to take a break, that was perfectly feasible and encouraged. The interview was held in a room with multiple windows and entrances, all of the doors which were left open to foster a very open flowing environment. The interviews were semi-structured, with the first question being the same for all participants and then a variation of follow up questions based on the respondents answers. The interview consisted of a maximum of three question with the allotted time being no more than 15 minutes. This method of data collection followed an exploratory nature. All interviews were held in May 2019 over the course of a two week period with no more than one interview taking place on any single day.

3.2.4 Limitations

This study analysed the effects of social care programs on the employment rates of adults with autism. Many components add up to full employment and because of this several factors were looked at to make determinations about the effects of these programs. Attitudes and perceptions of individuals, family members are direct support workers were used with the goal of understanding how job preparedness, training, support staff, ASD diagnosis etc. all potentially impacted employment. Because this study was addressing the perceptions related around employment, only individuals with verbal language capabilities were surveyed and interviews. For the parent and DSP survey however some reported that they were working with individuals across all categories of language ability. The need for more research to be done on employment of minimally verbal/significantly impaired adults with autism was noted. As a result of this some may interpret it as selection bias, however there were not other qualifications for this study other than language ability and ability to self report.

The focus of Chapter 4 is to present data which was collected over three consecutive months relating to the effects of social care programs and the employment rates of adults with ASD. This chapter presents the findings of self reported surveys and qualitative interviews from individuals as well as surveys from the family/direct support staff. The results are discussed and ends with a list of recommendations for how to improve employment outcomes.

CHAPTER 4 - ANALYSIS

4.1 Quantitative Results

For the quantitative data, five surveys were collected from participants who wished to talk about their employment experiences. In order to analyse the results of the quantitative surveys they were first broken down into two respective categories based on the two different types of surveys which were distributed. These categories were split into those responded to by parents/direct care workers and individuals with an ASD diagnosis. From here the results were further broken down into the following sections where they could be grouped together via trends and similarities.

The interviews were to remain completely anonymous with those participating being informed that I would not be collecting any type of identifying data nor would I be recording with anytime of digital recorder. They were informed that at anytime they could withdraw participation with no consequences. Each participant consented to note taking where I would paraphrase when applicable and write down direct quotes when necessary with any personal information which could identify an individual was taken out of the transcriptions for confidentiality purposes. I completed a thematic analysis of the data by using open coding techniques as described by Braun and Clarke to find common themes.[233] I did this by going through each answer and putting them into general categories (social stigma, personal requirement, job satisfaction etc). This process continued with all five interviews. A new piece of data was added into each of the lists as I went through each of the interviews. If more than one interview consisted of the

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[233] V. Braun & V. Clarke, “Using Thematic Analysis in Psychology” *Qualitative Research In Psychology,* University of the West of England, 2006, pp.77-101. ISSN 1478-0887

same new data, a new category was created. I went through each interview approximately 3 times on 3 different days in order to catch any mistakes which were made. From the Qualitative Data there were 3 major themes/categories which were recognised: a) Satisfying Personal Requirements b) Awareness of Difference and c) Job Satisfaction. These themes were then further coded into sub-themes which consisted of the many different coding words that were used in order to create the larger categories.

Data

Each Survey began with asking what was the relationship they had to an individual with Autism. These results were differentiated in order to later compare differences in perceptions of service between family members recovering services as well as those providing it.

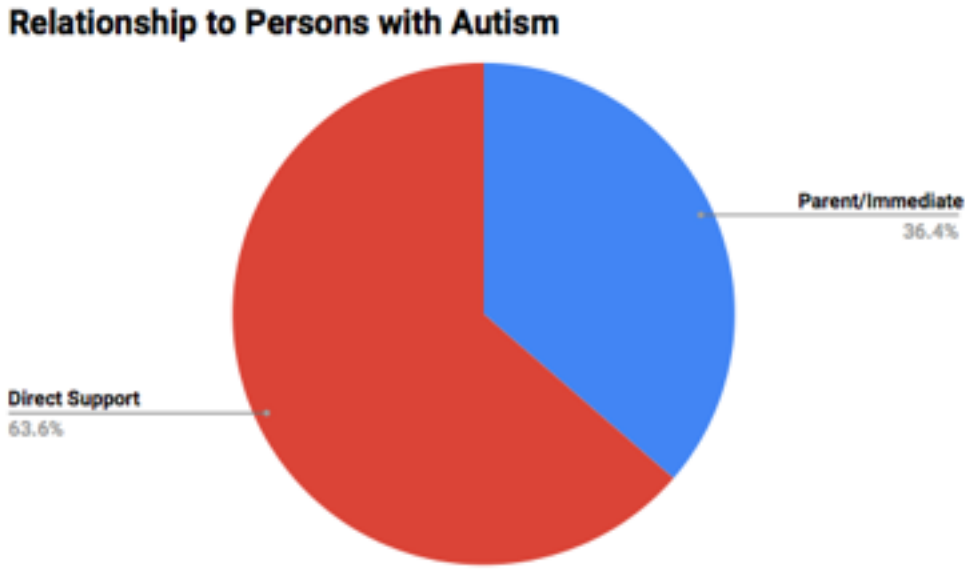


Figure 1. *Source, Parents/DSP Survey. Identifying Data*

Are you the parent and/or legal guardian of an individual or do you work directly with someone with Autism?

Figure one identified the difference of relationships to adults with autism. In total n= 88 (family/direct care workers) responded to the survey, 32 responded that they were the parent or legal guardian of someone with Autism while 56, responded that they otherwise worked with adults with autism. Figure two identified the age brackets of the individuals which responded (n=32) to the survey with 56.3% (n=18) being aged 18-35 and 43.8% (n=14) being over 35 years old.

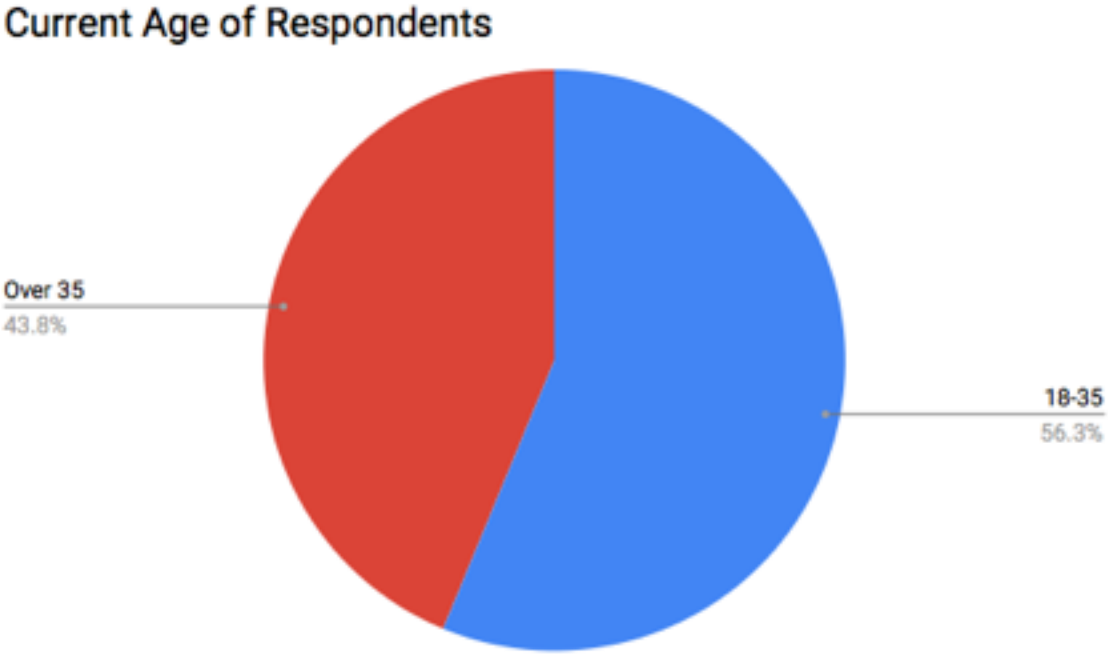
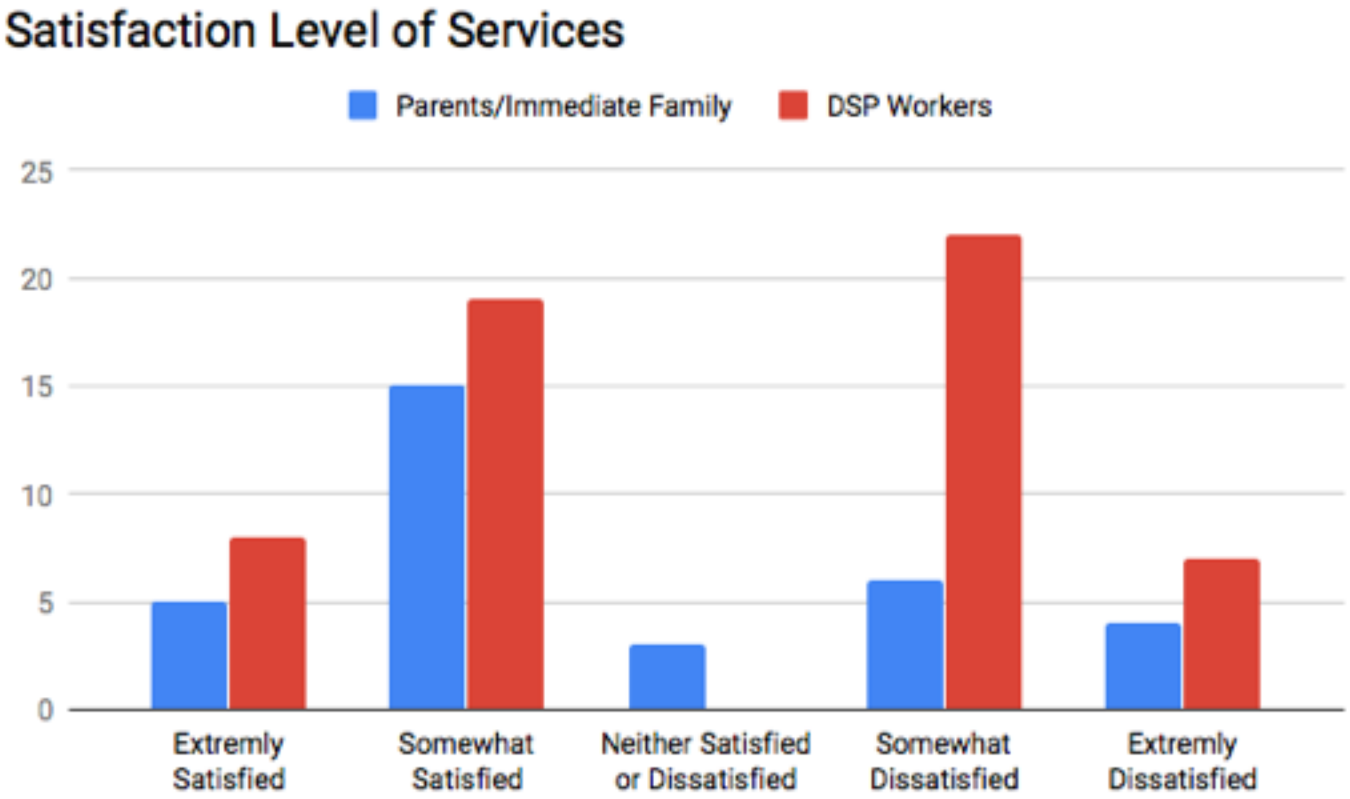


Figure 2. *Source, Individuals Survey.*
Current age of respondents

Participants in the survey were asked which age bracket they fell into. The available responses were 18-35 and over 35. Ages were divided this way so that data



was able to be collected on young adults just entering the work force as well as older adults who have been eligible for work for an extended period of time.

