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# Autonomy in the California Disability Services System

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Walden University
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Abstract

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Dissertation Submitted in Partial Fulfillment

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# Abstract

Legislation concerning California residents with intellectual and developmental disabilities (ID/DD) requires recipients of services to be treated as independent individuals while emphasizing self-determination. At the same time, under regulatory procedures, recipients are considered dependent on the delivered services and not self-determinant. Neither the California Department of Developmental Services nor the trade associations representing community service providers have established a unified, systematic practice to support self-determination. This phenomenological study explored the experience of adults with ID/DD working toward self-determination.

Specifically, it explored how medical and social models contribute to shaping and actualizing the independence of this population. Interviews with eight adults with ID/DD explored the perceived barriers to, and opportunities for, achieving independence through self-determination. Under the current statutory regulations, the study viewed two conceptual lenses. The first lens, social role valorization, is based on the study of normalization. The second lens, social reaction, emphasizes a response to the disparities that acknowledge the political, cultural, and social beliefs associated with theories of deviance and social role valorization. The findings demonstrated that self-determination requires collaboration between coordinated services, primary social systems, and theoretical services supporting social role value. The discovery of these key elements may help California's disability service system fulfill legislative requirements to increase opportunities for personal choice.

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# Dedication

This is dedicated to my mother, June Maxine Carbone. Thank you for your infinite support and encouragement. You have taught me to be kind, to apply what I have learned from experience, and always to act with integrity. The love and vision you share with me continues to guide and influence my life.

The honor of achieving this degree is devoted to my brothers. Their zeal, compassion, and proclivity to find humor in life have been ineffaceable contributions to my development.

My partner, Jesse Carbone, has been a bastion of strength and support. I am deeply grateful for her camaraderie and love as I pursued this degree.

This research is especially dedicated to people with ID/DD, whose voices and histories deserve to be heard and acted upon. I have been privileged and grateful to share their lives and experiences.

# Acknowledgments

I wish to recognize Dr. Elaine Spaulding for the many hours of talent and support she has contributed. I am especially grateful for the wisdom, insight, and mentoring you shared with me, and above all, for your ability to bring humor into our conversations. Words can never be enough to show my gratitude for your encouragement and continuous motivation. Thank you Dr. Andrew Garland-Forshee for your expertise and interest in my study. I appreciate your valuable advice. It was an absolute pleasure to work with you. To my colleagues, thank you for your tireless efforts. Your commitments to supporting life quality for individuals with ID/DD have positively impacted many lives.

I also am grateful to those individuals diagnosed ID/DD, who contributed to this research, as well as to those who have shaped my philosophy through the years.

I would like to recognize the organization that agreed to take part in this research. Although it must remain unidentified, I am grateful for its involvement. This agency readily embraced the prospect of research that promotes positive change, self-determination, and maintenance of opportunities for people with ID/DD.

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# Chapter 1: Introduction to the Study

## Background

Intellectual disability and developmental disability (ID/DD), also known as mental retardation and various pejorative terms throughout the last 50 years, has been shown to have three consistent and essential elements. These elements include (a) decreased intellectual functioning, (b) socially unacceptable behaviors utilized for adaptation to environmental demands, and (c) onset during early development (Shalock, Luckasson, & Shogren, 2007). As tragically evidenced by Rosemary Kennedy, individuals with ID/DD, who seek autonomy or display self-determination in ways that differ substantially from the norm may be subject to punitive handling. They have historically been subject to unpredictable treatments and practices, such as unstudied psychosurgery and overmedication, despite extensive reforms (Henley, 2009).

During the 1960s, California operated 24-hour psychiatric or medical institutions that housed a majority of individuals with ID/DD. Theoretically, only individuals with severe disorders who were determined to be a danger to themselves or others were eligible to receive treatment in these facilities. However, in practice, these facilities held individuals who had less severe disabling conditions including alcohol use or conduct disorders. Subsequently, not all residents benefited from care and treatment afforded them by the institutions.

In 1977, California enacted the Lanterman Act and related laws (AB 846), affording individuals with ID/DD the right to treatment, habilitation, and individualized planning in their communities. This legislation was expected to provide mandates to represent and support self-determination for the state's vulnerable citizens. In doing so, these individuals were expected to receive the services and supports needed to live like people without disabilities. However, practical difficulties arose in implementing opportunities for self-determination, not only in how to develop regulatory policy but also in response to the conditioning of the public distrust of persons with disability.

Social constructs relating to self-determination are consistent in the way society conceptualizes differences between those perceived as normal and those perceived as deviant (Turner, 2005). California has defined and explored two methods for implementing services and supports. These systems are the medical model and the social model (Wolfensberger, 1972; Mercer, 1973; Racino, 2002; Rosenthal & Kanter 2011; Rothman, 2010). The simultaneous use of these models over time has led to spending billions of dollars to construct self-determination systems. Significant time and money have been devoted to seeking out techniques that are most likely to succeed, as well as investigating what the implications of success are and how improved life quality would be measured.

Polarization between the models has caused tension between promises of improved outcomes and the efficient use of resources for individuals with ID/DD (Rothman, 2010). The pledge to secure integrated and inclusive opportunities are at cross-purposes with service delivery goals and coordination efforts (Wolfensberger, 1975).

Research literature discussed the impact of current systems and structures, contemporary notions of deviance, and traditional influences that continue to affect opportunities for self-determination. The experience of persons with ID/DD was explored in this study to impart experiential validity to the confusion of accountability and progress arising from conflicting and competing priorities between the two models. In many cases, the source of self-determination failure is the view that the individual is flawed at the onset of life. In other situations, the individual fails because of environmental stresses. The community or legislated support systems may not be funded or prepared to support choices outside of the regulatory systems of care. Other causes of failure for ID/DD persons to achieve self-determination include a lack of belief in the ability of the individual to succeed without external support.

The focus of this study was the role that systems play in supporting self-determination contextually as they pertain to concepts of pathology and environment; rights and equality (AIDD, 2010). The conceptual model of self-determination has been put forward by Wolfensberger (1975). In some cases, self-determination is dissolved in split concepts related to notions of deviance (Becker, 1963; Mercer, 1973; & Wolfensberger, 1975). These divisions in the system provide a channel for distributing regulatory procedures throughout the system and also result in degraded unpredictability, depending on the construct of the time.

Advances in cross-disability collaboration produced significant activism for rights for individuals with disabilities, with perhaps the most far-reaching and well-known success being the Americans with Disabilities Act (ADA) in 1990. Despite these achievements, however, people with disabilities are intimately acquainted with social isolation, discrimination, and neglect (Becker, 1963; Mercer, 1973; Noll, 1995; Carey, 2009). Such experiences inhibit a full range of inclusive opportunities for those with disabilities (Wolfensberger, 1975). These opportunities are implied in self-determination concepts. The naturally unpredictable course of ID/DD persons achieving self-determination is exacerbated by the multilayered decision-making process involved in translating federal and state regulations into practice and delivery of services (Rothman, 2010).

Statutory provisions are destabilized by implementing regulations that restrict the scope of practice (Wolfensberger, 1995). Where self-determination is concerned, concepts about people with ID/DD as both entitled to and capable of this state of mind remain inconsistently agreed. The involvement of these individuals in the development and implementation of supports, including those pertaining to their lives, remains unstable and unguaranteed.

An individual program plan (IPP) is a comprehensive guide for each that utilizes information gathered, as well as assessments conducted, to determine goals, abilities, desires, and obstacles (Disability Rights California, 2012). However, these critical decisions on the types of supports to be provided and the persons responsible for furnishing them are dictated by program vacancies and available funding at the time of placement.

The infrastructure to support self-determination of ID/DD persons remains underdeveloped. In order to improve this, a fundamental temperance between the social and medical models is required in a broad range of service delivery policies and practices (Rothman, 2010).

A function of the social model includes societal integration and inclusion. Supporting this social ideology, the California Welfare and Institutions Code stipulates that ID/DD persons should be empowered to seek futures of their own. To achieve this goal, services are required to be creative, individually tailored, and adequately funded. The social model's focus on community-based service delivery is centered on productivity, independence, and inclusion.

Contrasts to regulatory procedure are perspectives about the individual's with ID/DD readiness to be included in matters affecting their lives. The medical model makes assumptions about inclusion based on an individual's physical health. Some of the assumptions regarding an individual's readiness for inclusion are adaptive behavior, strengths, and needs (Rothman, 2010). Historical perceptions related to the individual under the medical model have compounded views of inferiority. In California, the Client Development and Evaluation Report (CDER) determines services based on an ICD-10 Code scale that rates the severity of a persons mental retardation (California Department of Developmental Services [DDS], 2008).This coding system interprets eligibility decisions and remains deficit-based (Hanson et al., 2002). Related to systems associated with the population are assumptions of incompetence and dependence (Green, 2007). These perceptions not only affect treatment approaches, but decisions involving preferred futures, ability, and informed choice.

Historically, people with disabilities have been legally identified as feeble-minded, idiots, imbeciles, morons, and subhuman and consigned to living in unsanitary conditions in institutions both underfunded and over utilized (Wolfensberger, 1975).

Their fundamental human and civil rights were often abrogated (Noll, 1995). Rooted in the institutional model of disability treatment was an intentional negligence aimed at warehousing the population out of sight of the rest of society. This resulted in lost opportunities for both those with disabilities and the communities from which they were removed, leading to social ignorance, irrational fear, and emotional trauma (Hanson, Wieseler, Lakin, & Braddock, 2002). Traditionally, a lack of clarity in regulations has created confusion among many disability treatment frameworks. Still today, differing methodologies of service delivery and varying levels of support to individuals with ID/DD often result in ineffective or inconsistent programing (Carey, 2009).

Distinct measures were delineated in the Lanterman Developmental Disabilities Service Act (1969) that established and reinforced the civil rights of ID/DD individuals as well as the planning and delivery of services to them. The Lanterman Act, a landmark civil rights legislation for California, provided a model for community-based supports for other states. The greatest benefit of the Act lay in its fundamental principle to provide education that allows life choices to be made by ID/DD individuals. This measure was designed to develop community-based alternatives to previous institutional services. Despite using the less-stigmatizing language of the social model, however, it remained rooted in the medical model. The state declared it a priority to promote opportunities for employment, self-direction, housing, self-advocacy, inclusion, education, health care, transportation, and protection, and it was expected that these opportunities would continue throughout the individual’s lifetime (Disability Rights California, 2012). This support became the first and most prominent change accomplished by California

(CASCDD, 2011). The state appointed 21 regional centers to coordinate management and guidance in disability policy and to reduce or eliminate stigma and discrimination (Disability Rights California, 2012).

The California Department of Developmental Services (DDS) operates as a social service organization. DDS is tasked with the management of all institutional and community-based organizations receiving public funds that provide services for individuals with ID/DD. DDS is charged with supporting individuals’ informed choices and decisions about residence, community, exercising rights, and responsibility (Disability Rights California, 2012). The Lanterman Act also encourages these individuals’ pursuit of life quality and that they make contributions to communities. Individuals receiving services, service providers, and other individuals intimately involved in the disability system are principal partners in the decision-making process regarding those issues (Disability Rights California, 2012)

Despite the Lanterman Act’s effort to increase social equality, the medically based perception of disability still guides services and supports. This approach has not changed since its enactment. Regardless of the interests of the person with ID/DD, skill acquisition supersedes personal choice (Mercer, 1973). While there are benefits to skill acquisition, there are challenges associated with perceptions of deviance that impact the natural inclusion of people with ID/DD (Smull, Bourne, Sanderson, & Rothman, 2009).

When a community attributes deviance to a vulnerable population, devaluation and separation of that population persists (Mercer, 1973). The social model was intended to promote a fair, equitable life for ID/DD persons. Despite system reform, there are continued issues associated with integration, economics, politics, and equality.

Social and medical models both serve to limit the approaches used to support those with ID/DD. The medical model focuses on limitations, not normalization (Rothman, 2010). Through institutional habit, policies and procedures–whether social or medical–are grounded in the medical model. Research indicates that human services have the tendency to keep people “disabled” and devalued and perpetuates dependence (Wolfensberger, 1975). The success of a service system depends on tailoring the resources and supports to the specific interests and needs of each person (Wolfensberger, 1974; Rosenthal & Kanter, 2011). Regulatory practice rooted in medical models divides systems and structures and can deprive individuals of their dignity by disregarding principles of normalization (Carey, 2009; Rothman, 2010).

## Problem Statement

The two models of service delivery in California’s disability service system include the social model and the medical. Neither systematically encourages those with ID/DD to act of their volition (Wolfensberger, 1972; Carey, 2009; Fletcher, 2012). The medical framework focuses on deficits and norms, not self-determination. It serves as the gatekeeper and regulates the right to use services and programs (Rothman, 2010).