Figure 3. *Source, Family/DSP Survey.*
Please rate how satisfied you are with the level of services you have experienced/observed?

Of the general services which were experienced and observed, only 5 Parents reported being extremely satisfied and only 8 DSPs reported being extremely satisfied with services they witnessed. DSPs were unlikely to respond to neither satisfied or dissatisfied, with zero reporting compared to parents. The findings suggest that family members and direct support workers expressed different levels of concerns about the level of service they were observing. With 39% of DSPs reporting that they were "somewhat dissatisfied" with the services they were witnessing. This aligns with xx report which acknowledges the level of dissatisfaction among staff in the field, with xx stating that more structure is needed to job programs and other services. Contrarily, 59% of parents reported that they were somewhat satisfied with the services that their loved ones were receiving.

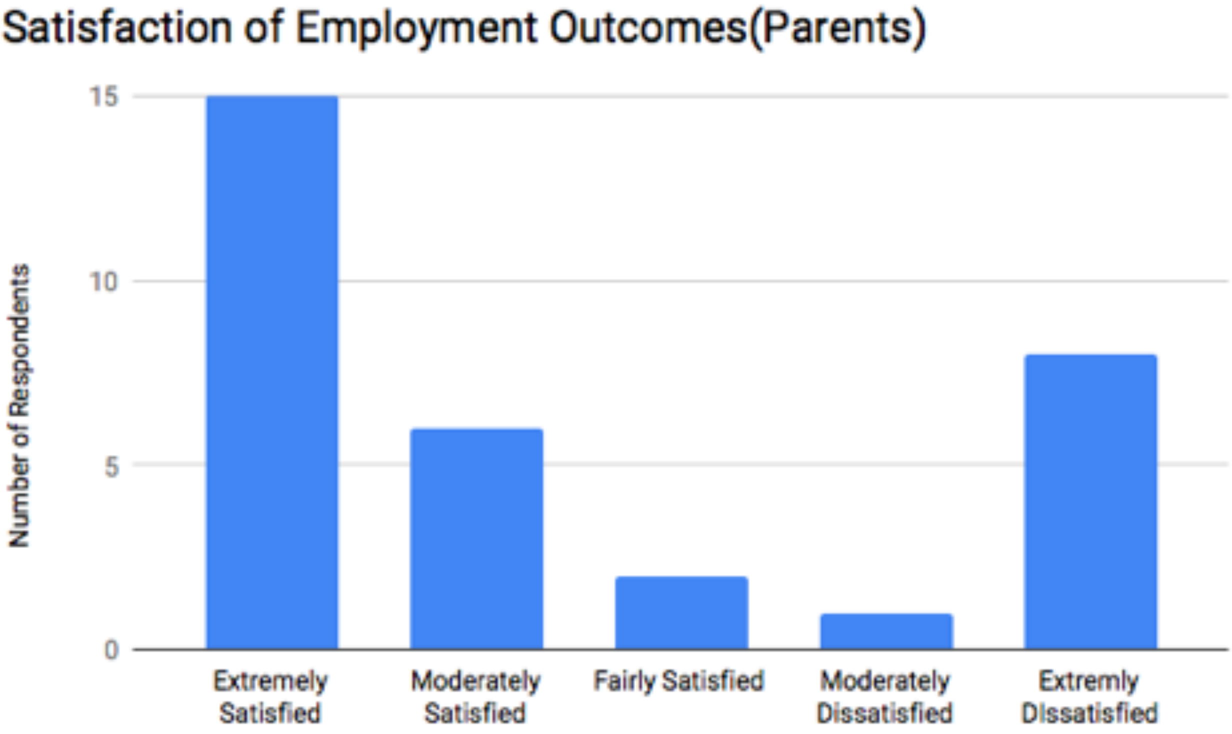


__Figure 4.__ Parent satisfaction levels of employment outcomes for children receiving social care services.

Satisfaction of employment outcomes from the parents perspective were included to show different variation the perceived experiences from the programs. As suggested, the data here shows that 47% of parents are “extremely” satisfied with the employment outcomes of their children via the program which they are in now. However, 25% do report being “moderately or extremely dissatisfied” with the outcome of their child’s employment status.

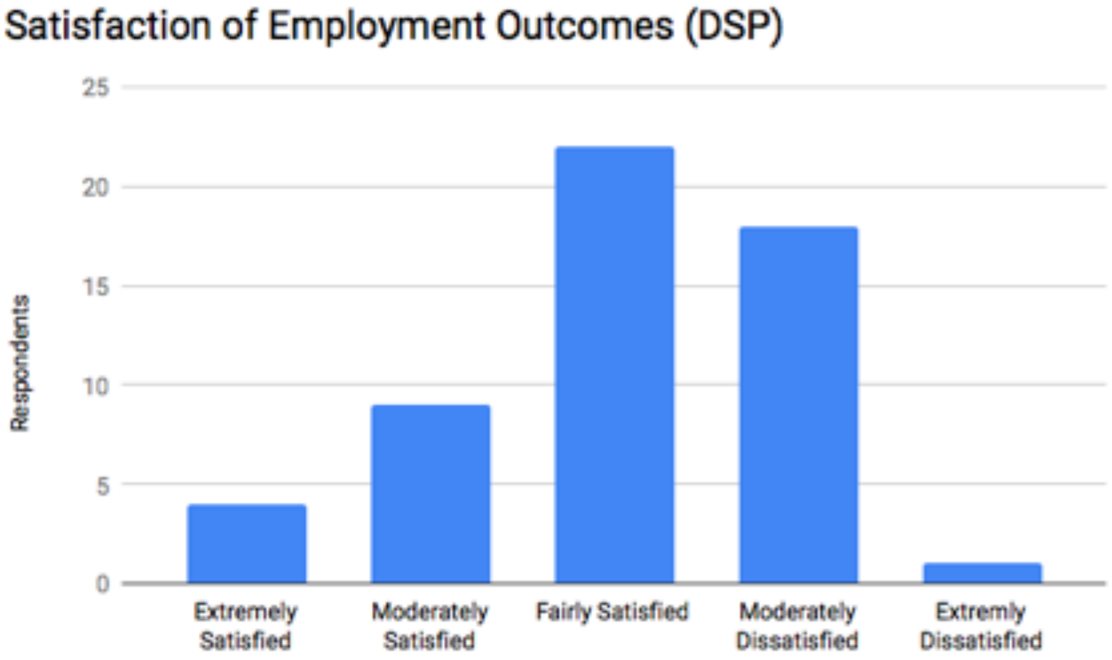


Figure 5. *Direct Support Workers satisfaction levels of employment outcomes for the individuals which they serve.*

Figure 5 illustrate the satisfaction level that DSP’s have with he employment outcomes of the individuals which they serve. DSP’s also rated satisfaction of employment outcomes 14% higher than parents.

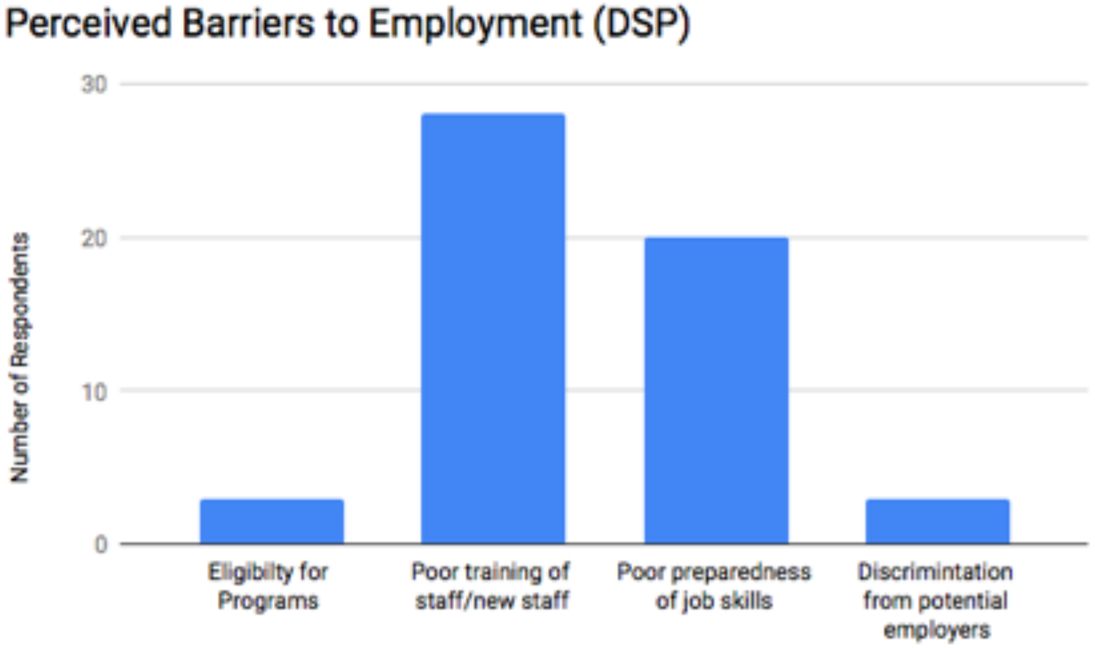


Figure 6. *Direct Support Workers perceived barriers to employment for the individuals which they serve.*

Figures 6 illustrates that 50% of DSPs surveyed believe the poor training of staff and rotations of new staff directly contribute to employment barriers for individuals in the programs they service. N=2 staff responded saying that they each thought eligibility/access to programs or discrimination from potential employers was the reason for encountering of barriers to employment. N=20 respondents also listed poor preparedness of job training skills as a perceived reason for barriers to employment.

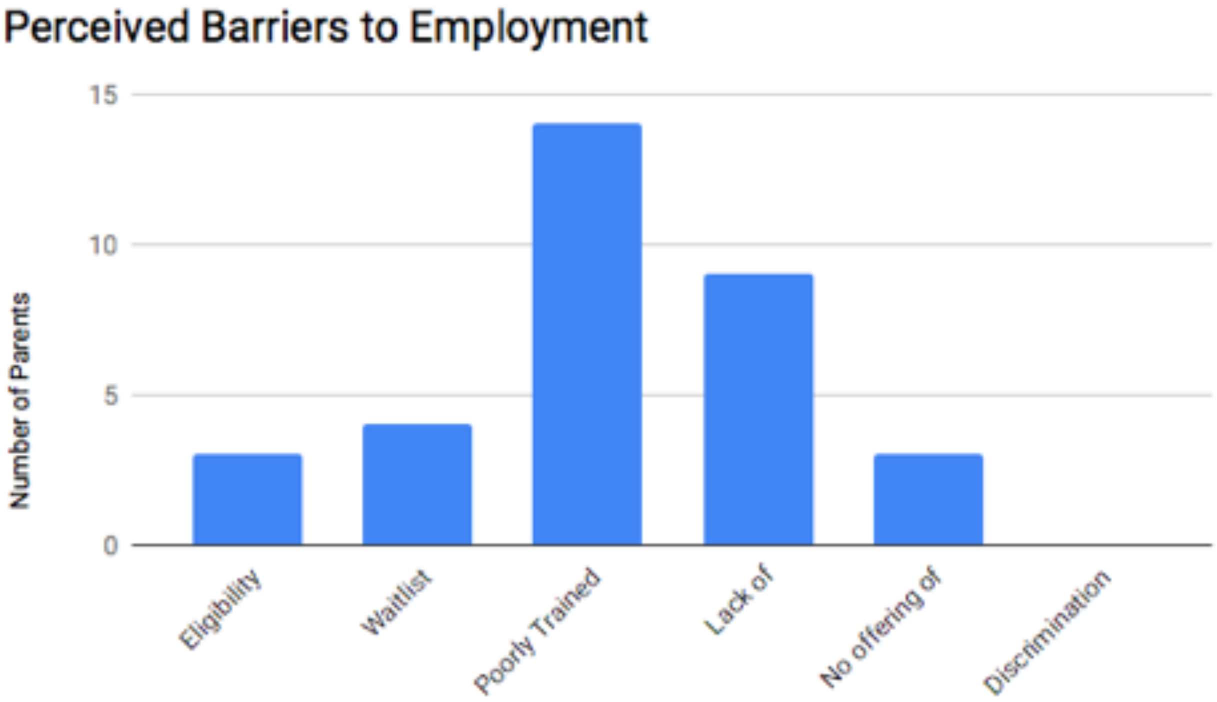


***Figure** 7. Source, Parent/Individual Survey.*
Parent/Guardian perceived barriers to acquiring employment.

Above there were five possible categories to be selected from when addressing the main perceived barriers to employment from the perspective of the parent or family member. These categories of barriers to acquiring employment ranged from eligibility for programs (job training or vocational), waitlisting for those programs, poorly trained staff, lack of preparedness of their child, no offering of employment services and discrimination. N=14 parents selected that they thought poorly trained staff was their child or family members main barrier to employment. Lack of preparedness was the second highest option selected with n=9. There is a correlation between the effectiveness of staff/their ability to preform necessary job functions required to help adults with ASD enter into the workforce and the preparedness of individuals to fulfil job roles.

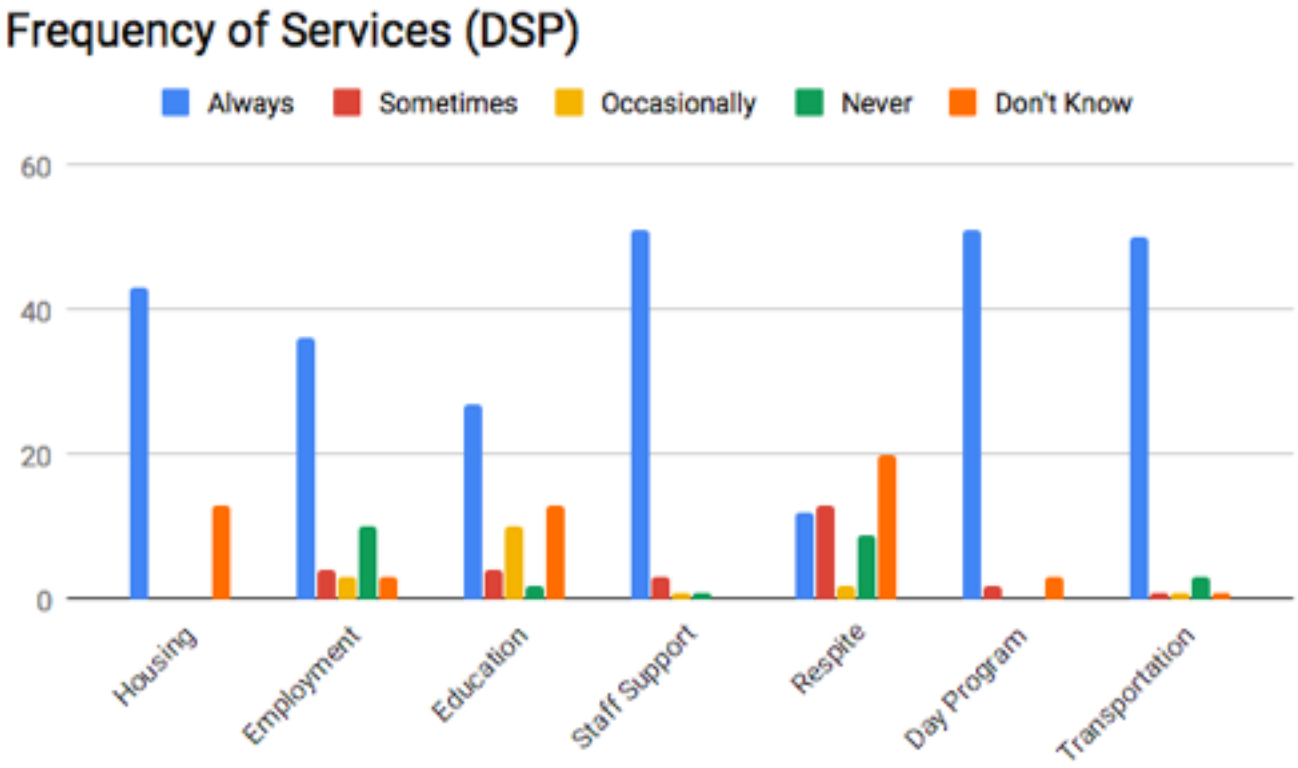


Figure 8. *Source, Parent/Family Survey,*

How frequently does your child use each of the following services?

Figure 8 presents a chart which shows the reporting of frequency of services used by the family member with ASD. This information provides a picture how how many services/which types of services are typically used by the individual and provides insight into the level of dependency on programs. Parents/family were encourage to rate each category.

Figure 9. *Source, DSP Survey.*

How frequently do you observe the individuals you serve using each of the following services?

Similarly to Figure 8, staff were also encouraged here to list the frequency of services that they observed being used.

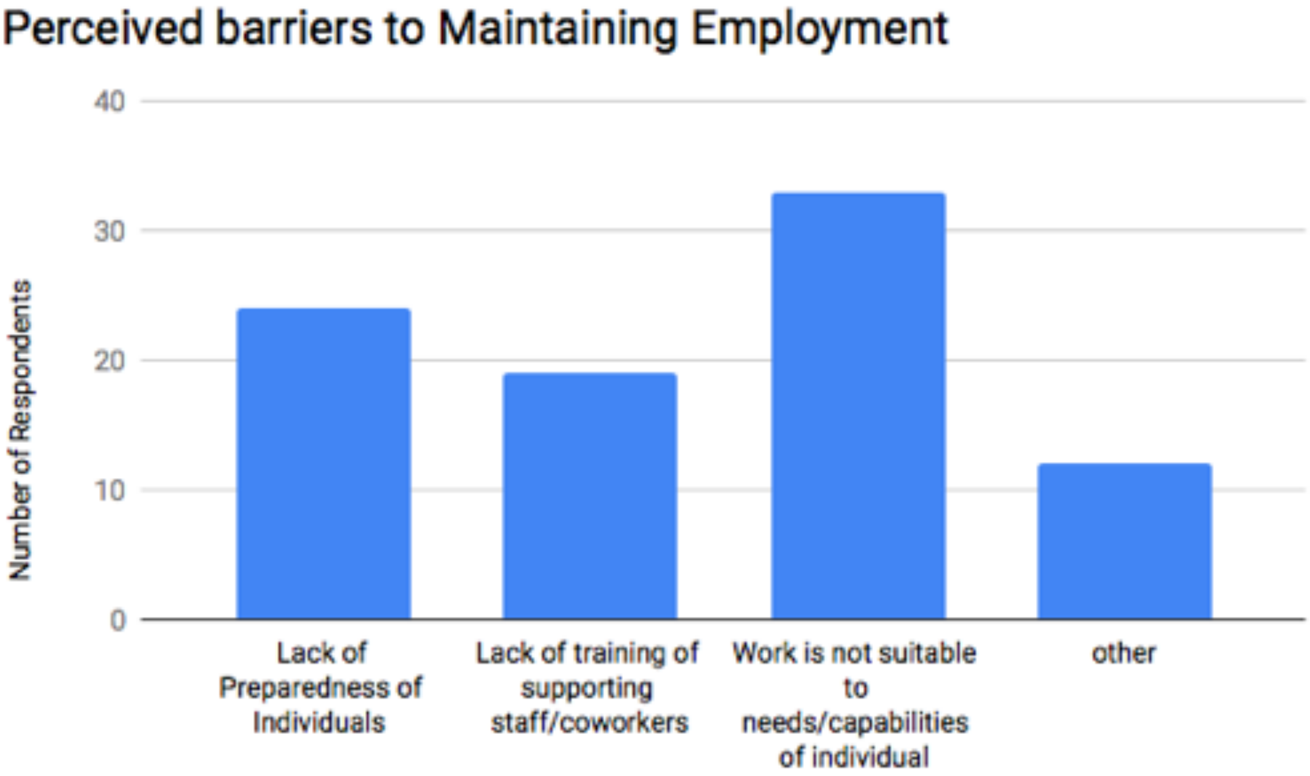


Figure 10. *Source, Parent/DSP Survey.*
what are the perceived barriers to maintaining employment?

There are many barriers that hinder a person with autism's ability to find employment, these barriers can range from personal to environmental to other. The survey question above combines responses from parents and DSPs. Much of the literature currently available today suggests that much of the problem comes from lack of social understanding of people with Autism by their "normal" coworkers.[234] The data collected shows that a combined 32 parents and DSPs responded an individual would most likely lose employment because their job does not suit their needs or capabilities of the individual.

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[234] E. Harmouth ET AL. Barriers and Facilitators to Employment for Adults with Autism: A Scoping Review, *Annals of International Occupational Therapy,* vol. 1, no. 1, 2018, pp. 4.