However, challenges also exist in the social model. These include a recent depopulation of state-run institutions combined with past negative social constructs and implications. Resulting from these implications are social deviance perspectives and depreciatory labeling. These stigmatizations affect the distribution of concurrent community-based services and opportunities for self-determination (Carey, 2009).

As indicated in the Welfare and Institutions Code:

> Long-term care services in California include an uncoordinated array of categorical programs offering medical, social, and other support services that are funded and administered by a variety of federal, state, and local agencies and are replete with gaps, duplication, and little or no emphasis on the particular concerns of individual consumers (Section 14139.05).

Despite regulation, the continuum of long-term care services tends to be limited by inflexible and erratic funding and ambiguous state and federal regulations (SHSC, 2010). The literature has not explored the social and medical  models of disability intervention together. More importantly, individuals with ID/DD in California's adult day programs have not been asked about their experiences regarding their opportunities for self-determination

## Purpose of the Study

This phenomenological inquiry explored the experience of adults with ID/DD working toward self-determination despite stigmatizing perceptions of deviance and disease, and incongruous frameworks for service delivery. The overarching aim of this study was to explore and understand how effectively service delivery systems provide standardized continuity of care while maintaining the principles of self-determination.

Participants meeting the following criterion were appropriate candidates for this study:

1. voluntarily self-selected;
2. ranged in age between 22–65;
3. were enrolled in the organization as a recipient of services from the organization at the time of the interviews being conducted;
4. maintained a diagnosis of ID/DD;
5. were not self-identified as experiencing acute emotional or medical distress;
6. identified as either gender;
7. identified as being in satisfactory standing with the agency;
8. identified as having the primary mode of verbal communication; and
9. identified as having the spoken language of English.

This study was comprised of 14 semi-structured interview questions (see Appendix A).

## Research Questions

This study addressed the overall question: What are the self-determined experiences of individuals with ID/DD receiving services in the state of California, and how are those experiences actualized? There were three main sub-questions:

1. What are the perceived barriers for achieving independence through self-determination efforts in systems provided in California?
2. What are the perceived opportunities to achieving independence and self-determination by participating in California programs?
3. What are the perceived ways that service delivery in California can promote efforts to increase self-determined opportunities?

## Conceptual Framework

The structure of the Lanterman Act differs diametrically from the intent of the medical model. Critical in the key theoretical underpinnings of contemporary disability policy are the promotion of self-determination and reduction of stigma and discrimination. These underlying principles are grounded in the ideals of social justice and individual autonomy.

One conceptual lens of this study was social role valorization (Wolfensberger, 1975) Social role valorization, intrinsic to the idea of normalization, is centered on respect for culture, community, and self-determination. This conceptual lens is used to advocate political, social, and economic independence of ID/DD individuals and their families. Anecdotally and throughout this research, it is assumed that all individuals, regardless of disability status, seek to control their lives and destiny.

The lens of social reaction is also relevant to the disability system. A history of negative public attitudes toward disability and the social isolation of people with disabilities are worsened by incidents of abuse and inadequate safeguards (Gettings, 2011).

Finally, a related perspective, the social construct theory, was at the heart of this study. This theory posits that individuals develop a broad-based subjective value of their experience through multiple complex meanings. It is through the socially inductive and interactive process that reality for individuals with ID/DD is formed and provides context for this study.

## Nature of the Study

The phenomenological method enhanced the goal to examine phenomena associated with the self-determination process of adults with ID/DD. Semi structured interview protocols and member checking allowed insights from participant experiences.

The phenomenological method included exploring the experiences of adults from California who diagnosed with ID/DD and who sought to live, work, or recreate independently. This study explored the perceived barriers in service, support systems, and processes that promote self-determination.

The agency selected for study has served Californians with disabilities for over 50-years. Programs developed by the agency have been outside of public school settings and have included recreation, therapy, and vocational enterprises. The agency aims for societal acceptance of all social, legal, and technological changes that increase accessibility and independence. More than 176,000 children and adults received services and supports from this organization in 2012 (Company Confidential, 2012).

Eight semi structured interviews explored personal perspective and interpretation. Follow-up interviews ensured clarity and accuracy of responses. The theoretical population voluntarily participated in this study and ranged in age from 22 to 65 years. Each participant was enrolled in the organization at the time research was conducted. A medical professional diagnosed each respondent with ID/DD prior to the start of the study. No participant indicated acute emotional or medical distress. At the time of this study, respondents were in satisfactory standing with the agency. Both male and female respondents used verbal communication utilizing the English language.

Employing an approach used by Vartanian (2011), data were triangulated using interviews and public documents. Data were collected from the corresponding interviews using detailed notes culled from participant responses. Data coding was completed utilizing compiled and analyzed responses. A classification system was developed and presented themes from which data aggregation and analysis were coded.

Semi structured and open-ended questions and interview testimonials were solicited to extract data elements. The identification, coding, and aggregation of all unprocessed data were maintained in information journals.

Through an informed consent process (Walden Approval # 12-01-0133454 exp. 11/30/15) all participants were provided an explanation and reason for the study. Potential risks and benefits were disclosed. Respondents were informed that access to the results would be provided on request. The most appropriate location to conduct the face-to-face interviews was a place where the members of the population frequent and are comfortable. Direct data entry from interviews were coded and entered into a Microsoft Excel spreadsheet and were translated, summarized, and interpreted. The subjects' personal experience permitted understanding the actualization of self-determination through a California based adult day program.

## Operational Definitions

*Americans with Disabilities Act (ADA):* The ADA is a congressional act passed in 1991 intended to eradicate inequity experienced by individuals with disabilities (ADA (Title 42: Ch. 126-Equal Opportunity for Individuals with Disabilities).

*Adult Development Center:* An adult development center operates as a day program service that endeavors to enhance the self-help and independent living skills for individuals with ID/DD in a natural, community environment. Individuals served by these programs may require significant and ongoing support and/or guidance in order to form appropriate social and community relationships, communicate their desires and needs, and respond as necessary to instructions and requests. As such, the focus of these programs is on sustaining practical skills necessary for representation, inclusion into the community, rewarding employment, and self-care (Title 17, California Code of Regulations).

*Coffelt v. Department of Developmental Services (1990) (Coffelt):* Coffelt was a class action lawsuit arguing against the restriction of individuals with ID/DD to developmental centers rather than more appropriate and integrated community-based settings. Settled in 1994, the case was an antecedent to over 2,000 residents of developmental centers joining their local communities in a span of 5 years (CHHSA, 2013).

*Community Integration:* Community integration refers to attendance, contribution, and involvement in ordinary community-based settings. Community integration may be referred to as the least restrictive environment.

*Community-Based Day Programs:* Community-based day programs provide local services ranging from employment to activities of daily living up to six hours a day and five days a week. These programs may also be known colloquially as adult day programs or adult day care facilities.

*Consumer:* A consumer is a person determined eligible and qualified by the requirements of the Welfare and Institutions Code. The regional center assumes full responsibility for the coordination and protection of individuals served. This term is synonymous with client, person in service, participant, member, and individual with intellectual and physical disability (California Welfare and Institutions Code, Div. 2, Ch. 3).

*Department of Developmental Services (DDS):*

Agency combined with California's Health and Human Services. Authorizing organization of services and supports provided through both developmental centers and community care facilities which ensure compliance and regulatory standards. Californians with disabilities living in the community may receive coordinated referral to services approved by independent, nonprofit regional centers.

*Developmental Disability:* A developmental disability is one that originates before age 18 and may include one or all of the following functional deficits: neurological, sensory, metabolic, and degenerative conditions. The term includes disabling conditions including those conditions that necessitate treatment akin to that for mental retardation or other, physical, conditions are also included (California Welfare & Institutions Code Section 4512; The California Code of Regulations [CCR] Title 17, Section 54000).

*Direct Care Staff:* Direct care staffs are employees of an organization that provide direct services and supports to service recipients. This term is interchangeable with direct support professional, and care provider (Title 17, California Code of

Regulations, and Ch. 3).

*Direct Services:* Direct services refer to training and education provided by direct care staff at adult day programs as required by a participant's individual program plan and the California Code of Regulations, Section 56720.

*Disability:* A disability is defined as any substantial limitation, impairment, or disruption of significant life activities, including the publics assumption of impairment. See: Intellectual Disability and Developmental Disability.

*Major Life Activities:* Major life activities include, but are not limited to, self-care activities, the performance of manual tasks, sight, auditory ability, self-feeding, ambulation, balance, strength, dexterity, vocal communication, respiration, auditory and visual comprehension, thought processes, and vocational pursuits. This may also include the ability to independently perform functions, such as those normally carried out by the immune, respiratory, circulatory, endocrine, and reproductive systems. This term is also referred to as ID/DD (Title 17, California Code of Regulations).

*Disabled Persons Act:* Associated regulations were put into effect to support the inclusion of persons relocated into their communities, including the Disabled Persons Act, which can be found in sections 54 through 55.2 of the Civil Code. The Disabled Persons Act expressly states in subdivision (a) of section 54 that "Individuals with disabilities or medical conditions have the same right as the general public to the full and free use of public facilities and other places" (Unruh Civil Rights Act, 1959.).

*Empowerment and Advocacy:* These terms refer to the coaching of individuals to help them eliminate, reduce, or cope with societal and legislative labels and obstacles

(Rothman, 2010).

*Essential Lifestyles Planning:* Essential Lifestyles Planning (ELP) may also be referred to as Individualized Planning and Person Centered Planning. The ELP is a structured approach to learning how a person with disability wants to live while addressing issues of health and safety. Plans are rooted in a process of learning and communicating what the person needs and how best to help that individual get what is relevant while ensuring that health and safety needs are met in the individual's desired living context (Smull, Bourne, & Sanderson, 2009).

*Generic Supports:* Generic supports are services and products made available to the public through voluntary, commercial, nonprofit, or similar entities in the community. (Title 17, California Code of Regulations).

*Individual Program Plan (IPP):* The IPP is a written plan outlining services and supports that is required from the regional center, as laid out in a legal agreement or contract.

*Integration:* Integration encompasses a comprehensive, meaningful relationship between the individual and the community, including the individual's opportunity to contribute to and enjoy independence and choice making in community affairs

*Intellectual Disability:* This term replaces the term mental retardation. With intellectual disability, adaptive functioning is impaired in three or more domains that determine an individual's ability to cope with everyday tasks both conceptually and socially. In the social domain. This impairment may include  psychosocial skills such as empathy, judgment of social situations, interpersonal interactions, and relationship building and retention. In the practical domain, impairment may manifest in learned skills required for independent living such as personal hygiene skills, vocational abilities, money management, leisure, and organization of tasks. Intellectual disability spans all genders and age groups, but symptomatology is required to begin during the developmental period; diagnosis is based on the level of deficits in adaptive functioning. This chronic, life-long disorder may be comorbid with associated conditions (Luckasson et al., 2002; DSM IV, 2013).

*Lanterman Developmental Disabilities Act (1996):* This Act authorized access for those with disabilities to services and supports commonly made available to those without disabilities. It was through this Act that the responsibilities of the California regional centers were established.

*Medical Model:* The Medical Model of disability views it in terms of dissimilarity, insufficiency, or deficiency (Rothman, 2010). The medical model is a deficit-based, norm-centered framework with focus on the deviation of the body and mind from standards of the norm (Rothman, 2010). It is also referred to as the Clinical Model or an Institutional Model.

*Olmstead v. L.C. (1999), 527 U.S. 581 (Olmstead):* Olmstead v. L. C. is a U.S Supreme Court decision confirming that individuals with disabilities must be provided with community-based services, with the understanding that services are appropriate and desired or not opposed by the individual served, and that they can be provided in a reasonable manner with available resources without negatively impacting the services of others (CHHSA, 2013; ADA, 2011).

*Regional Center:* A regional center is a service coordination setting established and operated pursuant to the California Welfare and Institutions Code §4620-4669 to provide diagnosis, counseling, and referral to either state-funded vendors or general resources (Title 17, California Code of Regulations). Twenty-one designated catchment areas have been defined in the state of California, with one regional center providing service to each.

*Self-Determination:* A wide range of actions that would allow persons with a disability to better manage their lives and destinies, including choice and control over individual activities, schooling and education, level of independent living, and the provision and comprehension required to participate in decision-making and problem-solving. Self-determination requires receipt of the respect and dignity to which all persons are entitled and includes such individual opportunities as choice making, asserting oneself, self-management, autonomy, and independence (Wolfensberger & Nirje, 1972).

*Services and Supports:* Services and supports refer to generic or specialized programs or aids aimed at decreasing symptomatology associated with ID/DD, with a goal of the normalization or rehabilitation of aspects of an ID/DD individual’s life and encouragement of the individual’s ability to live an independent, productive, and rewarding life (California Welfare & Institutions Code, Section 4512).