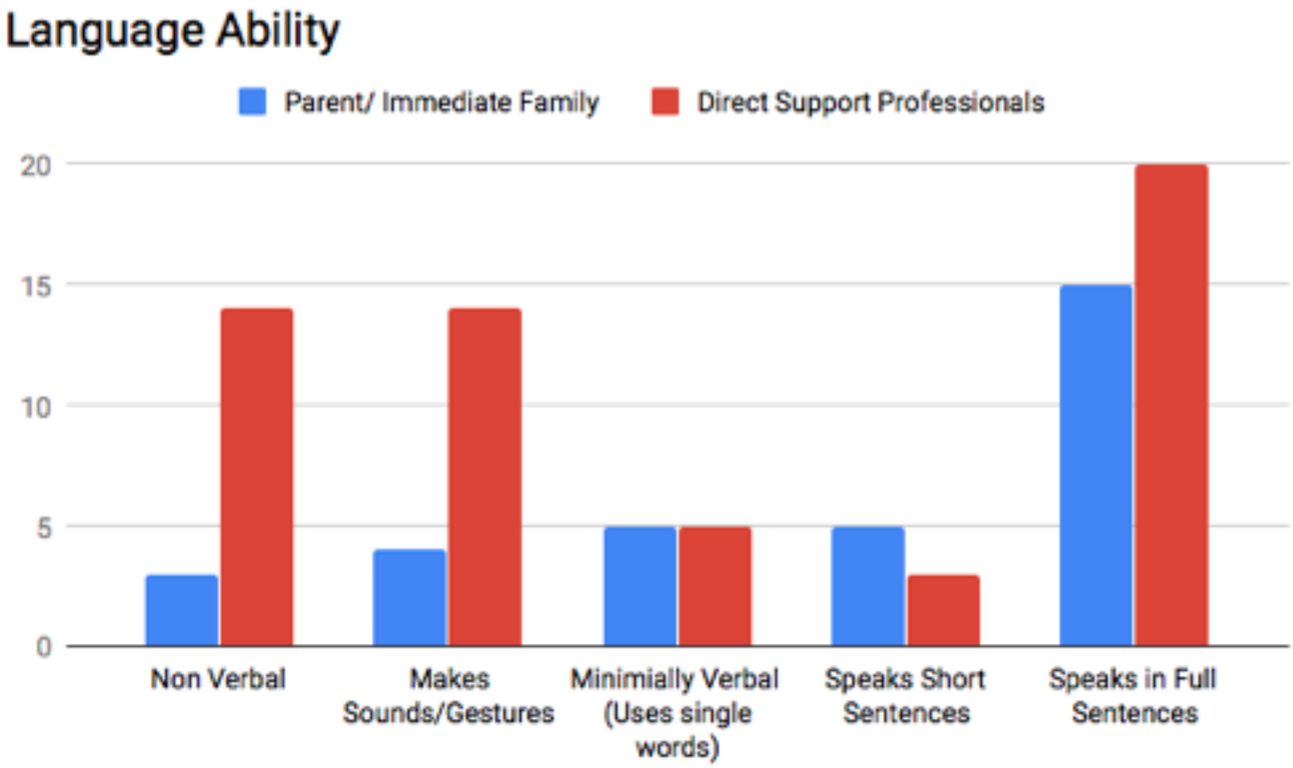

Figure 11. *Source, Family & DSP Surveys*
What is the language ability of your child/ those which you observe in employment?

The above graph demonstrates the different levels of language ability of Individuals as related to both parents/family and DSP workers. The categories available were non verbal, makes sounds or gestures, minimally verbal (uses single words), speaks in short sentences or phrases or speaks in full and complete sentences. This chart demonstrates that DSPs observe those in employment who are non-verbal with no sounds (n=14) and those who make small sounds or are able to gesture (n=14) at almost the same rate which they encounter those adults with ASD who speak in full sentence or are higher functioning (n=20).

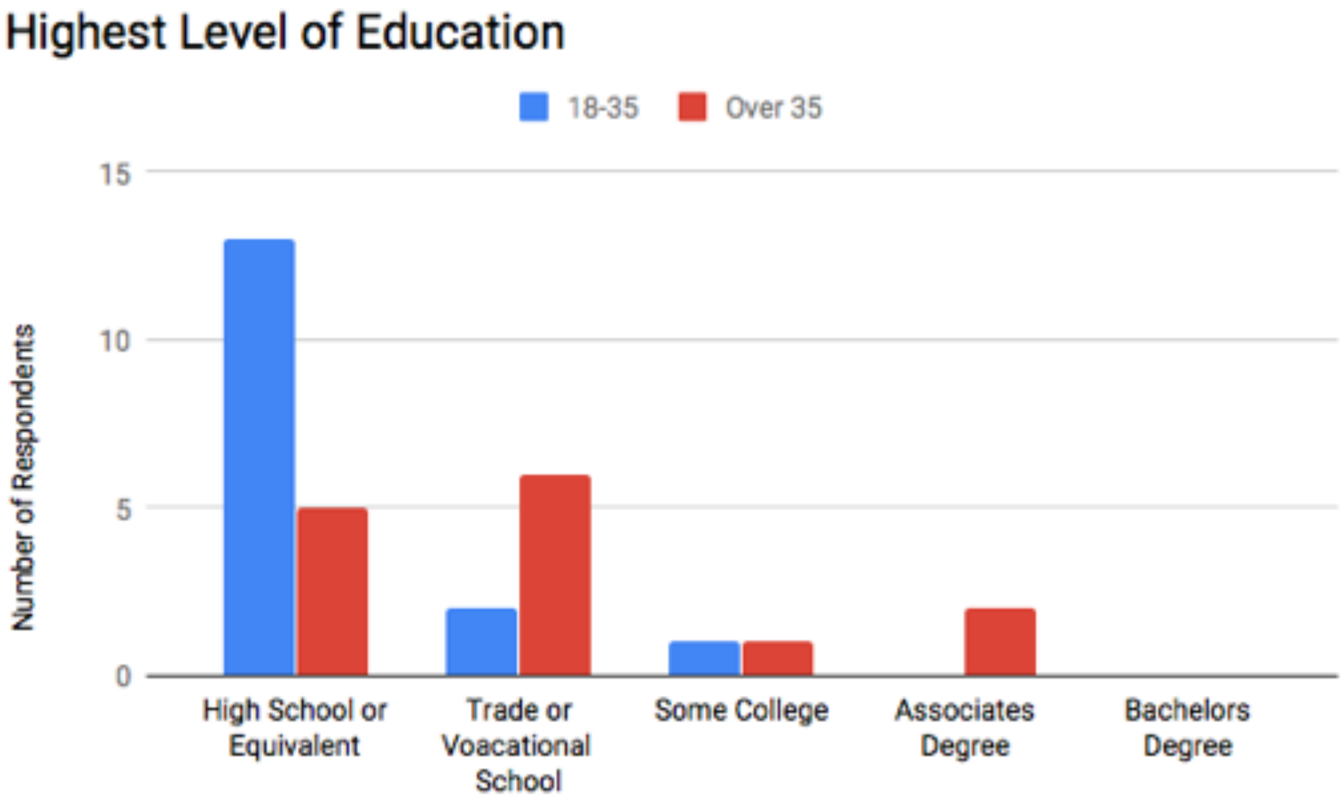

Figure 12. *Source, Individuals Survey*
What is your highest level of education?

All of the respondents have completed at least their High School diploma or its equivalent which is supported by data findings from the Annual Report on Disability Statistics and findings which says that the gap between people with disabilities and their peers an the completion of a high school diploma has gone down to 9.8% from 12.4%.[235] Data suggests that younger adults age 18-35 have completed more postsecondary education that adults over the age of 35. This correlates with recent education statistics that find earlier interventions and creation of IEPs for children with ASD leads to better outcomes for postsecondary schooling.

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[235] Annual Report on Disability Statistics, 2018, pp. 16.

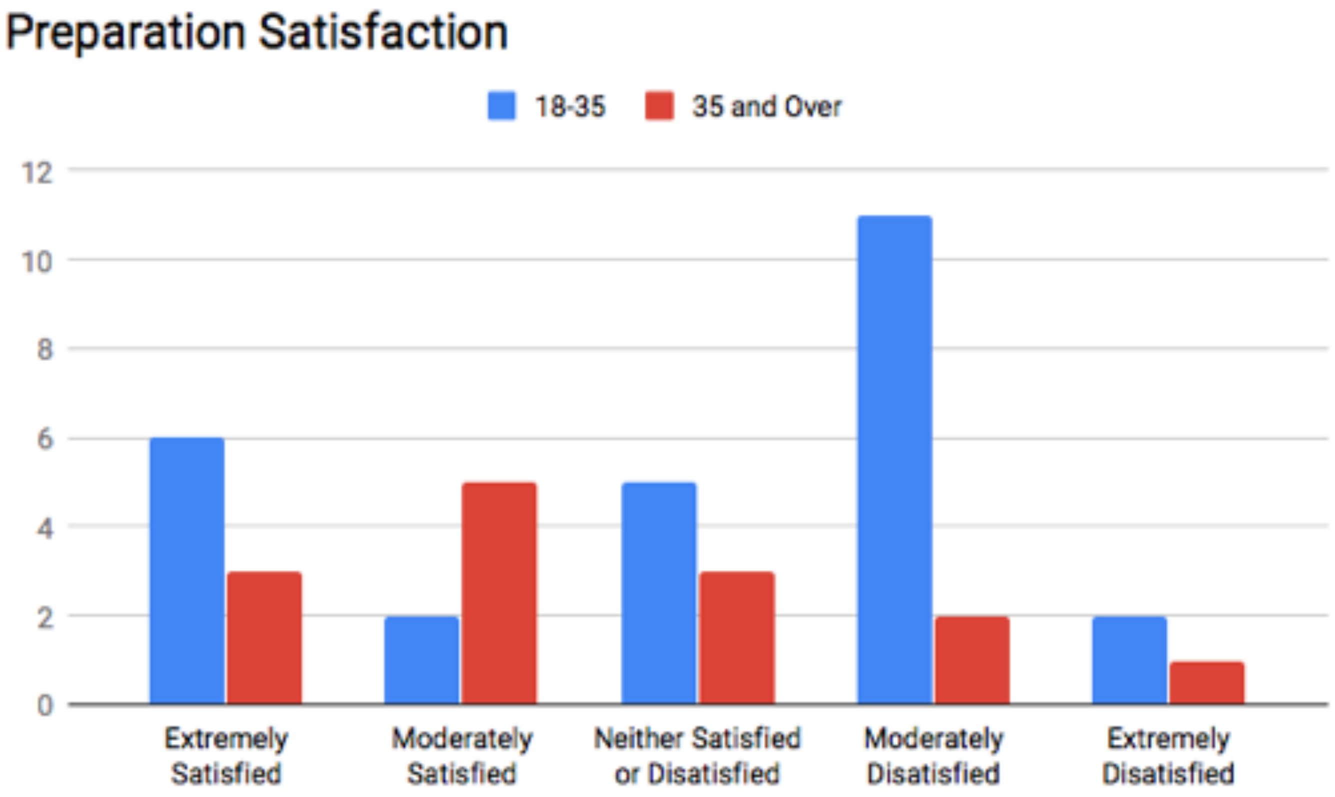

Figure 13. *Source, Individual Survey*
Please rate how satisfied you are with how you have been prepared for employment

From both age groups, a combined thirteen individuals reported being “Moderately dissatisfied” with the training and levels of preparedness that they felt before entering the workforce while three reported being “extremely dissatisfied” with services. This includes preparation for job interviews, job applications and proper ways to deal with a new workplace environment. Nine individuals reported being “extremely satisfied” with the preparation which they received for employment. There total number of individuals were split between satisfaction and dissatisfaction with both having sixteen, it was further split with eight individuals reporting natural outlooks on the services. Which is consistent with different levels of perceived experiences from individuals.

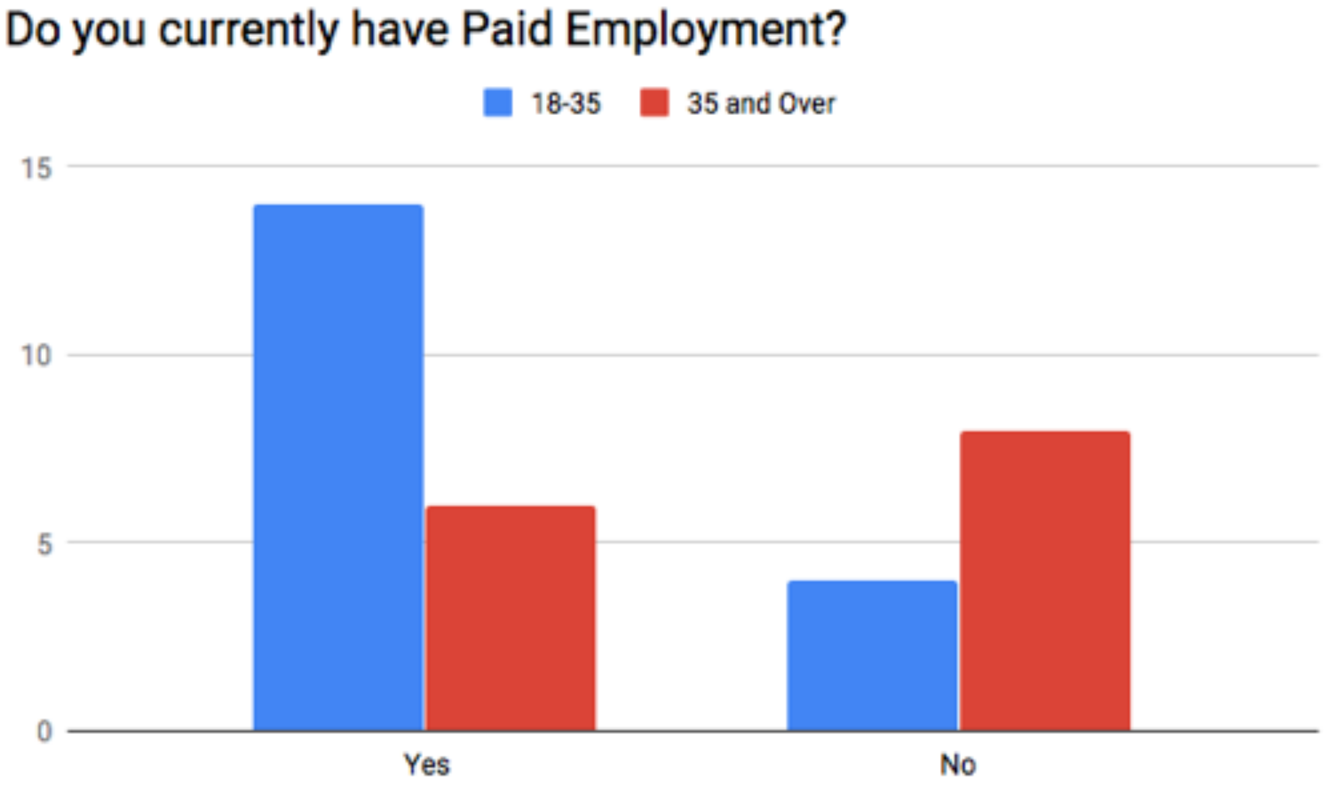

Figure 14. *Source Individuals Survey*
Do you currently have paid employment?

Fourteen individuals aged 18-35 responded that they do have paid employment and in the same age bracket 4 individuals reported that they do not have employment. The hourly wage was not reported. Six individuals aged 35 and over reported having paid employment and eight individuals in the same age group reported not being employed. The number of people aged 18-35 are more likely to be employed which is consistent with national reporting where more young people are entering the workforce earlier.

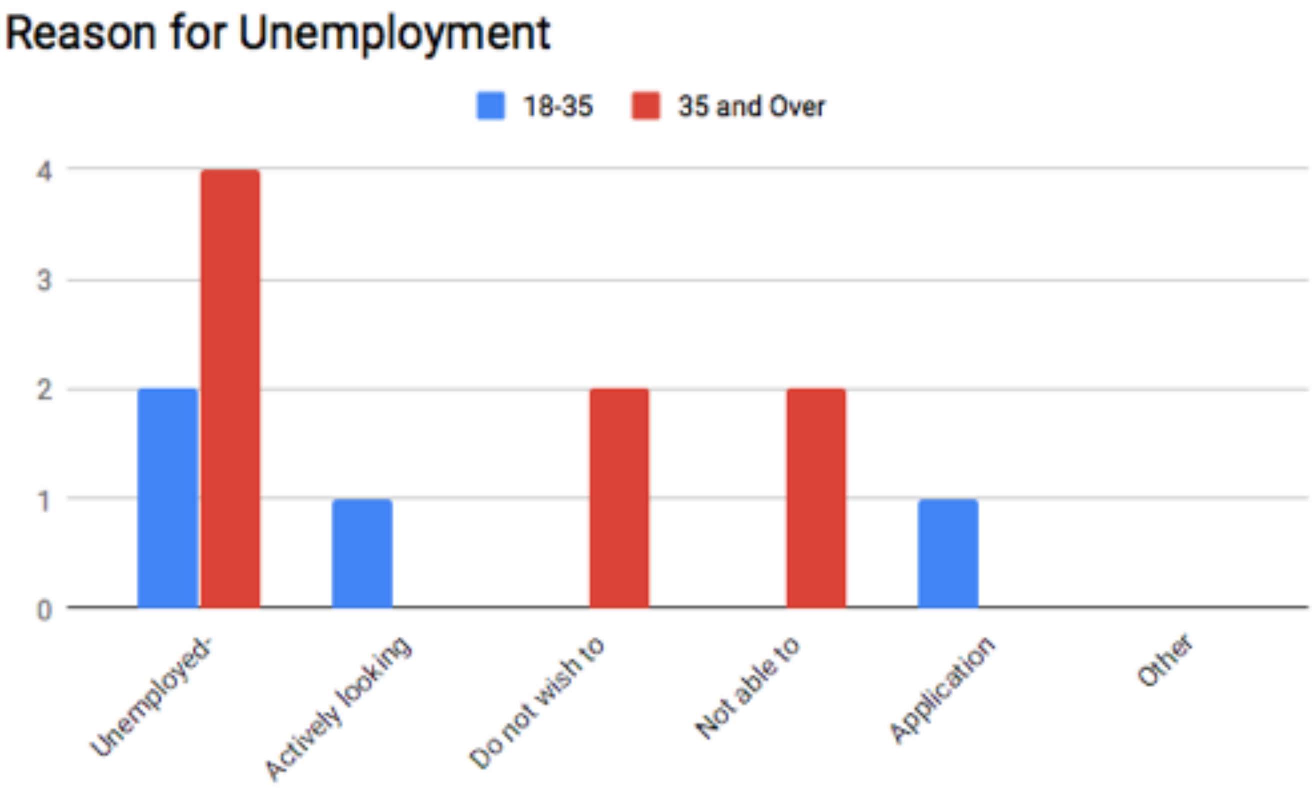

Figure 15. *Source Individual Survey*
If you are unemployed, please select all that may apply

As previously reported fourteen individuals self reported that they currently did not have employment. Above, individuals were then asked to again self report the reason for which they believed they were unemployed. The choices provided were "unemployed—want to work but can't find work" "Actively looking but faced discrimination from employers" "do not wish to work at this time" "unable to work because it would interfere with current state benefits" "application process too difficult" or "other-not specified". It was mostly reported that individuals wanted to work but could not find work, with a combined 6 individuals reporting that.

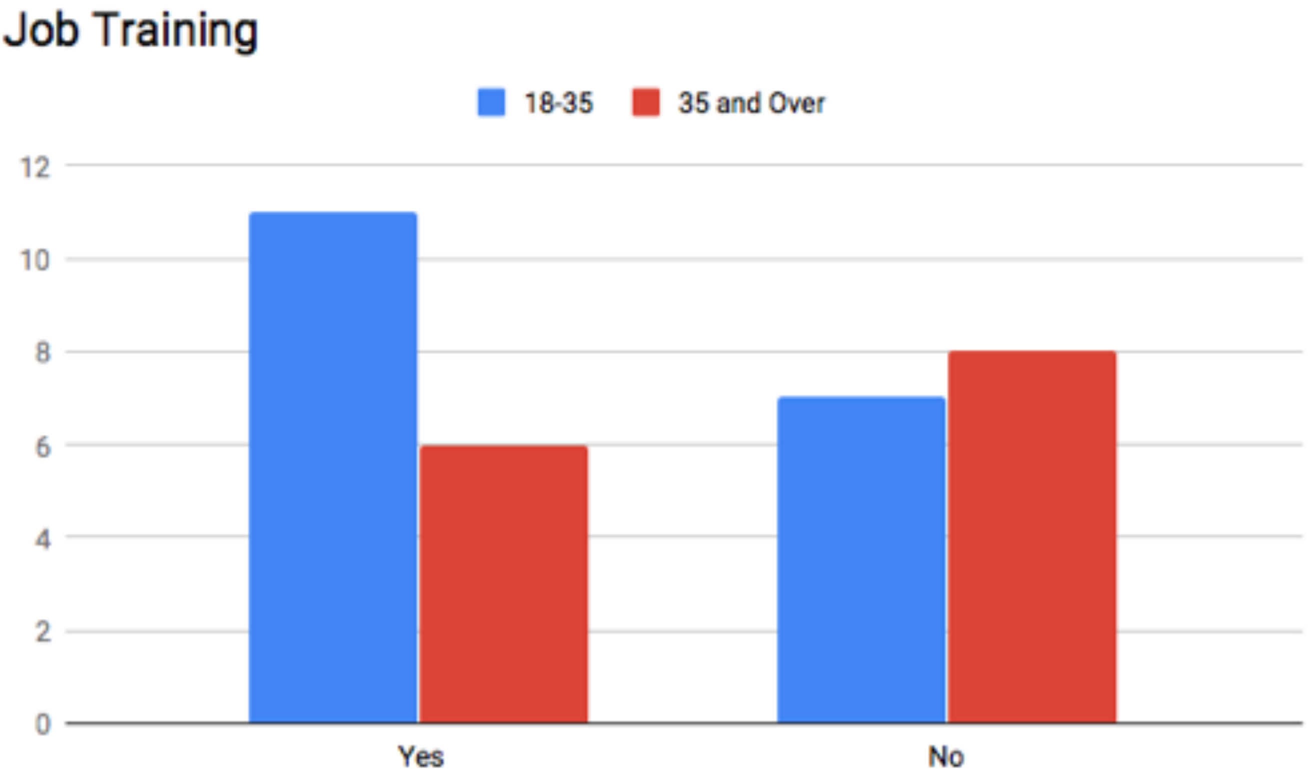

Figure 16. *Source Individual Survey*
In the last year, have you received any job training from an agency program?

Seventeen individuals self reported that they received job training in the last year from an agency program. This could be anything from vocational programs, a job training program, skills workshops etc. These numbers were divided with five more individuals reporting being from ages 18-35. A combined fifteen individuals reported receiving no job training from their agency program.