*Social Construct Theory:* Individuals develop broad-based subjective value of their experience through varied and with multiple meaning. These views tend to be complex. According to research, views are involved rather than narrow, and the focus relies on the participant's impression of the point of the study. Cultural and historical underpinnings inclusive of situations in which people live or work, as well as how meaning is interpreted. The world of meaning is rich with historical and cultural connotations; it is through this socially inductive and interactive process that reality is formed (Creswell, 2013).

*Social Model:* The Social Model of disability focus on the social outcomes that result from an individual's physical or mental deficiency. The social model views impairment as an effect of the society or environment (Rothman, 2010).

*Social Reaction Theory:* Social Reaction Theory (SRT) is a theory of deviance as a social construct rather than specific acts or behaviors. Such behavior remains constant, while the labeling of it varies based on societal norms, held by a vocal majority or minority, that impact the creation of formal and informal rules held by society. These rules may be applied inconsistently due to a bias toward facilitating favorable outcomes (Becker, 1963).

*Social Role Valorization and Normalization:* Belief series regarding discriminatory actions towards individuals with disabilities' social roles and/or attempts to decrease or extinguish discrimination while increasing social roles (Wolfensberger, 1972).

*Vendor:* A vendor is a provider who has completed the process stipulated in 54310 (d) and (e), California Code of Regulations, Title 17, Division 2 to provide services to persons with disability.

## Assumptions

Due to the vulnerable nature of the population of individuals with ID/DD, this study made four assumptions:

1. Respondents would maintain integrity in their responses and provide experiential information based on the context of the study. This study employed the informed consent process, IRB approval and member checking. The setting was familiar to the participants.
2. Research findings will contribute to furthering best practices, self-advocacy, and validity of existing theories. Familiarity with the historical context, regulatory requirements, and choice of method were key considerations for this study. A comprehensive literature review for this study was provided.
3. The instrument (semi-structured interview), design, and method were appropriate for this study. Due to the nature of this study, there was potential for learning and comprehension barriers. This was addressed by assuring an opportunity for prompt member checking.
4. As interviewer, I would remain unobtrusive and objective. This was addressed by arranging flexible meeting times with the agency and individuals and choosing respondents from an agency with which I am not affiliated.

## Scope and Delimitations

The definition and usage of ID/DD have remained consistent for at least two generations. Minor variations reflect increased understanding of intellectual capabilities and functioning, as well as adaptive behavior. Research methods have bolstered advances in measurement theories and strategies to minimize errors in measurement and to account for changing practices and norms. Clinical judgment regarding evaluation designs, assessment selection, and interpretation of results account for the remaining changes (Buntinx & Schalock, 2010; Schalock et al., 2007).

The evaluation of individuals' limitations included professional awareness of the setting, resources, and neurotypical patterns consistent with those without disabilities. Observance of age, sex, culture, and language as well as sensory, motor, and behavioral components were considered, as well as personalized long-term supports. It has been shown that the inclusion of these factors in analysis and evaluation causes improved life functioning (AIDD, 2010). Self-determination and social reaction were the particular focus of attention to illustrate how historical and current perspectives support this community in practice.

This study was delimited to persons who are medically eligible for California Regional Center services. This study was delimited to individuals having a diagnosis of ID/DD as defined by the California Welfare and Institutions Code and who were also enrolled in an adult day care facility at the time of recruitment.

The potential for transferability of the findings in this particular study is limited, as the findings may not necessarily hold true for a similar agency. Services in California are regulated by the Department of Developmental Services and Titles 17 and 22 of the Welfare and Institutions Code. Other groups and individual agencies are operated under varied agreements and contracts with regional centers.

## Limitations

This study was subject to limitations, which include the following: (a) There was a potential for social desirability to skew the responses by participants; (b) autonomy may not be a unitary construct; (c) internal consistencies of question meanings were not expected; (d) due to the limited sample size, results may not be able to be generalized to larger populations and programs; (e) a significant demand on the participants in terms of their commitment to time and attention was needed, which may have caused a degree of attenuation to question meanings and a response degradation; and (f) due to the nature of the disabling conditions, there remains a possibility that the research and interview questions may have been misunderstood or not completely understood by respondents.

To mitigate the effects of these limitations, I implemented a variety of measures. Interview questions were phrased in a manner that did not suggest a particular answer as being preferred, and I provided feedback that was neither immediately positive nor negative to avoid influencing responses. I had not worked with respondents in this study in any capacity, and therefore individuals remained unknown in order to ensure that an authoritative or friendly relationship that could potentially skew results did not exist.

In regards to the understanding of autonomy and various interview questions, open-ended prompts were written on a level to encourage understanding regardless of intellectual disability and education. If misunderstanding or confusion was noted, I rephrased questions to improve comprehension. A member checking process was performed after questioning ceased to ensure that participant responses had been correctly transcribed and comprehended.

While the sample size was limited by me, other demographics were not controlled, such as gender, race, or age (beyond the California Regional Center requirement for all participants in day programs to have attained the age of 22). Participants were self-selected and not directly recruited by me, decreasing potential bias and encouraging diversity in respondents.

Interview sessions, which ranged from approximately thirty minutes to one hour, were controlled by the speed of the participant, who was allowed frequent and unlimited breaks.

## Significance of the Study

This study was expected to contribute to an understanding of the medical model's impact on existing service delivery to individuals with ID/DD. This study may contribute to recognition that ID/DD is multifaceted and involves symbiotic engagements between mental ability, adaptive behavior, community and family inclusion, and individualized supports (Wehmeyer et al., 2008).

The bulk of research on frameworks for delivery and supports under these models has been conducted among traditional providers, such as those who provide direct services. There is little known about the experiences encountered by individuals served and the actualized self-determination resulting from participation in an adult day program.  Few research studies have been conducted to assess life quality related to service delivery and self-determination. Information gained from this study also has the potential to help community-based facilities recognize and clarify incongruence between regulation and practice. Where service delivery is concerned, identifying limitations may contribute to developing and articulating supports.

This study endeavored to understand and expand the existing knowledge base using a phenomenological approach to identify themes and patterns. This study evaluated themes and patterns that contribute to self-determined opportunities of individuals with ID/DD. This study could also enhance support to people with ID/DD in everyday settings in California by increasing their engagement in meaningful activities.

Honoring those who with ID/DD whom speak a challenging historical and present day truth regarding social perceptions may lead to increased awareness, self-representation, and positive legislative outcomes. This research could potentially add to the regulatory-body of information and service delivery best practices. Understanding the problem as an issue related to systems and not the individual contributes to improved life quality for persons with ID/DD. This research increases the likelihood for self-determination to become a priority for legislators, community members, service providers, and those with a vested interest in life quality for people with ID/DD.

## Summary

Historically, despite extensive reforms, individuals with ID/DD have been used as unwilling or unknowing subjects in unpredictable treatments and practices. In California, state lawmakers responded with the Lanterman Act and related laws, which ensure the responsibility of lawmakers, lay persons, and service providers to follow system designs that support self-determination for vulnerable citizens. However, practical difficulties arose and continue to arise in implementing opportunities for self-determination, not only in how to interpret regulatory policy but also in response to the conditioning of the public to distrust persons with disabilities.

Existing structures for care and treatment are grounded in two dominant models, a problem-centered medical model, and an environmentally focused social model. However, in both models, socially constructed notions remain. Rejection, isolation, or discrimination strengthens social barriers to entry (Wolfensberger, 1974; Carey, 2009; & Rothman, 2010).

The aim of this phenomenological study was to explore the phenomena associated with individuals with ID/DD and their experiences in working toward self-determination. First, I discussed open-ended survey questions to be delivered to study participants in an adult day program. Second, I discussed intent to explore the main perceived barriers to achieving self-determination. Third, I discussed the impact of program services and support systems in their movement toward self-determination of individuals with ID/DD. Finally, I discussed processes aimed at improving the overall experience of self-determination in California.

The open-ended, semi structured, qualitative phenomenological study presented limitations. Efforts were made to mitigate these effects. The impending literature review (Chapter 2) will present and explore concepts related to this study. Disability concepts will include self-determination, social role valorization, and social deviance, service provisions and perspectives related to the medical and social model.

# Chapter 2: Literature Review

## Introduction

This literature review concerns three key issues. First, it examines the polarity between existing models of treatment and care. Second, it explores the lack of clarity between regulations and services. Finally, there is focus on major theories, including social role valorization and social reaction.

The aim of this study is to explore and understand how service delivery systems provide standardized continuity of care while maintaining the principles of self-determination.

The Association of Intellectual and Developmental Disabilities (AIDD) defines disability through a construct that states that the major difference between the terms Intellectual Disability and underlying mental retardation is in regard to where the disability resides. The latter construct (mental retardation) viewed the disability as a defect within the person. Contemporary constructs view the disability as a mismatch between the person’s capacities and the context in which the individual is to function. The term mental retardation referred to a condition internal to the person (e.g., slowness of mind); ID refers to a state of functioning, not a condition. Both views regard the condition or the state of functioning as best defined in terms of limitations as compared to functioning of neurotypical people (AIDD, 2010, p. 13).

Self-determination refers to having opportunities to make choices (Wehmeyer, 1996). Research methods used in earlier studies focusing on self-determination centered on this population’s experience in the areas of autonomy, competence, and contribution

(Emerson et al., 2004). Self-determination has been studied within varied settings, including the home, classroom, business, clinic, and among cultures (Emerson et al., 2004).

The quantitative approach focuses on impairment and efficiency of intervention (Emerson et al., 2004). A focus on impairment is useful in policy planning, but is hampered by the lack of reflection of variation and unusual cases. The challenges inherent to the use of quantitative experimental approaches include the interference of multiple treatment modalities and the transferability of learned skills between environments (Kazdin, 1982; Emerson, 2004). The introduction of the social model, however, presented opportunities for reflection on the social construct of disability.

Qualitative studies interpret social context using ethnographic methodology or a combination of methods (Edgerton, 1967; Ryndak, et al., 1999; Emerson et al., 2001; Stancliffe, Abery & Smith, 2000; Wehmeyer & Bolding, 1999). Qualitative approaches allow examination of differences between settings, and ultimately increase choice, as well as access to and availability of services (Emerson, 2004).

Services for individuals with ID/DD in California function under a set of guiding principles reflected in the Lanterman Act, which requires certain services and supports to be made available. These principles are supported by the Welfare and Institutions Code, Division 4.5, which stipulates that individuals must experience the opportunities and relationships available to those without ID/DD. This includes the ability to make choices in all areas of life, have the opportunity to join typical communities, and to be self-determining and useful.

Key issues for self-determination include appropriate and available job opportunities, housing, and policy development. Self-determination also requires appropriate access to, and input in, public education and health care, accessible transportation, and protection from crimes.

Quality services and supports are funded using taxpayer monies to achieve outcomes and client satisfaction, which are measured through a variety of approaches. While the design of services and systems is intended to be responsive and accountable, research has shown inconsistent levels of satisfaction.

## Literature Search Strategy

Using a modified Thames Valley Health Libraries Network's literature review process (2005), I identified the best available literature that addressed the research question. A search planning form was used to clarify the key concepts and the scope of the research topic. This planning form included the research topic, applicable categories of the research topic, and alternative words. These criteria included the population and problem, intervention methods, comparison items, and outcomes or effects.

Using research questions as a guide, search restrictions included articles or text dated between the years 2001 and 2006. Because of limited availability of articles in this time period, the search parameters were expanded to include the years between 1995 and 2000 prior to an exploratory search of the literature. The research topic was phrased as a question, incorporating elements identified in the models.

To be considered an article or book that provided evidence on key search questions, quality had to be addressed. Self-determination had to be a topic of sufficient significant that the source could plausibly provide primary data and include systematic review. Some citations were reviewed and articles were retrieved. Online social services research databases (e.g., Sage publications) and the Google search engine were used.

Population terms included: *agency/provider/individuals with intellectual disability*, OR *day program*, *adult day care facility*, *community services*, *mental retardation*, *developmental disability*, and *intellectual disability*, along with *moderate mental retardation*, *mild mental retardation*, and *severe mental retardation qualitative case studies*. Intervention terms included: *medical model or clinical model, pathological model, diagnosis, labeling, deviance, regulations, systems, and institutionalization*. Comparison Intervention terms included: *social model or community model, environmental model, social and environmental frameworks, regulations, and systems.* Outcome or Effect terms included *self-determination or free will, autonomy, independence, social reaction, oppression, deviance, discrimination, marginalization, stigmatization, rights, access, de-institutionalization, normalization, and social role valorization.*

## Theoretical Foundation

Wolfensberger's (1972) definition of social role valorization (SRV) is adopted in this paper . Social role valorization replaced the term normalization and characterized the fundamental give and take of social interaction between individuals, with the key principle being that when people are socially valued, their quality of life increases. When social roles are supported, opportunities are accessible. There are two groups of people who fall into this role, those who are valued, and those who are not (Wehmeyer & Schalock, 2001).

Historic and universal actions surround devaluation. SRV is a method that counters devaluation via the enhancement and empowerment of an individual's self-image and competency (Wolfensberger, 1972).

SRV is an empirical definition rather than a qualitative value system or ideology. This theory was selected to examine the application of self determination in contemporary society and to provide perspectives into system development (Wolfensberger, 1992). The research questions related to this theory in that each addressed, from a different angle, influences into the value of the vulnerable individual. This theory builds upon the polarity between medical and social systems supporting those with ID/DD.

Social Reaction theory (SRT) is used to describe a societal reaction to individuals who carry "criminal labels" (Becker, 1963). Labels are used to classify a person into a status that ultimately shapes the person's views of his or her environment and others. Regardless of any prior held status, the label applied is established by the norms of society and accepted by those so labeled. Once this label has been established, pressure to conform to the expected standards will take place (Wolfensberger, 1972). This theory was selected in response to the impact that labeling has when implemented by a community and invested in by participants. This impact includes opportunities that may or may not be made accessible to those labeled. The research questions related to the theory of SRT because of their relevance to attitudes, systems, and constructs.

## Literature Review Related to Key Concepts

A person becomes an individual partly through the choices he or she is allowed to make. For those identified as intellectually or developmentally disabled, personal choices are limited. As the focus of self-determination was concerned, it was in this context that basic civil rights were considered. The purpose of the examination and review of the literature was to explore the clinical and social perspectives that represent autonomy of the individual. While systems are not silos, they are treated as such (Fletcher, 2012).The characteristic experiences of persons with ID/DD related to physical, intellectual, psychological, and sensory identity contributes to a disconnection from governing mores and institutional discourses (Fletcher, 2012).

This study explores a problem with the overarching disability systems related to policy and practice in California. While it is acknowledged changes in the disability system have occurred, they continue to require organizational communication (Carey, 2009).

Underpinning this study is the notion that the disability system has not developed structures to help people reach their full potential because of a dichotomy between existing service and regulatory procedures. In general, the population of persons with ID/DD is highly regulated (Fletcher, 2012) whether through systems, structures, or supports. This study examined barriers at the state level, interagency collaboration, principles in service planning, and frameworks requiring cross-system collaboration (Wolfensberger, 1975; Carey, 2009; Fletcher, 2012).

Individuals with ID/DD are a challenging population to serve, and there are competing, contrasting theories and modalities in use (Fletcher, 2012). Subsequently, a breakdown occurs in planning services, funding flexible services, and obtaining the assistance to support fully the success of varied contributions (Carey, 2009). Further, flaws in the system prevent adequate training, transferring, joint responsibilities between agencies, and the articulation of policies (Carey, 2009, Fletcher, 2012). When policy and practice are disengaged, issues of devaluation and collectively imposed limitations surface (Becker, 1963; Carey, 2009; Mercer, 1973; Noll, 1995). This phenomenon of expected deviance reinforces vulnerability factors through pervasive feelings of inadequacy and disempowerment (Fletcher, 2012).

Concepts related to independence are valuable because they promote self-reliance (Wolfensberger, 1983). People with ID/DD can experience independence by self-determining their lifestyles and activities. Individuals vary, however, in how much support they need when making choices (Reiss, 2010).

Behavior or expressions outside of what is perceived to be normal, and exhibited by those identified as having an ID/DD, have compartmentalized this population into subgroups. These groups are identified as feeble-minded, mentally defective, mentally deficient, moronic, imbeciles, idiots, mentally handicapped, crippled, and mongoloid (Mercer, 1973; Noll, 1995). Those with a disability were also referred to as omens, prodigies, and visitations of sin, freaks, and curiosities. For many, this sanctimonious terminology induces mockery, compassion, or embarrassment from community members (Turner, 2005), regardless of the clinical boundaries for the diagnosis.

Applied titles and beliefs about this population result in feelings of inadequacy and defeat, as well as failed experiences (Fletcher, 2012; Noll, 1995). Systems must determine a methodical approach to instilling hope for the future, as well as pride in accomplishments, to this population. It must instill dignity, worth and value of the individual (Fletcher, 2012).

The mechanistic viewpoints of disability utilize the medical and statistical representations of what is considered to be atypical in order to develop a pathological diagnosis (Mercer, 1973). Attempting to balance this framework, the social systems model determines and shapes both language and the environment to represent the status of one's rank and affiliation. A system can negatively affect any person at any time, as it is contingent on all systems in which the individual is engaged (Bertalanffy, 1968; Mercer, 1973; Wolfensberger, 1983; Carey, 2010). Societies conceptualize normal and pathological to maintain sustenance of the system's influence and authority and to preclude stigmatized deviance (Turner, 2005).

Stigmatization endeavors to set apart what is perceived as normal and abnormal; however, it reflects the tangible foundations of authority (Adler, 1978; Mercer, 1973). Systems are designed to govern policy and practice, though a perpetuation of socially manufactured deviances supports the role and those assigning the role (Becker, 1963; Mercer, 1973; Noll, 1995).

Concepts of inferiority and superiority (Adler, 1978), when applied to at-risk populations, demonstrate the causal relationship between both normal and deviant (Noll, 1995). The manufactured and mechanical perceptions of the population reflect the care and treatment that is afforded them (Carey, 2009; Noll, 1995).

Not surprisingly, the internalization of these expressed social responses can result in consequences for fragile persons that subject them to isolation and adverse conditions (Becker, 1963). The individual begins to accept these concepts as truth and fundamentally exists to reinforce society's applied deviance labels (Becker, 1963).

Historical annals displayed an urgency to protect society from these unstable deviants (Noll, 1995). For centuries, this class of persons has been viewed as troublesome to the community; unable to contribute to the general collective, inactive, and costly to the state. Societies rendered these individuals ineffective and wayward, demanding of time and attention, and classified this group as a threat to the common order (Howe, 1972).

Social systems are a constructed practice within the human service field and present a configuration for contemplation (Bertalanffy, 1968; Wolfensberger, 1975). The social process is a manifestation of developing and employing strategies about one's environment and all the elements that stand in interrelation (Becker, 1963).

It is within these social structures that potential existed to understand the multitude of interrelated networks related to the emotional, motivational, social, cultural, and linguistic amalgamations of decision-making (Bertalanffy,1968). Members of these social structures expand and perpetuate their systems and structures to establish the manner in which role affiliation will be determined (Adler, 1978; Mercer, 1973). Where intellectual and developmental disabilities are concerned, divergent systems are formed around the notion of the level of responsibility allowed of the individual, and the expectations associated with that responsibility (Mercer, 1973). The implications in which social systems affect those with ID/DD include practices that shape and influence rules, sanctions, and assimilation (Becker, 1963; Carey, 2009; Mercer, 1973; Wolfensberger, 1975).

These systems are institutional and of a functionally reactive nature (Bertalanffy, 1968). Simply stated, these systems comprise clinical perceptions and social perceptions. Actions occurring out of policy and practice are a response to conflict (Fletcher, 2012). When this occurs, the response is often conditional and may include avoiding, ignoring, accommodating, or becoming acquiescent (Bertalanffy, 1968; Wolfensberger, 1975). This process influences the power relationships that maintain concepts of inferiority and superiority (Adler, 1978) and have resulted in outcomes that have compromised the health, well being, safety, and security of many individuals diagnosed with ID/DD (Carey, 2009). Research indicates that abuse and unexplained injuries (California Watch, 2012) and a lack of access to resources available to the public are examples of this disparity. Administrative perspectives determine to a large degree the value of a person (Mercer, 1973) and are actualized through systems, structures, and supports (Adler, 1978).

The reliance on administrative perspective determines to a large degree what resources the individual will qualify for (Fletcher, 2012; Carey, 2009). Similarly, this perspective results in power differentials that promote, potentially unintended, labels, stereotypes, segregation, degradation of status, and discriminatory actions, (Rothman, 2010). Promoting socially reactive labeling supports the recognition and acceptance of differences, including assigning social salience toward trait differences that separate accepted social significance (Green, Davis, Karshmer, Marsh, & Straight, 2005). Excessive attention to differences hampers the productivity of the individual, lowers his or her sense of belonging, causes continued deviation and potentially increases the appearance of inappropriate behavior (Becker, 1963).

Individuals with ID/DD are caught between two contradictory models to which systems pertain: the medical model and the social model. These heavily practiced human service frameworks are presented as the theoretical basis to explore how self-determination is encouraged and actualized for individuals with ID/DD.

## Medical Model

The medical model is problem-centered and views the person with a disability as a unit of distinct physical or cognitive limitations (Lo Bianco & Sheppard-Jones, 2007). Pre-existing conditions of the individual involve bio-behavioral presets, instances which one has little means for change. These presets may be prompted by developmental experiences, genetic material, diagnoses, or persistent well-being issues.

Where the medical model is concerned, etiological conditions are the consequence of behavioral phenotypes, genetic predispositions or acquired brain disturbance (Fletcher, 2012). An individual requiring the use of mobility aids may have difficulty communicating. He or she may also be diagnosed with a co-morbid learning disability, be visually impaired, wear hearing aids, or be unable to participate in any activities of daily living. Under this model, one is regarded as unwell or unhealthy.

Contrary to the medical model, contemporary perspectives of disability are environmentally focused (Lo Bianco & Sheppard-Jones, 2007). Social accountability counters the view of the individual as a product of his or her illness, instead postulates the idea that the individual is a product of society's reaction to the disability.

When labeling disability, it is recognized that language is constructed out of and by society (Lo Bianco & Sheppard-Jones, 2007). Further, labeling mirrors limitations to those with disability and focuses on how society creates environments with little consideration for the barriers that impede one's progress (Lo Bianco & Sheppard-Jones, 2007). Historically, biological issues, early development, and developmental progressions revealed patterns of inability or cognitive impairments and were considered responsible for, and indicative of, one's potential social status affiliation (Haber & Smith (1971).

While etiology is central to one's development, people do not develop at an equivalent rate developmentally because of genetic issues, prenatal care, prenatal environment, or prenatal trauma (Wolfensberger, 1975). These factors add to lifespan experiences, including survival, protection, dependence, and shared relationships (Haber, 1971). The empirical desires to acquire faith, feel affection, examine humanity, or any experience that assists the person can occur at any chronological age (Wolfensberger, 1974).

The capacity for expanding adaptive behaviors, to self-direct thoughts, or to create beliefs and survival methods may correspond to speculations of managing pain or emotional distress (Rivera, 1978). Determining one's ability to adapt to the environment often reflects communication aptitude. The general theme of the medical model is the interconnected organizations, ritual systems, positions, and occupants holding the positions. Aspects of affiliation and belonging within this system progress through reciprocal practices and are related to one’s status and one’s role (Becker, 1963; Mercer, 1973).

The social influences affecting the individual are not recognized under the medical model, which continues to focus on deviance (Wolfensberger, 1974). Pragmatically, disease-centered models perpetuate views of individuals with ID/DD as a "subhuman, pitiful, a holy innocent, diseased, object of ridicule or eternal child” (Wolfensberger, 1972, p. 12).

These concepts of those with ID/DD represent frameworks originating from practice and literature. This collective view poses barriers to recognizing one’s development, family involvement, and ability to make friends, attain an education, or become involved in the culture of a community (Wolfensberger, 1975). These perspectives may increase potential segregation, disconnectedness, and limited options, and decrease a sense of belonging (Mercer, 1973; Wolfensberger, 1975; Rivera, 1978; Carey, 2009). Individuals with ID/DD survive by a veil of learned powerlessness and age or developmental failure (Fletcher, 2012). These approaches and perspectives have led to apparent discrimination, role failure, and removal of power (Green, Davis, Karshmer, Marsh, & Straight, 2005).

The notion of chronic conditions and impairments do not necessarily require a need for social control over the vulnerable individual; in order to live in a self-actualized manner, one must have authority for decisions affecting his or her life (Haber & Smith, 1971).

The value of the sick role or the diseased organism referred to by Wolfensberger (1974) depends on the expectation society holds of the individual's longevity. Should the individual be alleged terminable, his or her ability to contribute is constrained by the collective (Adler, 1978).

The medical model presents predicaments regarding interactions, preventing them from occurring organically.  Reactions about uneasiness and hesitation, specifically, when interacting with persons with physical handicaps are familiar encounters (Comer & Piliavin (1972). In these circumstances, this recognizable discomfort has the propensity to lead to an abrupt termination of the interactions between individuals with and without disabilities, indistinct views of individuals with disabilities, and less knowledge regarding the behavior of individuals with disabilities. Experiences between those with disability and those without result in a distorted self-awareness and embellished language or expression (Wolfensberger, 1974; & Green et al., 2005). The potential negative contributions, whether to a conversation or society as a whole, of the individual with disability influence private reactions and encourage dissimilarity (Green et al., 2005).