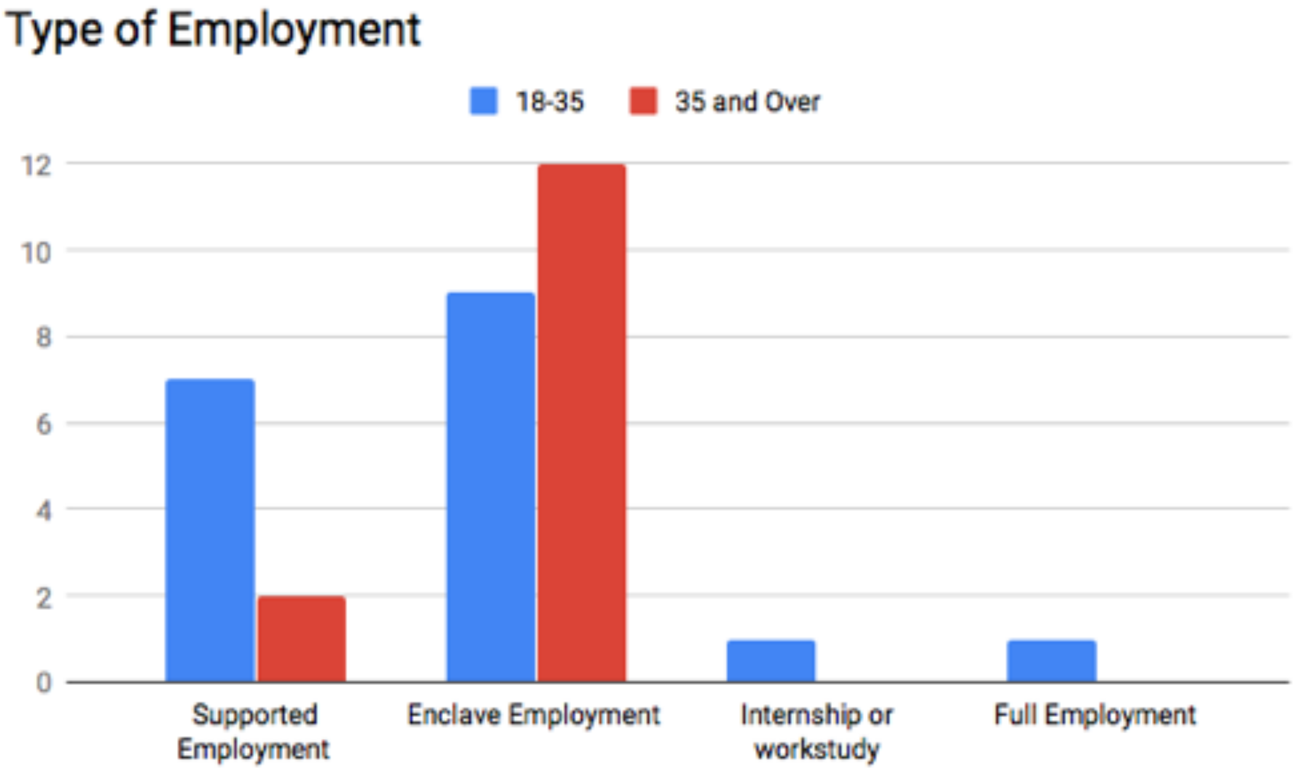

Figure 17. *Source, Individual Survey*
In what type of employment do you currently work?

Individuals were presented with four options to disclose the type of employment which they currently held. The options were “supported employment” where individuals are helped with obtaining and keeping employment, “enclave employment” where individuals work within a group of other individual within a company, which can be largely segregated from their peers, “internship or work study” where individuals work for a stipend amount of money and “full employment”where individuals are working amongst their peers with out without reasonable accommodation from their employer. Enclave employment was the most reported type of employment with twenty one individuals self identifying. Only one individual aged 18-35 reported having full employment with no individuals over 35 reporting the same.

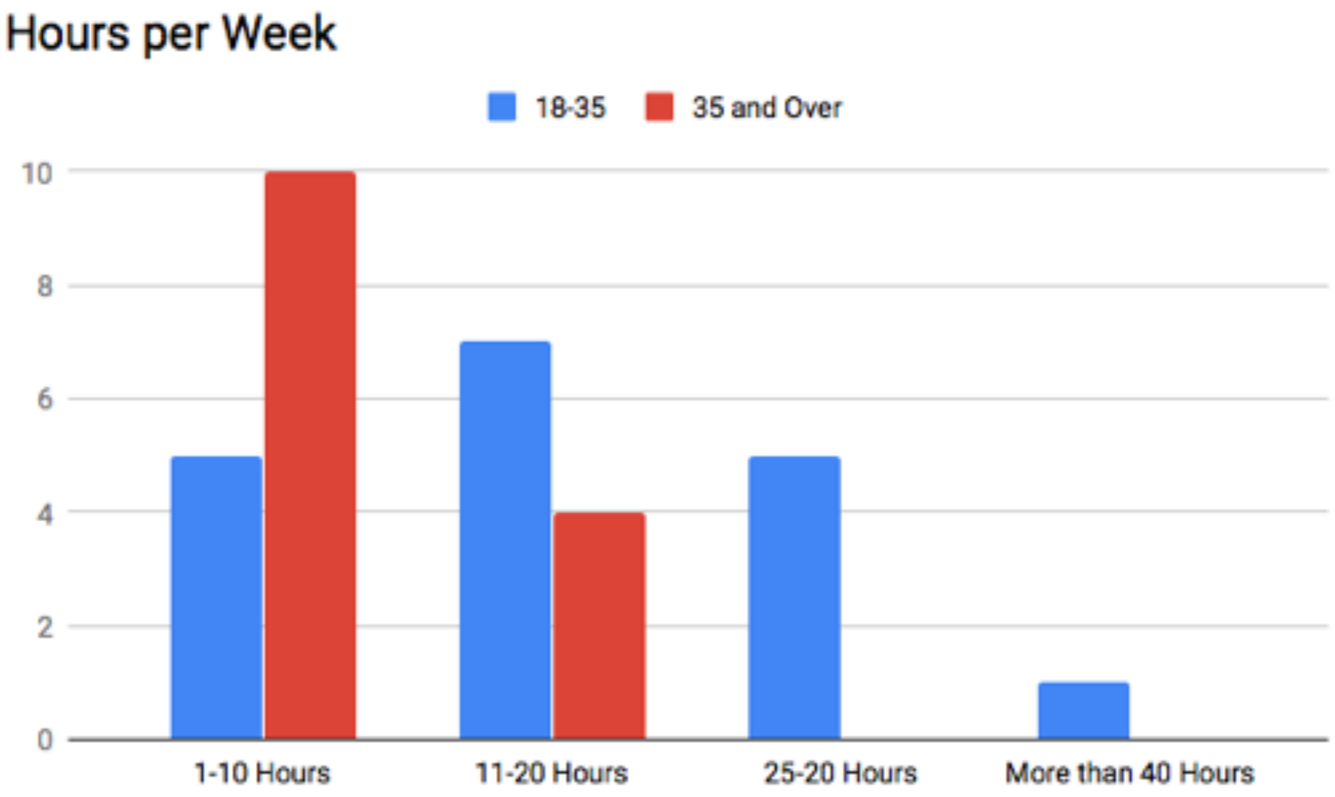

Figure 18. *Source Individual Survey*
Approximately how many hours a week do you work?

Individuals self reported the amount of hours that they worked in any given week. Only one individual reported working more than 40 hours a week. The most individuals combined (n=15) reported working only 1-10 hours in a week with the majority (n=10) being aged over 35. Twelve individuals reported working between 11 and 20 hours a week and 5 Individuals reported working between 25-30 hours a week. The different hourly was assumed to be the effected by the type of employment which that person had. With the one individual who reported having full employment, most likely being the individual who works more than 40 hours per week.

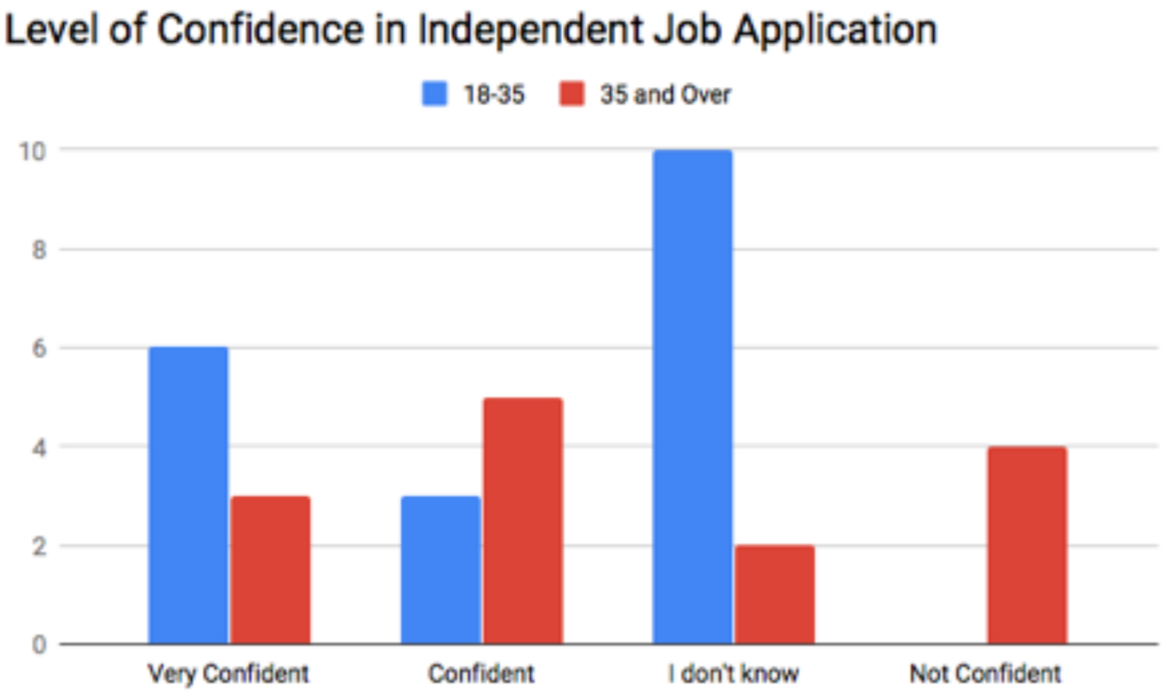

Figure 19. *Source, Individuals Survey*
How confident are you that you could independently apply to a job of your choosing?

A confidence measurement was added to this survey because data was already collected on whether or not an individual received job training skills. This question helped further measure the effectiveness of that job training by having the individual self report how confident they were with one specific aspect of the job application process. Nine individuals reported that they were “very confident” in filling out a job application and eight reported that they were just “confident”. Twelve individuals reported that they “Don’t know” whether or not they were confident in filling out a job application. Four reported that they were not confident in being able to fill out an application alone.