This model of disability does little to recognize the consequences of stigma and subsequently, identifies and equates disability with dependence and genetic impediments (Wolfensberger, 1975, Greene et al., 2005). While it is the responsibility of the clinician to diagnose, the early experiences of disconnection and dissimilarity become reactionary to the general public (Green et al., 2005).

Extending support to those in disabling circumstances implied a displacement of resources (Carey, 2009; Davies, 1930). In fact, tolerating reproduction suggested perpetuating poor genetics, failing to protect the community and allowing for future criminal activities. Inactivity in controlling this population seemingly substantiated poor decision-making by the state (Davies, 1930). Efforts to keep the public safe resulted in relocating persons with disability into institutional environments distancing them from the community at large, as well as subjecting them to cruel and unnecessary medical procedures, including sterilization (Howe, 1972).

Inhumane treatment protocols continue to manifest in present day care and highlight systems and structures that remain unclear and inconsistent (Carey, 2009; Haber & Smith, 1971; Rothman, 2010). As of 2008, California had five active institutional settings, but due to a provision of the Lanterman act requiring the least restrictive environment for all persons served, these facilities have been steadily depopulated (DDS, 2008).

Modern approaches are required to take into consideration the interest of the individual and the availability of resources. Where these resources do not exist, a plan is supposed to be developed to move the individual in a preferred direction (Title 17, Welfare and Institution Codes). However, despite the attempts of authority and legislatures, the “least restrictive environment” does not always place the individual under the minimum of regulations (Fletcher, 2012). In fact, while individuals are offered the promise of living in the community, and in their homes, they continue to reside in segregated settings with individuals who share similar disabilities (Fletcher, 2012).

Services provided under a medical framework continue to provide the chief impetus in the development of rulings, curricula, regulations and services (Rothman, 2010). While notions of disability filter into the social processes of humanity, the propensity remains to treat disability as an extension of the sick person or a deviant (Becker, 1963). This misrepresentation decreases the ability for the individual to adapt to community norms. Through these standards or positions, unclear expectations remain for how treatments support a person's dignity, value, respect, high regard, and reverence (Fletcher, 2012). If treated poorly, the individual may take on the role assigned (Adler, 1978; Becker, 1963; Schweik, 2009). Historically, individuals with ID/DD labeled as immoral, having character flaws, and being guilty of illegal conduct were subject to isolation in an institutional setting (Becker, 1963; Noll, 1995).

Words reinforce the impression that hygiene law prevails, illustrating the principle of contagion (Schweik, 2009). As a result, regulations are developed around the body's deviance often with free rein in the making of law and policy (Haber & Smith, 1971). For those with a disability, their experiences are not limited to issues of inclusion, but rather, issues related to the circulation in environments that constantly retell their stories of exclusion (Schweik, 2009).

Power relations are contingent on disability systems, as well as the extent of the disability and rates of deviance associated with the individual (Haber & Smith, 1971). Control of the condition may be a logical reflection of an institutional perspective. However, a person who recognizes this relationship may begin to exhibit strange or underdeveloped behavior in response to the power differential (Becker, 1963). It is expected that clinical assessments will support social contingencies. Value rests in the perceptions applied to a person (Schweik, 2009), and in the case of those with disabilities, they are considered to be the source or cause of disease. The very act of disenfranchising any group based on personal characteristics assumes the undesired traits are more significant than all the others within the individuals (Wolfensberger, 2001).

Disability has advantages and disadvantages. Human mediocrity serves as a catalyst for change. By nature, people will compensate for their insufficiency, lack of self-confidence, or sense of being substandard (Adler, 1978; Becker, 1963). Through imperfection, humankind will be forced to survive. Concepts related to integration imply that all actors form the web of consistency of any cultural framework (Bertalanffy, 1968). These frameworks are a natural system that depends upon the nature of the individual and the group with which he or she belongs.

However, other factors including those transitional experiences encountered by an individual should be considered (LoBianco & Sheppard-Jones, 2007) essential to one’s life. Transitional opportunities, including those affording individuals access to employment or housing, promote long-term shifts to social perceptions of disability (LoBianco & Sheppard-Jones, 2007). Self-determination is not always considered to be a right, but, instead, something one must fight for or have support to do so (LoBianco & Sheppard-Jones, 2007; Carey, 2009).

Social dynamics have self-governing and noteworthy outcomes not only for an individual with a designated disability, but also to all individuals with the specified disability. The cultural esthetic is obsessed with problems of appearing and appearance

(LoBianco & Sheppard-Jones, 2007). People with ID/DD have a heightened attention to appearance-made words such as repulsive, grotesque, dirty, and slovenly (Schweik, 2009). The only solution to incorrigible ugliness is to hide it; the proper outcome of aesthetic failure was permanent invisibility, such as sterilization, lobotomization, or death (Schweik, 2009). As a result, the relationship between the community and the individual determines the potential for success, superiority or inferiority (Adler, 1978; Becker, 1963; Schweik, 2009).

The burden of those marginalized requires having courage despite adversity. One's ability or aptitude to perform should be such that it is impervious to outsider perceptions and unaffected by the effects of those perceptions over time (LoBianco & Sheppard-Jones, 2007). Implicitly, individuals that society deems healthy and attractive have been disciplined to not view illness; individuals with a disability remain invisible to them (Schweik, 2009). Therefore, disability prevents natural sociability.

The mechanical application of labeling disease shapes decisions about allocation, obligations, and commitment (Haber & Smith, 1971). Research indicates disability would not exist if it was not for mere terminology shaping and associating service delivery models (LoBianco & Sheppard-Jones, 2007).

Beyond definitions and these two models, achieving acceptance from within any group and the sense of belonging to a community supportive of individuality and potential remains a challenge in service structures (LoBianco & Sheppard-Jones, 2007). Research indicates the Medical Model is constrained by the need for practical identifiers applied to those with ID/DD. However, concepts related to these misrepresentations have negatively impacted the creation of laws, while simultaneously attributing the burden of immorality, illegal conduct, and character flaws to individuals encapsulated in these misunderstandings. Accusations of moral and mental failure, as well as the more obvious esthetic transgressions, are often associated with this clinically focused construct. As evidenced from the literature, chronic stigmatization and marginalization persist, leaving little room for exploring the ability of the individual and his or her preferred futures.

## Human Management and the Medical Model

A historical basis for the interpretation of meaning and existence continues to have an effect on potential future service options for those with disabilities, as their experience has not been significantly altered in the recent past (Noll, 1995).

To understand the medical model of disability is to understand the requirement to cure (Dale & Melling, 2006). The actual, lived experiences of those with disabilities continue to be disregarded, in favor of associated phenotypes with negative outcomes (Stagg, 2006). Treatments of individuals served by a medical model has included involuntary placement in institutions, abuse, and neglect. Such decisions made by authority figures reflect a continued deprivation of individuals' with ID/DD fundamental right to be considered equal citizens (Rosenthal & Kanter, 2011). Treatments that purported success in the deterrence of subhuman characteristics included methods to "purify" a diseased body to promote the representative concept of cleanliness (Schweik, 2009). Notions of cleansing also reinforced concepts of intellectual hygiene and prompted further "protections" from those perceived as different to the public. A response to the management of difference was to eradicate reproduction of the mentally deficient, known colloquially as eugenics, and to limit integration (Morris, 2006).

Eugenics received support from medical and cultural terms, such as idiot, imbecile, cretin, moron, dullard, backward, and defective (Morris, 2006). The 1913 Mental Deficiency Act was a governmental approach to integrating the ID/DD population into mainstream society. Political ideologies have historically been hostile towards individuals deemed inferior, which has led, directly or indirectly, to the usage of permanently damaging, disabling, and immoral methods (Alemdaroglu, 2006; Morris, 2006).

When communities become complacent with trends that determine deviance based upon the phenotypic quality or intellectual perspicacity, it multiplies the challenge of relating naturally to this population (Wolfensberger, 1974). This reactivity and salience promotes regulation and control over the individual (Fletcher, 2012; Green et al., 2005). Control may be instituted in an outright manner, or through inconspicuous measures involving choices about life, work, recreation, and health (Fletcher, 2012). Research indicates repeated polarization between groups lowers the value of members of a disenfranchised population, and increases pervasively challenging behavior (Becker, 1963; Green, Davis, Karshmer, Marsh, & Straight, 2005).

Inequity occurs when an unspoken status loss hinders an individual’s ability to participate fully in the community (Becker, 1963; Carey, 2009; Mercer, 1973). The assigned label of deviance further endorses stigmatization (Green, et al., 2005). Nonverbal and subtle signals of separation of the person may include limited positive physical contact, carriage, facial expressions, or gestures often evident in institutional care (Rivera, 1978). The use of skin shocks, restraint, and harmful drug treatments have been used to sedate individuals with challenging behavior (The ARC, 2010, Office of Ombudsman, 2010, and Fidler & Hodgetts, 1992).

While many believe that barbaric treatment is restricted to the long-ago past, as recently as 2011, reports of staffers kicking residents, striking them in the head, and forcing them into staged fights were reported in the local media. This demonstrated institutional breakdown in both the developmental centers and in the local, community-based service systems (Disability Rights California, 2003, 2012).

A dynamic tension exists between regulation and service delivery where transparency and accountability is concerned (Morrison, Shin, Wheeler, Kurtz, Miller, Jones, McDonald, Anderson, Callanan, & Rose, 2003). The regulation requires choice-making, protection, and evidence of an IPP, which serves as a legally enforceable contract entitling an availability of services as well as adequate funding and investment in services to actualize choice-making and options (Disability Rights California, 2012).

However, gaps persist between this provisional requirement and the system of delivery that allegedly establishes and allows for individual capability in decision-making (CDSA, 2011). Actualizing these services is complicated by a lack of clarity in systems and structures that attempt to support outcomes. To illustrate:

- Systems do not promote continuing education beyond high school special education, and systems for transitioning 18- to 22-year-olds from special education classes to adult programs fail to prepare individuals and their families to utilize available and accessible resources.

- Families are ill prepared for the legislative changes that affect the care and well being of their loved ones. This affects their understanding and knowledge of the need to speak with legislators (CDSA, 2011).
- The choices available to an individual, as well as the level of individual incorporation in those choices, are subjective.
- Concepts related to self-directed services do not allow for new ideologies or policy reform.
- Regional center caseloads continue to grow due to legislative cuts, causing case management to operate under outdated models, limiting the individualizing of cumulative services, and failing to demonstrate outcomes that incorporate the entirety of an individual's life and experience, rather than simply their disability.
- The regional center's utilization of preferred vendors for approved services may limit individual choice and negatively impact equitable access to individualized resources.
- Only one representative currently seeks to improve vendor understanding of systems and services; this representation is not provided by local regional centers, and is insufficient to support system reform.
- Partnerships between vendor agencies fail to manifest, causing perpetual competition for services.

- The lack of clarity of regulatory changes among regional centers fails to prepare vendors for budgetary cuts.
- The use of technology in providing direct support is limited, inhibiting freedom, necessitating continued and often-inconsistent staffing patterns, and increasing personal dependence on paid supports.
- Options for online learning that promote choice making remain largely unavailable.
- The continued operation of failing state developmental centers has a negative fiscal impact on the community-based programs serving individuals with autism and related developmental disabilities post-discharge.
- State developmental centers and the regional centers of California have not yet changed and integrated budgets to promote community development, supports, transitions, and integration.
- The ability to improve services to address population needs is delayed by regional center approvals.
- Purchases of service reimbursement rates do not provide fiscal reimbursement at the rate required to sustain profitable business ventures.
- The Lanterman Developmental Disabilities Act is a fundamental entitlement that worked to improve the conditions in which individuals with ID/DD are treated, but it fails to address civil rights.
- The IPP is the only agreement that fosters recognition of continued independence and transition, but it fails to promote true choice.

- The Federal Rehabilitation Act of 1973, as well as regulations of the Department of Developmental Services, remains inconsistent in application.
- Relationships between the Legislative Analyst's Office, the Department of Finance, the Senate Office of Research, and the Center for Excellence are underdeveloped, contributing to delays and dysfunction in system reform.
- Fragmented services impede the achievement of outcomes, leaving communities ill prepared for the integration of persons with ID/DD.
- Employers are ill-prepared to incorporate the needs of the individual with the employers' business needs (CDSA, 2011).

The membership of California's Disabilities Services Association (CDSA, 2011) argued necessary revisions supporting these discrepancies should include:

- increased clarity and transparency from regional centers, as currently required by legislative trailer bill language that also requires promotion of individual choice, and
- local forums must consider models that have been proven to be effective in other states and regions.

It is argued that families are not consistently advised of their role in decision-making regarding progress and outcomes as reflected in the legal and binding contract referred to as the Individual Program Plan (CDSA, 2011). Another gap in the literature indicates that a holistic perspective is lacking. The IPP acknowledges the presence, soul, intellect, and emotion in terms of life quality (Rothman, 2010). Self-determined outcomes, according to the literature, include sustaining intimate relationships, accomplishing life goals, and enjoying a higher level of well being and self-acceptance. It is expected these core areas will lead to a high quality of emotional well being, health, and wellness.

The pervasive institutionalizing of persons served not only seeks to protect the community, but also to protect the individual from a perpetual exploitation of his or her weakness, immorality and unnatural behavior (Schweik, 2009). Supporting principles for integration require protection of the individual, support and encouragement, and a balance of the mind, body, spirit, and soul (Rothman, 2010). A departure from the problem-focused medical model of institutional care and treatment focuses on the person as an integrated whole. Despite regulations of services appearing aligned, systems remain disjointed due to inconsistent delivery (Carey, 2009).

When considering the ability of an individual to make free-will decisions, the following services, supports, and skills must be taken into account:

- Ability, financial or otherwise, to access equipment and supplies, including adaptive technology as necessary.
- The ability and willingness of the individual to self-represent and self-advocate
- Assistance or facilitation of self-representation
- Assessments, including results.
- Support in identifying, adapting, and remaining independently in a home on a long-term basis.
- Promotion of positive behavior
- Extinguishment of maladaptive behavior

- Childcare.
- Facilitation and support to access community resources
- Appropriate psychological services for the individual and their immediate supports
- Activities of daily living
- Development of and training on a 24-hour plan of support and response
- Development of voluntary natural supports.
- Education.
- Emergency and crisis intervention.
- Emergency housing.
- Promotion of relationship-building
- Additional supports for co-occurring medical or physical complications, including occupational and physical therapy.
- Education regarding, and protection of, civil and legal rights.
- Appropriate and specialized medical and dental care.
- Communication assistance as necessary, including speech therapy and adaptive technology.
- Technical assistance training.
- Transportation services.
- Training to utilize public transportation (DDS, 2008).

While varied services are required and available, individuals' knowledge of these resources remains limited; the actualization of programs and opportunities despite counterforce’s regulating providers is also questionable. Welfare & Institutions Code § 400 (1992 Amendment to the Lanterman Act) requires a person-centered approach to individualized program plans when participants have stated preferred interests and abilities (Disability Rights California, 2012).

Theoretically, funding has not been able to promote this concept because of agency limits to the provision of services available. Purchase of Service (POS) budgets is distributed by local regional centers; they have not consistently required providers to identify their specific support of methods to increase autonomy. Regulatory agencies also lack this specification, and have not distinguished expectations of outcomes between providers, individuals served, and funding structures (Fletcher, 2012).

Reduced funding allocation remains a constant threat, as services to individuals in need are often the first to be cut in a time of budgetary crisis (CDSA, 2012). Individuals served by the Department of Developmental Services have case-management services provided by local regional centers, which are obligated to provide or obtain services utilizing cost-resourceful sources. They must use all generic sources available, including those provided by other agencies not affiliated or funded by the center. Since 2004, age group variation in persons receiving regional center services has fluctuated widely. If an individual encounters local services that will not accommodate disability challenges, then he or she requires support from the center to access these services and supports (Disability Rights California, 2012).

While services and funding appear to be extensive, the need for services is also great and no documentation supports the need for self-determination beyond explicit standards for care and treatment. As of 2015, the governor of California has continued to propose budgetary cuts to health and human services. This proposal included more than $2 billion in cuts, and targeted MediCal programs, developmental services, in-home support services, and a complete elimination of caregiver resource centers (CDSA, 2012).

Lack of clarity persists in how the system intends to support its most vulnerable population in experiencing equity in the full range of social and personal opportunities available to those without disabilities. Budget shortfalls in the health and human services arena threaten hope for continued institutional closure and community integration (Carey, 2009). As of 2008, California served 3,025 persons in such institutions (Braddock et al.)

ID/DD are often a source of fear and shame (Wolfensberger, 1972). Stigmatization among neurotypical communities may be attributed to a lack of understanding and skills required to relate to this population. Education and the improvement of motor and sensory skills are utilized to promote the integration of individuals to their community.

The medical focus evolved from a concentration on the origins, status, and values of the management of education of individuals with disabilities (Rothman, 2010). Rather than focusing on the inherent qualities and potential of the individual, the inherent needs of the system took priority (Braddock et al., 2008). Habits and comfort levels created challenges when changes in practices and supports were proposed (Rothman, 2010).

The stigma of those with developmental disability continues, and leads to reflex-like rejection regardless of changes that have been made (Carey, 2009). Vulnerability of all individuals with disabilities is increased due to emotional and psychological experiences, as well as community factors (Ticoll, 1994). Intertwined with these elements are attitudes toward those with disability, which result in isolation, lack of access and opportunity, and decreased opportunities for social interaction. Perhaps most importantly but least discussed is a lack of control when an individual reports, discloses, or has evidence of abuse due to ineffective safeguards (DRC, 2003).

Preservation of equal access presents a predicament where disability is concerned. Management of state regulation and policy has potential to limit the person with a disability due to classification systems intended for homogenized groups (Mercer, 1973; Carey, 2009). The medical model postulates certain beliefs about people with disabilities that further socially disable the population (Rothman, 2010). The historical and contemporary viewpoint of disability as seen through this lens seeks to restore health and normality to individuals deemed pathological. These institutional practices, systems and structures weaken the population, promoting differences (Wolfensberger, 1975).

## Social Model

The social model may be viewed in terms of collective rank and performance among diverse social class, age, genders, and norms (Mercer, 1973; Rothman, 2010). The social system perspective is a status that is acquired and assigned based on behavioral manifestations of the person and applied by the culture (Wolfensberger, 1975). This shifts awareness to one’s capability.

Representations of superiority and inferiority are coupled with community integration concepts, including both biased and intentional factors (Adler, 1978; Vine & Hamilton, 2005). Life quality, as it applies personally or to another, is a manifestation of variables that include choice making. However, choices are viewed through the lens of the institutional model (Vine & Hamilton, 2005). Where the clinical model leads to an achieved status of the individual because of perceptions of incompetence, the social model establishes a status based on the individual's experienced world as a whole (Rothman, 2010). Social roles contribute to the interplay between interactions within one's environment and with society in general (Wolfensberger, 1975). Disability is not a social disease but rather an establishment through the environment in which it occurs.

There is an applied push-and-pull between approaches that emphasize structural and institutional barriers, and the attitudes and mechanisms actualizing them (Carey, 2009). Approaches are not merely an issue of attitude, bur rather outcomes resulting from shared beliefs that lead to fewer choice-making opportunities. Beyond the issue of self-determination, conditions that the individual must resolve include the basic essence of belonging to a community, including housing arrangements, employment, recreation, and leisure issues (Carey, 2009)

The quality of life and perceived value of one's environment are continually and mutually interactive and reactive (Rothman, 2010). The entirety of a community, rather than a specific individual, is responsible for improving the fit of societal reactions (Bertalanffy, 1968; Wolfensberger, 1995). Improvement validates interactions; consequences negatively impact processes (Bertalanffy, 1968).

The contemporary and collective configurations of the social framework tend to lean toward an imbalanced medical paradigm, evidenced by lack of access resulting in supposed diagnoses, labels, assumptions regarding roles, and limited availability of generic services and supports (CDSA, 2012). The act of labeling used extensively in the medical model (Rothman, 2010) occurs differently once in the community. The individual is forced into established constructs of which he or she is powerless; these roles are not limited to ID/DD, but include prescribed behaviors and individual expectations (Adler, 1978).

Inclusion in everyday activities is important for an individual's learning. The main feature of human growth and development is having meaningful interactions (Bronfenbrenner, 1999; Dunst, Bruder, Trivette, & Hamby, 2006). The barriers that prevent participation in everyday activities are the lens through which the social model of disability is viewed (Rothman, 2010); therefore, it is the society (Becker, 1963) that fails to take into consideration the impact of the environmental barriers produced.

Environmental factors associated with where people live and how they conduct their lives interact with personal factors, impacting human functioning. Personal factors are features that are not medically related, and include age, gender and coping methods (AIDD, 2010). The core problem of the social model does not rest with the person; rather, an individual's involvement in society is limited by their impairment and limitations (Rothman, 2010).

Physical, organizational, and attitudinal barriers in society lead to discriminatory behavior (Dewbury, et al., 2004). Discrimination, in order to be eliminated, would require a massive overhaul of the entire societal process.

Beyond the social and medical model, society could benefit from a model introduced by Tanya Titchkosky, which addresses both the social and medical models while countering them. This model suggests drawing meaning from disability rather than considering only the medical condition. If the disabled population was viewed in the same manner as “normal” society, the feeling of needing to exert control would be reduced. This model encourages discerning between differences that make a human unique, reducing preconceived notions of what is acceptable. Disability still exists, but differences are due to the nature surrounding humanity; humankind is aware of the aberrations in general terms applying to all individuals (Titchkosky, 2000)

Integration, which concerns geographical locations of individuals rather than institutionalized management, further supports the social model (Cummins & Lau, 2003). It is concerned with physical inclusion, as well as the presence of normalizing activities in close proximity to individuals.

Contingencies are associated with integration, which is often confused with objectifying the individual. Confusion remains regarding the idea that physical attendance in public is promoting the right of entry and therefore inclusion. Rather, inclusion is a feeling of belonging, as well as a sense of equity in access to resources and supports (Wolfensberger, 1975). Inclusion should not be confused with integration; politicians and service providers alike pay little attention to this area of need (Cummins & Lau, 2003).

Many people with a disability are not a part of their community. Paradoxically, individuals who experience challenging behavior receive opportunities for growth and development because of a response to the obvious inability to integrate (Vine & Hamilton, 2005). Challenging behavior may create opportunity for fewer choices while eliciting efforts to control or limit prospects available to join groups the individual is not currently a part of. For some, assistance in this area may be an example of a positive experiential outcome, but for many, this concept reinforces Becker's earlier concept of deviant behavior causing or forcing socially induced acceptance of an assigned role.

Barriers persist between service ideology and service actuality (Cummins & Lau, 2003). It is within these barriers that full integration is difficult to support. The closest contact between those with disability and those without tends to occur through paid persons or family members. While a service provider may promote choices and increased accommodation, their efforts to integrate do not recognize needs, desires, or dangers related to integration in real-time (Cummins & Lau, 2003). Further, the service provider does not bring with them tools for advocacy groups or lobbying efforts. In a supplementary study about community integration; integration was the hope of respondents but not actualized by an increase in friendships

There are ethical considerations involved in utilizing community exposure as a means to attract attention and shift perceptions (Cummins & Lau, 2003). This stark reality may be enough for the individual with a disability to merely mirror those power relationships that bring with them potential for conflict and harm.

Worthy of mention is the reference to the exaggerated use of resources found in the supported employment model. The idea behind supported employment is to provide opportunity and gainful living. A job coach is available throughout the individual's workday to ensure the person's success. It is not general practice to have a support person speak of our weaknesses, strengths, or failures to a supervisor, but this is a standard part of supported employment.

Agencies that provide the supported employment may benefit from the disabling conditions of the community and the individual. The employer is required to have systems in place to support employed members of the organization. The level of integration is evident when barriers in the workplace are reduced or eliminated, as required by the Americans with Disabilities Act (Cummins & Lau, 2003).

California uses a variety of indicators to measure true satisfaction. These measures include biological, social, psychological, cultural, and spiritual needs (Rothman, 2010 & Fletcher, 2012) of the individual. Submitting to the social model, it is evident that individuals with ID/DD are a part of our fiscal, environmental, and cultural civilization (Carey, 2009; Rothman, 2010).

Obstacles preventing individuals from fully participating in society reflect back on the community as a whole (Schweik, 2009). Many ideologies involving the social model involve sociological interests and explanatory accounts of social life (Dewsbury, et al., 2004).

While inclusion is essential, physical exposure is not sufficient for creating a sense of community. While physical integration provides access to contact with members of the community at large, it does not always occur through positive responses or outcomes. The intent of integration is to remove barriers and promote equality regardless of ability (Wolfensberger, 1983). Through this ideology one can identify personal lifestyle preferences and attain the means to manifest those them (Wolfensberger, 1975).

However, research indicates that increased social opportunities do not equate to increased well being and quality of life (Wolfensberger, 1975; Cummins & Lau, 2003).

Where the social model exists, the ability to change roles within an environment is modified depending on the need of the individual. A sense of stability for the individual is critical and should not be based on the needs of the practitioner, but, instead, should flow from varied situations as they present. Cummins and Lau (2003) further argue that participation in recreational opportunities does not equate to valued roles. In fact, rather than exposing an individual to larger events and activities, it may be beneficial to initially assist in the facilitation of smaller functions. Increasing opportunities to persist in a larger network may be beneficial in the future.