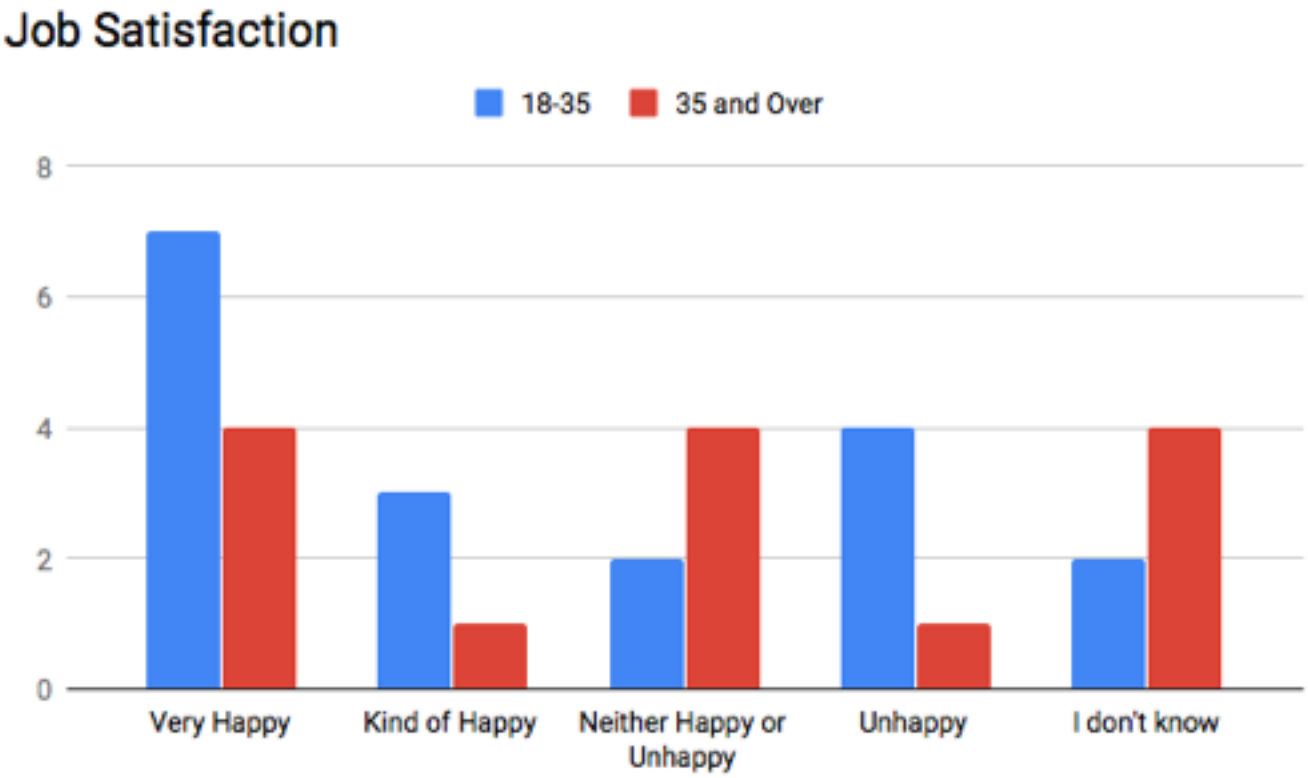

Figure 20. *Individual Survey*
Please rate how satisfied you are with your current job

Job Satisfaction was included in this survey because as reference in previous literature, is crucial to understanding the experience of employment. The options provided for job satisfaction ranged from levels of happiness a person felt from their place of employment. Eleven individuals reported that they felt “very happy” with their job and this question yielded consistent results for the rest of the options with there only being a one or two person difference amongst the variations of satisfaction.

4.2 Qualitative Results

The interviews which were used for data collection were conducted from 5 individuals all with different levels of employment. I did not limit my sampling based on sex or age but all participants were between the ages of 18-35 and diagnosed with ASD. The participants indicated that the services which they have been provided were not sufficiently supporting their respective needs when it came to obtaining or maintaining employment. The data was coded using existing grounded theory approach as set out by Corbin and Strauss where ideas and concepts were original bits of data which then were grouped together to form respective categories or sub-themes. These sub-themes were representative of a larger over arching them which generally appeared more vague when compared to the initial code words.[236]

The table below lists the coding of the data into the recurring main themes, sub themes and coding words which were analysed from each interview:

Main Theme	Sub-theme	Code word(s)/Initial Concept
Satisfying Personal Requirements	*Managing Stress*	Environmental needs Planning/structure
	Self development	General Interests
Awareness of Difference	*"Othering"*	Social Isolation

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[236] J. Corbin, A. Strauss, "Grounded Theory Research: Procedures, Canons, and Evaluative Criteria" *Qualitative Sociology,* vol. 13, no. 1, Human Sciences a Press Inc, 1990, pp. 7.

Main Theme	**Sub-theme**	**Code word(s)/Initial Concept**
		Stigma
		Stereotypes
		Job Placement
		Forced Inclusion
		Diagnosis/disclosure
		Dependence
Job Satisfaction	*Preparedness*	Training Mentoring Coaching Likes/dislikes Abilities
	Support	Advocacy
	Inclusion	Discrimination
		Understanding
		Professionalism
		Friendships

Figure 21. *Source, Interviews*

Three main themes were highlighted when going through each of the interviews which were a) Satisfying Personal Requirements b) Awareness of Difference and c) Job Satisfaction

4.2.1 Satisfying Personal Requirements

The theme of satisfying personal requirements was developed out of the interviewees own individual experiences in job preparation and the job field. The language is person specific—so that it focuses on the individuals own requirements before taking into account the needs of the job. This theme consisted of sub themes such as managing stress and continuous self-recognition/development.

Managing Stress

One of the major personal goals or requirements that came across was stress management, this was most easily noticed through unforeseeable changes in environment. There was a noticeable difference in demeanour and personal satisfaction when there are fewer deviations from the standard routine. Planning and a structured curriculum in a job training program or work environment can vary exceptionally. In a job program, much of the routine can stay the same, i.e. how daily interactions can and will occur. When one individual had transitioned from vocational training to supported employment they found that “it was really hard to go to work everyday knowing that I could have to mop all the floors. I don't like seeing water on the floor. When I knew I had to go to the front some days to clean I decided to stay home.” Expressing the need to keep control of the situation for that individuals own satisfaction, they would rather stay home than be faced with discomfort. This was a recurring theme in most of the interviews but far less severe. Another interviewee responded that they “didn't really mind not knowing exactly what was happening all day. But I made sure I was allowed to take breaks when I need it so I could think better and relax.” The need for a change in the way which job trainers/staff and employers approach the expectations of a “normal” pace was apparent based on these conversations.

Self development/Recognition

Three of the respondents in the interviews mentioned that their own general interests were a large part of their own personal development. Interests were a necessity for all respondents when it came employment with the consensus from all five interviewees being that they would not do a job if they were wholly uninterested in it. Two acknowledged that there were certain aspects of their jobs which they did not like, and each had a different approach to the situation. The first noted that "I said I didn't want to learn how to press the shirts because its too loud and I just wanted to fold them I thought he would tell me too bad. He said they would find someone else to press the shirts for a little but then we would try something and now I would just have to fold more. He got me these special headphones that look like Dr. Dre's and when I put them on I can't hear anything." This interaction not only shows the employers accommodation, but it also shows that the individual was committed to expressing what he or she's did not like/want and was willing to express that so it would be recognised. They were also willing to try a suggestion (i.e. the noise cancelling headphones) which helped them master a new skill which they otherwise would have been unable to.

Another respondent stated "I hate water on the floor. I cannot mop. I cannot. Its messy. I told him I won't mop. He said I have to because it's my job. But I told you I didn't go" (referring to the previous quote mentioned in managing stress). This response shows the opposite type of reaction where the individuals own self awareness is so advanced they recognise that they will be unable to complete a task because it effects them so and as such does not further their self development but does overall satisfy their personal requirement.

This theme epitomises how important it is for adults with autism to be able to manage their stress and have the available support an coping mechanisms to deal with highly stressful environments. The need for a scheduled environment can be essential to the success of a person with autism, but that does not mean the schedule should be one which is created for them to follow. The schedule should intact be created with or *by* the individual so that they are able to benefit the most from it.

4.2.2 Awareness of Difference

The awareness of being different is something which affects many people with ASD not just in everyday life but specifically within a working environment and job training programs. It i more prevalent in conditions where the number of individuals with ASD is significantly less than the number of their peers in a given situation. This awareness of a difference can most simply be sub categorised as an “other-ing”. As mentioned in previous chapters the “other-ing” of the individual is unfortunately not a new phenomena and not one that people with out a disability are particularly cognisant of. This ”other-ing” can manifest in many different ways all of which can be damaging to the overall functionality of a person with Autism in the workplace. The most obvious way it is presented is by the exclusion, whether purposeful or not, of the person who is “different”. While there were many coded words which came out of this, social isolation was the most common appearing in all 5 interviews.

“Other-ing” and Social Isolation

The question of whether or not to disclose ASD reported by one of the respondents during the interview, increased feelings of social isolation. They said “No one ever told me if I should say it or not. I don’t want them to think I'm weird if I don’t tell them but if i need help i don’t want them to get mad.” This left the individual feeling alone out of fear of potential isolation.

Stigma and stereotypes were also reported in the work place. Autism has often been portrayed in movies and media as one of two extremes. The person who is unable to do things for them self and has aggressive behavioural tendencies or the quirky, highly intelligent or “gifted” individual who has poor communication skills. While both can be true ASD is comprised of a wide array of symptoms and tendencies. Two individuals describe feeling like their colleagues were extremely surprised to find out that they seemed “relatively normal”.

Job placement and “forced” inclusion were interesting recurring experiences when paired with social isolation. Job placement in an atmosphere where there is only one person with ASD automatically creates a space for other-ing when it is supposed to promote the opposite effect. The interviewee was completely at ease when mentioning that inclusion can be forced and that forcing is what makes him feel isolated. “You can tell that they don’t want to talk to me and the manager will be saying all this crap about team work but everyone looks at me and rolls their eyes. I rather stay by myself.” It is interesting to think that the pushing of inclusivity could actually have to opposite effect on staff to further exclusion. The opportunity to support an individual entering the workforce is overshadowed by poor training and the wrong introduction into a work atmosphere.

Dependence came up in the context that an individual felt like they would never be able to work by themselves because they “don’t really do a lot” in their vocational program. The individual describe the program as being somewhere they work on small tasks daily but it doesn't seem like they would ever learn how to do things like work a register, cook, do maintenance etc. An experience like this can be perceived as extremely negative and further deter a person with ASD from entering the workforce. This could also be used under the next sub theme of job satisfaction, preparedness.

4.2.3 Job Satisfaction

Job satisfaction as described by Edwin Locke, is the measurement of a persons relationship with their job, whether they like or enjoy it as a whole or only parts of it which is measure by having a “pleasurable or positive emotional state resulting from the appraisal of ones job or job experiences".[237] This applies to all people who take part in the labour force, especially those with intellectual and developmental disabilities. The sub themes which were found from the data under job satisfaction consisted of preparedness, support and inclusion.

Preparedness

This sub theme was comprised of many different levels which all lead to the preparedness of an individual. Specifically the interviewees focused "preparedness" on being able to preform what was asked of them in a job, or being able to navigate the job application process by themselves. This was effected by things like professionalism, mentoring, training and their respective abilities. Mentoring and training had more mentions and were placed as the most important reasons behind job satisfaction. With positive outcomes the relationship with that mentor/trainer was inherently valued. "I'm happy with my job because I know how to do it" and this person stated they knew how to do it because the training was long and essential to the process, the support which they received from staff was extremely beneficial to the overall ability and outcome of the job itself. Negative experiences with mentoring led to negative outlooks on feelings of preparedness which translated to feelings of being unsatisfied with the position they currently held.