The medical and social models agree that a person's genetic attributes may increase the likelihood that he or she will be assigned a low-level status. Society will ultimately determine the status that an individual holds (Rothman, 2010). That is, the norms and mores of the culture will establish where an individual and his or her characteristics belong. If someone wishes to change the sociological perspective applied, that individual will need to change the social group of which he or she is a part (Mercer, 1973). Where ID/DD is concerned, the components of measurements, methods, and diagnoses are labeled; therefore, disability is a social construct (Manion & Beersani, 1987). It is subject to exploitation by redefining the impression of what is customary.

Disability as a social construct implies notions of superiority and inferiority; ultimately, it is a matter of exploiting vulnerable persons. Unless integration encompasses the ideological sense of community that ought to be readily obtainable, encouraging, and reliable, true assimilation only transpires through the containment of the home (Cummins & Lau, 2003). The social model may be viewed as an interface with a disability where construction and accountability are a collective responsibility (Dewsbury, et al. 2004). However, the medical model necessitates expert-driven affiliations and an endeavor to restore to health or alleviate problems occurring in the individual.

Disability history is wrought with weighty tensions on the notions of science and body (Rothman, 2010). In particular, archives illuminate value structures in action and exploit disability identities that transform over time. Social constructivists perceive disability as a corollary to the environment (Rothman, 2010). The medical model uses health as the indicator for social status. Individuals in poor health are regarded as having a diminished capacity for self-sufficiency, role accomplishment, and making noteworthy contributions to society (Moore, Schumacher, Kahana, & Kahana, 2004). Physical limitations tend to be classified limitation for all persons involved. When the medical model groups syndromes into a cluster for examination, it assumes that this is the most effective model for the individual (Wolfensberger, 1975; Cummins & Lau, 2003). The danger of using only one model equates to assumptions solely of a biological nature.

Ethical concerns must \be taken into consideration. Where disability is concerned, labeling carries a potential for discrimination and violation of rights (Carey, 2009). The medical model may be the most influential model for determining how people are treated. The limitations of the medical model are fundamental to outcomes of poor self-esteem and identity, and choices in housing, employment, and education (Rothman, 2010). While these issues are not directly impacted by disability, they indirectly affect one’s access. For example, historical developments attributed to social constructs of disability persist and influence not only individuals, but also communities, movements, and politics (Carey, 2009; Rothman, 2010). Further, this conceptualization of disability promotes awareness of differences and deficits and considers society the locus of disability. As the center of disability, society structures access, marginalizes groups, stereotypes individuals, and defines the social order.

Early identifiers, such as taking more time to complete tasks, requiring extra support, or appearing disabled, unhealthy, or in poor health, highlight gaps between definitions of optimal well being and health status (Cummins & Lau, 2003). Characterizations for intellectual and developmental disabilities tend to have a biological basis (Mercer, 1973), whether it is an unremitting condition or an untreatable disease. Incessant endeavors to restore health through nutrition, manipulation of the senses, exercise and drug therapy have prevailed (Mercer, 1973). Exploitation of reproduction and standardized tests demonstrated that those considered abnormal have that status validated by a medical model that considers the person to be the source of inability or incapable of reciprocating social cues (Kahana, et al., 2004).

When behavior is quantifiably studied, it demonstrates only systematic patterns that conform to social and political psychometric evaluations of the culture (Mercer, 1973). Focusing attention on public structures, however, perpetuates limitations for individuals to access their potential, needed, resources and services (Rothman, 2010). Support of social need requires the understanding of therapeutic systems (Rothman, 2005). In contrast, social labels play a noteworthy role in how the individual evolves, and the manner in which accepting these labels undermines personal value (Kahana, et al., 2004). Implying the person is lacking and incapable, coupled with the individual's skill at having desires and needs met, results in conflicting outcomes (Carey, 2009).

Prejudiced assessments of the quality of life are multidimensional and unreliable (Emerson et al., 2004). External assessments of one's health through friends, physicians, or family are often focused on physical health (Kahana, et al., 2004). However, a typical person does not rate well-being expressly through health aspects, but, instead, in terms of subjective supports, behavior, and attitudes (Emerson et al., 2004).

Little information exists about the impact of social well being when an individual with disabilities accepts the label assigned to him or her. When impairments are viewed as disability, there is greater potential for social exclusion from activities of daily living. Disability, therefore, is not the same as infirmity or pitiable health. Instead, disability is a social attribute of varied characteristics of persons with obvious substantial impairments (Rothman, 2010). As a result, society perceives an inability to accomplish goals, will avoid those marked as abnormal, and discriminates against those whose value appears to be less worthy.

True satisfaction is a core value but requires systems and individuals becoming clear in identifying needs and values. How an individual lives to affirm those values or gratify those needs is contingent on systems and structures providing support (Reiss, 2010).

## Perceptions of Disability as Deviant

Social constructs of the disabled population are referenced in various terms historically and include labels as subhuman, menaces, and dreadful objects of pity, diseased organisms, and objects of ridicule (Wolfensberger, 1974, p. 12). These terms and systems marginalize vulnerable populations and categorize them into a deviant class. These terms have also served the purpose of properly organizing virtue and disgust. The process of determining support outcomes results from the therapeutic and community design, whether valid or considered so. Deformity thrives as a type, but conventional standards threaten it (Schweik, 2009).

Either a person is perceived as deviant, wrongly accused of the deviant behavior, innately deviant, or deviant incognito (Becker, 1963). When mainstream society positions a group into this category that group will be marginalized and will either respond obediently through coercion, or fail to survive (Becker, 1963).

Moderating behavior occurs through incentives or penalties and is vital to administration (Haber & Smith, 1971). Approaches for commonality determine standards of motivation and normalization. Conforming does not determine one’s value, but does reinforce the culture’s willingness to accept transition and integration.

Collective standards between human rights and to whom those rights belong impact self-esteem and life quality (Carey, 2009) and reinforce systems that support subjective and acceptable behavior. While this may be required where integration is concerned, the uniformity of systems challenges power differentials and limits access to options (Wolfensberger, 1974). The manner in which a person with a disability internalizes this information in his or her quest to find a niche creates the cultural polarity. Becker (1963) succinctly describes his interpretation of persons as outsiders:

> …social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to certain individuals and labeling them as outsiders. From this point of view, deviance is not an attribute of the act the person commits, but rather a consequence of the utilization another's' rules and sanctions to an "offender." The deviant is one to whom that label has successfully been applied; deviant behavior is behavior that people so label. (p. 9).

When ugliness is applied to people with physical and mental disabilities, attention is heightened by words such as repulsive, grotesque, dirty, and slovenly (Schweik, 2009). It follows that accusations of moral and mental failure will be made as well (Schweik, 2009). Clearly, social and cultural constructs serve to identify forms of deviance communicated through the perception of those doing the labeling. The promise of disability-free neighborhoods was a historical ideal, and to achieve this, individuals were segregated in asylums or isolated in convalescent homes (Noll, 1995; Schweik, 2009).

Those labeled as intellectually and developmentally disabled begin to assume an identity of incompetence when events surrounding their restrictions are met with negative responses and restrictions (Moore, Schumacher, Kahana, & Kahana, 2004). This false identity is the result of an expectation of failure. The resulting and expected behavior becomes acceptable because the outcomes are preconceived (Becker, 1963). Until a person is placed into an achieved position, he or she lays prey to the interests of the collective (Mercer, 1973).

Society must agree upon a collective and, at times, unspoken knowledge of normalcy through methods that establish the extent violations of customs, traditions, or standards will be endured. Social systems are influenced by the memories, thoughts, and capacities of those occupying the power status (Adler, 1978; Mercer, 1973). Contingent to deviance is the norms that balance it. Individuals with disabilities are at a much higher risk for substance abuse, poverty, decreased social interaction leading to isolation, uncontrolled pain, and a lack of medical interventions than other individuals in their same normative groups (Haber & Smith, 1971).

Stabilizing events challenge the individual labeled as deviant because they perpetually obstruct the ability to move between alternatives (Haber & Smith). The individual with disabilities may seek to engage in various roles, yet will continue to maintain his or her position (Carey, 2009, & Schweik, 2009). When power is persistently assessed in all activities, it is particularly difficult for the person as he or she may incorporate that position as a part of an identity image (Haber & Smith). Hazards associated with assumed deviance merely increase utilization of the vulnerability and reinforce responses suited. Eventually, the person is diminished to the point of impairment and cast aside by stigma and inferiority (Carey, 2009; Fletcher, 2012; Taylor, 1989).

Connotations and shame associated with perceived ID/DD not only pertain to stigmatizing experiences but also become personal for the individual labeled (Wolfensberger, 1972; Taylor, 1989). Accordingly, expectations for fulfilling the atypical role encompass the individual and elicit a self-fulfilling prophecy originally suggested by those defining the role. Deviance is not a parallel to stigmatization though they may act symbiotically. For those with ID/DD, established norms may be violated simply because of social capacity limitations (Titchkosky, 2000). Stigmatization represents societal sensitivities and marginalization. This devaluation is not a characteristic of the individual, but is rather due to the personality and divergence of the observer (Becker, 1963; Wolfensberger, 1983; Titchkosky, 2000).

Where disability is concerned, normalization argues for a relationship between role structures and relationships that focuses on different forms of deviance, conformity, and regulation (Haber & Smith, 1971). Life is meaningless when true value and support from significant others are replaced by shame and loss (Reiss, 2010).

## Disability Constructs

American citizenship, as it pertains to individuals with ID/DD, is perceived as a failure of the theoretical and ideological dimensions of politics (Carey, 2009; Fitch, 2002). Citizenship should not entail inferiority but empowerment. Normative concepts suggest hard work and political affiliation increase an individual’s understanding and processing of information to communicate both expressively and receptively. Further, these concepts contribute to economic and social needs and work to enact or practice one’s individual rights (Carey, 2009). Self-determination, therefore, is a standard common to the collectively able. However, for the individual with ID/DD, the extent of being allowed access to basic rights is limited (Carey, 2009).

The American doctrine is based on rights established by the superior (Adler, 1978), which runs contrary to special differences posed by the disabled (Carey, 2009). To deprive one of rights fails to satisfy the established protections underscoring the individual’s vulnerability (Rothman, 2010). There are assumptions of incompetence of the individual, and perceptions about an inability to perform potential. Current systems suggest that disability is not just a symptom occurring within an individual; but, instead, a social construct that influences organizations, ideologies, and communications (Carey, 2009; Fitch, 2002). Marginalization occurs through interactions between those with and those without disabilities and tends to perpetuate differences between people.

These differences highlight what is normal and socially acceptable. Disability becomes an acceptable basis for exclusion and proffers indications for the denial of rights to those deemed unable to understand. Revoking individual rights provides the opportunity to replace them with entitlements (Carey, 2009).

Institutionalization was another concept that hedged promises for protection, yet clear segregation and marginalization was evident (Carey, 2009). Restrictions were apparent through enforced sterilization, exclusion from public education, and a denial of rights based on one’s diagnosis or ability (DRC, 2012). Limited accommodations are available to exercise rights that present and sustain continued dependence on external systems (Carey, 2009). Rights are important because people should have a voice in issues affecting them and the treatment that they receive.

Stigmatization becomes an aspect of one's identity (Becker, 1963), and while it is common for those with a disability to have experienced disturbing outcomes, those outcomes force recognition of differences. Discernment of difference is evident in services or lack thereof because of the dominance of compulsory institutionalized thinking (Carey, 2009). It is uncertain how one with a disability may participate equally in mainstream society when ready access to resources, including transportation, day programs, and education, is not available (CDSA, 2012).

Unqualified analyses of symptoms undermine empowerment while providing potentially unjust or incorrect classification. Individuals with ID/DD are, at least utilizing the wording of the laws, considered to be human beings, although perceived to deviate from accepted social conventions (Titchkosky, 2000). This known deviance supports the rationalization of denying basic human rights (Carey, 2009). The literature describes eugenics, forced sterilization, and aversive treatment methods as empirical approaches.

Conventional standards toward this population have led to assumptions and precursors for criminal activity. While this prediction may result from the individual's inability to understand legal systems (Carey, 2009) factors contributing to this construct are influenced by institutional epidemiology (Mercer, 1973). Many assumptions are based on visual representations of impairment that are perceived to be synonymous with dependence (Green, 2007). Acclimating to frameworks associated with medical models denies the opportunity for growth and development in social systems (Brendtro, Mitchell, & Doncaster, 2011).

The 20th century brought with it an acceptance of people with disabilities as citizens. Deinstitutionalization, public education, and the Bill of Rights were revisited to include opportunities made available in the least restrictive environment. These changes led to an awareness of civil rights, which legislation would eventually guarantee. The Americans with Disabilities Act (ADA) also established protections for vulnerable persons deemed unable to care for themselves. However, individuals remain limited in the ability to enter contracts, but are forced to endure caps to state and federal assistance. The outside control impedes one’s ability to contribute. Overtures of resistance remain in community willingness to permit individuals with a disability to contribute wholly (Carey, 2009).