Support

As referenced in the above sections A and B, support of individuals is crucial to the successfulness of people with autism in the workplace. Both professional and personal relationships had positive and negative effects on desired life outcomes. However, in this study it was found that communication and encounters between individuals and support workers were slightly more positive than those interactions between individuals and their respective families. The support worker in this case refers to respite workers

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[237] E. Locke, "The Nature and Causes of Job Satisfaction" *Handbook of Industrial and Organised Psychology,* 1976, pp. 31.

and direct support staff, as one individual reported that the experience had with a job coach was extremely negative. “I wanted to apply for a job that I could learn but grow in. I didn't wanna work at a fast food place because I want more but _____ told me that I have ASD and i need to be real about what I could do.” Here its expressly reported that the individuals desires were being cast aside and the professionals own idea of what the individual is able to do was taken over.

4.3 Discussion

The research done via surveys produced many different results relating directly to employment and employment services in New York. The results more specifically are a window into how certain programs support adults with Autism Spectrum Disorder in the preparation and fulfilment of job opportunities. The interviews produced many identifying themes and categories which help to better understand the potential barriers and effects of social care/agency programs on the employment outcomes for adults with ASD. Over 100 surveys and five interviews were collected, all with various perspectives and individual experiences. There were a number of similarities across the board with the data.

Challenges to satisfying personal requirements, social isolation, job readiness and job satisfaction were consistently noted throughout the data collection process and analysis. The barriers addressed within the study were found to have both positive and negative impacts on the individuals levels of success in employment. The results from this study support much of what has been previously found in research which advocates for the continual support of individuals pre and post employment. More support is needed in the areas of job preparedness and readiness, as well as information about how to deal with complicated working environments.

The data from the DSP/Family suggests that more training is needed to address the inconsistencies with support workers and the level of services which they provide to families and their individuals. The lack of an effectively trained supporting staff has less desirable effects on the individuals they are meant to be helping which is counterproductive to the goal of the care programs. Data provided by family members suggest a neutral experience in satisfaction of the programs and services provided for their children/family members of adults with ASD. Satisfaction of employment outcomes for parents were shown to be high, but this does not mention the type of employment which that person is currently employed with or the level of ASD diagnosis. A significant number of family members reported that the larger barrier to maintaining employment was the the job did not match the needs and/or capabilities of the individual.

Social isolation or the feelings of being “other-ed” were identified throughout the study and had potential negative effects on the performance of individuals in the work environment. Feelings of being “left out” and excluded overshadowed the willingness to preform job functions as well as employers tendency to overlook personal requests for the working environment. Feelings of isolation were further brought up by lack of preparation for job interviews and not knowing whether or not to disclose ASD diagnosis. This left participants feeling unsure of whether ASD was the reason for or against being hired for employment.

Job satisfaction was reported by individuals who worked in a variety of employment settings. With a significant amount reporting that are very satisfied with their job. Further research could be done to analyse the relationship between the type of employment a person has and their level of satisfaction with that job across different levels of ASD diagnosis. It was noted during an interview that social perceptions of individuals with ASD also affected job satisfaction. It was suggested that still many people are unaware of the complexity/range of Autism Spectrum Disorder and believe that a person with ASD is almost always “gifted” in some way”. This was found to lead to feelings of inadequacy amongst those working, and led to poor job performance due to negative feelings about themselves.

A need for more individuals in different types of employment was observed through Figure 17, with most participants in the survey responding that the type of employment which they had was “enclave employment”. While this type of employment should remain as a necessary sub category of employment types, it should by no means be the norm for which individuals should wholly be employed. Enclave employment keeps groups of adults with ASD separated from their peers without ASD. While this type of employment may be suitable for some adults with ASD it does not fully agree with the goal go competitive integrative employment standards. It is interesting to note that twelve individuals who reported being employed via enclave employment were all above the age of 35, potential suggesting that there are far less options available for jobs when it comes to people within this are bracket. Supported and enclave employment were the most reported choice for those aged 18-35 as well. There were however, other responses indicating that individuals within this age bracket were also employed in full time employment and an internship or work-study opportunity. Supporting the assumption that there are slightly more opportunities available for employment to those within a younger age bracket. The reasoning for this however is unclear, and more research could potentially be relevant in understanding why younger adults with ASD are more successful in finding employment.

As noted above job satisfaction was measured through qualitative interviews as well as the quantitative data. It was measured through the surveys which were distributed to individuals with ASD asking participants to rate their level of happiness in the job which they currently work. This was particularly interesting with respect to the data collected in Figure 17, which noted the different types of employment. Upon further inspection of individual surveys of the twelve individuals reporting enclave employment aged 35 and over, three reported being “very happy”, one “kind of happy”, three “I don’t know”, four “neither unhappy or happy” and one person reported being “unhappy” with their job. It was also shown that from the 2 individuals in supported employment in the same age category, one reported being “very happy” while the other responded “I don’t know”. This data provides us with a interesting relationship between the type of employment one has as how that relate to the level of job satisfaction which an individual has. The findings suggest that a majority of respondents in the over 35 age group are either unhappy or have a relatively ambiguous opinion to whether or not they are happy at their job. This could be for a potentially large amount of reasons including, they were not honest, did not understand the question, are not in a job environment which is conducive for their own personal needs or interest, etc.

The data for adults aged between 18-35 who respond to the same question was also further inspected where the results were somewhat similar. Of the nine adults who reported enclave employment there was, one “very happy”, three “kind of happy”, three were “unhappy”, one “I don’t know”, and one “neither unhappy or happy”. Which suggests adults in this study aged 18-35 are unhappy in enclave employment. For the seven who reported supported employment five were “very happy”, one “unhappy” and one “neither unhappy or happy”. Suggesting that a more individualised type of employment with support, but with greater integration with peers was more beneficial to individuals. The one participant with an internship reported being “very happy” in their situation. The participant with full employment responded “I don’t know” when asked about their level of job satisfaction.More research is needed in order to fully analyse the potential reasons behind the relationships between types of employment and job satisfaction. However the data from this study does suggest that their is a relationship between the age of an adult with ASD, type of employment and satisfaction with that job.

4.4 Conclusion

While there have been many steps forward in the support and treatment of adults with autism, there still is a disconnect between services provided and successful results. The aim of this research was to find out what is the relationship between social care programs and the low employment rates of adults with autism by measuring their effects. This was accomplished by collecting data which would measure if certain types of employment were more suited for individuals with ASD for successful job retention than others. It was also useful to understand if individuals need more preparedness/ skills training in order to successfully obtain employment. Measuring the effectiveness of these programs from the individuals point of view was essential to understanding the lived in experience of adults with ASD. The above findings as well as the acknowledgment of the history of people with intellectual and developmental disabilities in the United States, showed that there are a potentially larger number of reasons for why unemployment rates have been unsuccessful.

These include:

Social attitudes and perceptions which can lead to exclusion and discrimination. As much as people have evolved and are more inclusive of adults with ID/DD there still is a common attitude or way which people tend to “other”. This continuous “other-ing” negates the effects of programs because it preoccupies the individuals attention with questioning where the fit in to society thus not allowing them to reach their full potential in employment. The notion of lack of tolerance plays a larger role in the success of individuals with autism entering in the workforce. It begs the question of who wants to be somewhere they are only tolerated? Certainly these negative attitudes have their own detrimental effect not only to the psyche of someone with a disability who is trying to achieve employment but to any person without a disability who isn't wanted somewhere.

Poor training of staff also poses a significant barrier to individuals maintaining or obtaining employment services. A considerable issue is a person without ASD and their ability to recognise difference of social interactions for someone with ASD. Difficult behaviours such as outbursts, lack of registering social cues or the need for multiple sensory breaks can all be problematic for adults with ASD in the workplace if they have not been adequately taught how to deal with them or if staff has not been trained to recognise these markers. The results from this inability to connect with a person with autism resulted largely in two extremes, being too nice or pitying in some aspect or becoming “put off” by the person with ASD and regarding them as different.

It is important to recognise that the findings which were gathered form this research may not reflect the experiences of the majority of adults who are on the autism spectrum, however it does indicate relevant common themes for a considerable amount of adults at one particularly agency in New York City. This study was only able to provide a small insight into the millions of individuals experience with employment and employment services. It was also only able to provide that insight for adults with he ability to verbally communicate, which only emphasises the need for more research to be done on the employment outlooks for minimally or non verbal adults with autism.

4.5 Recommendations

In order to successfully combat the reasons behind low rates of employment for adults with ASD, below are recommendations which would be beneficial in correcting problems which have lead to their lack of employment.

Increased Advocacy and Inclusion, getting policy makers and officials involved in the advancement of employment services could be extremely beneficial to further developing employment first initiative within each state. Partnering with states agencies dedicated to supporting individuals with developmental disabilities to continue community driven care in order to further the immersion of adults with autism within the community. By promoting inclusion from a younger age and working with children to lessen "other-ing" of individuals with disabilities so that these will produce tangible differences in employment perceptions later in life. More education with regard to stereotypes and stigmas of people with developmental disabilities could have a potentially positive effect on the reported rate of feelings of social isolation by those without a disability.

Reduce Waiting Periods, dramatically decrease the amount of people waiting for HSBC waivers and services by proposing budgeting options will will allocate for the increasing of funds allowing for the expansion of services. Make necessary policy changes so that critical needs are able to be met in a timely manner and people are not waiting longer than necessary.

Increase DSP Salaries and Training, All across the United States there is a direct support workers crisis. There are many things which contribute to this but the most reported answer being that low wages for maximum responsibility and work were a major factor in high turnover rates. An increase in the Medicare budget which pays DSPs salaries is crucial to recruiting quality workers to care for adults with ASD in community settings. Proper training of staff is also crucial, with little or no federal oversight of training of staff in most states, it is crucial to the preparation for and success of adults with ASD.

State Monitoring And Information Sharing, more information is needed across all states on the employment of adults with ASD diagnosis specifically. There should be mandatory reporting of employment status of adults with ASD which includes a summary of wages paid, benefits received, disclosure of full or part time employment as well as supported, enclave etc. and the type of jobs available to adults with ASD in each respective state. This would give advocates an accurate depiction of what type of jobs people with ASD are more prone to be in/not be in and how exactly employment workshops and training programs should be further structured to meet the needs of individuals. It wold also provide an accurate picture of the different wages earned by adults with ASD in relation to their peers and address discrepancies accordingly.

Push Employment First Initiatives and person first planning, The use of employment first legislation across the United States has seen the inclusion of many adults with disabilities into the workforce. However some states still do not have any policies or their policies do not adequately accomplish what they need to. Competitive and integrated employment is necessary to yield optimum results for those with DD/ID. Just as many adults with autism have Individualised Education Plans, Individualised Employment Plans would also be beneficial. They would be used to figure out individuals needs and requirements for the most ideal employment setting. These plans could then be crossed referenced with different jobs available and the desired skills/reasonable accommodations that could be made in order to meet the needs of the individual.

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