The ability for an individual with ID/DD to be able to contribute to their community is questionable under these paradigms. Concepts that support personal choices endeavor to reverse devaluation and redefine issues of deviance or oppression (Wolfensberger, 1974). Beyond opportunities for choice are policies, social movements, and theoretical arguments. Surpassing one’s biological conditions leads to different understandings of the cultural and social expectations associated with disability constructs. Earlier in this analysis, conditions associated with an individual’s genetic or mental capacity were the foundation for supporting inability. The analysis of disability as pathology demonstrates the negative effects of labeling, segregation, and a potential for opportunity.

Once groups are separated, the structure of the social system becomes apparent. The root of disability as a biological or social aspect places individuals into a variety of labels for which there is no precise designation (Carey, 2009; Rothman, 2010). The process of labeling establishes a social order that clarifies a problem between normal and abnormal boundaries (Fitch, 2002). Beyond classification is the issue of rights and frameworks that establish who is deserving of what (Carey, 2009; Schweik, 2009).

The medical model occupies a central function in maintaining the suppression of autonomy and independence. Autonomy failure is evident when one attempts to enter into contracts, an unlikely endeavor for those with biological challenges (Carey, 2009). When a group is perceived as weak or inferior, society determines the degree of independence an individual will be granted. The social collective requires devalued groups to maintain policies (Wolfensberger, 2001). In fact, if these groups are not clearly present, society will create them (Carey, 2009).

The manner in which services and systems are coordinated creates an image that applies to devalued persons and the mode in which protections are afforded. Modifications to dynamics that perpetuate constructs and challenges models of dominance require re-evaluation (Fitch, 2002). Concepts supporting ideas for self-determination and inclusivity of the person as a whole must recognize potential. Current models identify individuals as disabled recipients of care and fail to recognize their disability as being interconnected with self-determination and inclusivity (Carey, 2009). The fixation on one's lack of abilities opposes intermingling, participation, creation, and maintaining a reciprocally interconnected collective.

To help individuals experience a better quality of life, systems supporting their most important human needs are essential. Life quality includes identifying basic needs and supporting activities that recognize personal preference (Reiss, 2010, p. 13).

## Adaptive Behavior

Intelligence standards, developmental processes, the ability to maintain and synthesize information, and uniformity in potential and perspectives are a social reality

(Carey, 2009). This perspective allows growth and development for all persons. Humankind can adapt to diverse experiences, histories, and boundaries, yet regulatory processes that surmise failure as outcomes deny an ideological approach (Rothman, 2010). Darwinist methods and the elimination of populations laid the foundation for such procedures (Rothman, 2010).

The conditional role relationships for individuals with impaired capacities are limited because they will not be able to sustain the skills required within the system for competition (Adler, 1978). As a result, they must either adapt or be replaced (Becker, 1963; Mercer, 1973). Once replacement occurs, individuals with a disability will interpret their value as one of displacement or expulsion (Mercer, 1973; Wolfensberger, 1975).

Commonly, there is a standard that values dignity, security, autonomy and individuality (Carey, 2009; Schweik, 2009). This recognition counters interdependence encountered by those with disabilities that renders them nearly helpless in circumstances where basic resources are available, and diversity is beneficial.

The Universal Declaration of Human Rights stipulated that freedom and equality shall be made available to all persons, and individuals retain the ability to embrace life, liberty, integrity, freedom of thought, self-expression, and assembly. Further, it includes opportunities for education, health, justice, security in government, employment, and living (Carey, 2009). Any denial or apprehension of basic rights challenges inclusiveness. The enforcement of these rights necessitates legal and governmental involvement for resources and support. It is under the same system that vulnerable populations are subjected to intensified segregation and stigmatization (Becker, 1963; Carey, 2009;

Mercer, 1973; Wolfensberger, 1974). Principles for inclusion generate exclusion. Disability, however, serves as an operating loss perpetuated by the standards grounded in the medical model (Carey, 2009; Fletcher, 2012; Rothman, 2010).

Standards grounded in the medical model perpetuate difficulty in adapting social service processes and standards to allow for independence of the individual. The processes of regulating services and access to those services consequently become the responsibility of professionals. To support an individual's potential for enhanced quality of life, understanding, negotiation, and recognition of the circumstances he or she is bound to be required. Clinical judgment, when contingent on intuitive, subjective evaluation, is a barrier to accessing the political, civil and social rights of those with a disability (Carey, 2009).

Systems are ambiguous. Limited opportunities do not benefit reciprocal relationships (Bertalanffy, 1968). The benefit of a reciprocal relationship does not promote segregation or the rationalization of habilitation of vulnerable groups to isolated and controlled cultures of known deviance (Wolfensberger, 2001). When groups of people with disabilities are congregated, people learn less because concepts for learning are generalized (Wolfensberger, 2001). Adaptive behavior is, in a primitive sense, an element in which social skills are expanded upon, and the individual learns to cope with situations where peer-related opportunities arise (Mercer, 1973). However, this, too, is limited because artificial role-play compromises adaptation to nature. An opportunity for shaping identity through interaction, negotiation, and use in settings where individual rights may be practiced, understood, and considered enforceable resources is necessary to promote skill building(Carey, 2009). Adaptation requires eliminating labeling groups to remove patterns that desensitize social mentalities (Wolfensberger, 2001).

The importance of categorical social status is not comparable to practical power and social relations (Carey, 2009). The manner in which categorical social statuses led to the eugenics movement and sterilization was purported to help those too challenged to care for and support their children (Rothman, 2010). The oppression of those with ID/DD simply ignored their needs in social settings. The systematic context for inclusion requires changing practical power and social relations rather than changing the individual (Rothman, 2010).

Segregation creates more uncertainty in policies, though disability obligations remain embedded in unequal relations (Carey, 2009). Customary and traditional concepts are not only based on theories of injustice and discrimination but also stereotypical messages.

Concepts related to inclusion argue for conformity (Carey, 2009), but individuals with ID/DD require social supports and relational options that do not necessarily match typical society expressions. Without adequate adaptive supports, people with ID/DD remain excluded from opportunities to contribute to their communities.

The Americans with Disabilities Act (ADA) challenges social perspectives in considering individuals with ID/DD valuable and contributing members of society. A first step toward promoting change in society was the elimination of inaccessible environments. Policy change has impacted the perspective that necessitated changing the person versus changing social and economic contexts (Carey, 2009; Fletcher, 2012).

One must achieve a degree of disability for accommodations to be relevant; without meeting specified criteria, the ADA does not require assistance to be provided. Without an accurate diagnosis, full integration continues to be stifled (Carey, 2009; Mercer, 1973; Schweik, 2009). A qualified diagnostician is a required to determine eligibility for benefits. However, the process for certification and labeling further socially exploits the person with ID/DD (Becker, 1963; Mercer, 1973).

## Community Life and ID/DD

Numerous people with ID/DD are placed in settings with others having similar diagnoses or applied labels (Wolfensberger, 1994). Historically, these settings were in distressed dwellings and encompassed torturous habitation (DRC, 2012, & Noll, 1995). The U.S. Supreme Court's Olmstead decision in 1999 and the backing of the ADA represented a milestone for individuals with ID/DD

Subject to the provisions Title II § 202 (Discrimination) ADA:

> No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity Americans with Disabilities Act of 1900, 42, U.S.C.A § 12101 et seq. (West, 1993).

A ruling against the continuous and unnecessary institutionalization of individuals with ID/DD prompted a shift to the least restrictive environment and a reevaluation of inclusion (Carey, 2009). However, the Olmstead decision and related laws were not adequately prepared for increased costs and identification of system weaknesses, nor did they provide methods for individual choice.

Challenges to the medical model were met with social ideologies for sorting and labeling, as well as various approaches to care. Social structures reinforced concepts that would transform people with ID/DD into contributing citizens (Carey, 2009; Wolfensberger, 1975). The idea that a person with ID/DD could participate meaningfully in the community suggested they could also have involvement in their own care. Rehabilitation of the person with ID/DD challenged the deviance perspectives of eugenicists (Carey, 2009).

If the persons with ID/DD were to be viewed as citizens, then basic civil rights were essential. Civil rights include concepts related to development, normalization, equity, and access (DRC, 2012). The civil rights movement further assumed society will treat each person with respect and dignity. However, fragmented procedural and service efforts continue to be a concern that negatively impacts system-wide implementation.

Relocation from an institutional setting to the local community is challenged by opportunities for housing, money management, education, employment and self-determination (Wolfensberger, 1983, & CDSA, 2012). Problems associated within a controlled, institutionalized environment, such as congregated placement, are equally concerning in a mainstream setting that may place individuals into other segregated areas, such as day programs and group homes, that could be similarly oppressing (Bell, Eells, & Dodder, 2002).

Problems of equality are perpetuated by social and clinical perspectives of the person with ID/DD, particularly if both models identify the individual as abnormal (Yong, 2007). It has been suggested that rehabilitative efforts will decrease reliance on public assistance. However, reliance on systems and services continue to be evident in congregated settings (Carey, 2009). Regulatory procedure may be a reflex of institutional habit that constrains full participation in one's community.

The Rehabilitation Act of 1973 (Sec. 504) prohibits segregation of individuals with a physical or mental disability and is consistent with the 1964 Civil Rights Act. However, social perceptions and habilitative environments continue to separate individuals with disability despite these decisions (Reiss, 2010).

## Summary

The literature review for this study found empirical evidence supporting the idea that the social world of individuals with ID/DD is constructed by interactions between those with and without a disability. It evaluated notions pertaining to theoretical foundations, key concepts and service models. The literature suggests that both the medical model and the social model are comprised of labels and segregation. The models are challenged by concepts related to normalization, pathology and deviance of the person with ID/DD. Despite the increase in community inclusion service models continue to perpetuate the congregation of people with ID/DD.

While many researchers attempt to evaluate individuals with ID/DD in quantitative terms, it is essential to explore the qualitative experience of the person

(Emerson et al., 2004). Integration and inclusion emerge from a variety of sources, both social and personal.

Social proximity and the actualization of self-determination are related to this study. According to the literature, gaps in the overall system involve power, inferiority, superiority, status, and inclusion. When the ADA was enacted, it was initially based on the Civil Rights Act of 1964 and the Rehabilitation Act, and offered alternative hope for equality also encouraged by the Lanterman Developmental Disabilities Act in California.

The core elements upon which this study develops focus on the ideas, concepts, and assumptions related to actualizing autonomy in the California disability system. Disability and deviance do not exist on their own, but rather as part of a subjective awareness established by ideas and interpretations, arranged for and by persons who may not be affected by ID/DD.

Chapter 3 presents the research design and rationale, related research questions, the sampling strategy, and participant selection. It also discusses the materials and instruments, data collection procedures, data analysis procedures and evidence of quality.

# Chapter 3: Research Method

## Introduction

California disability policy requires recipients to be treated as independent individuals, while simultaneously considering them dependent on the delivered services and lacking self-determination in regard to those services. Neither the California Department of Developmental Services nor community vendor groups have established a unified and systematic review of client self-determination in practice. The purpose of this study was to explore the experience of adults with ID/DD working toward self-determination.

This chapter includes discussion of the chosen research methodological analysis, instrumentation, and the selection of the participants. In addition, data collection processes, limitations and delimitations, and assumptions are discussed, as well as ethical assurances. A summary of the overall research methodology brings this chapter to a close.

## Research Design and Rationale

This study was of a phenomenological nature, designed to provide a description, exploration, and understanding of life quality for adults with ID/DD working toward self-determination in a West Coast state service delivery system. Language, culture, and narrative were supporting resources for this study. Meaning-making requires narrative, discourse, and metaphor, and occurs in certain contexts, including interviews and the setting described. This inquiry was, in part, to understand the cultural position and experiential claims of the individuals. The focus of this study was consistent with the phenomenological design, as it applied hermeneutic, idiographic, and contextual interpretation to allow a rich description of the lived experience (Kafle, 2011). Experience was the topic, and the individual and his or her meanings were the units of analysis (Smith, Flowers, & Larkin, 2009). This study was concerned with the individual experience, which is detailed, explored and collaborative. The focus on the actual components of human life was chosen in an effort to enrich the development of larger systems in the future.

Existing research literature did not explore the concept of self-determination for individuals with ID/DD receiving services in California; rather, much research focused on lack of self-sufficiency. It is expected that this study will provide basic knowledge of self-determination.

Other qualitative designs were not used due to a need for certain information that may have become blurred utilizing other methodologies. For example, a case study would provide an intense analysis of an individual, unit, or phenomena, but data may not be generalized to a larger population. An ethnographic study would provide the social-cultural lens through which data may be interpreted, but requires a point of view of an insider to the culture of study. For purposes of this study, an ethnographic study may limit an understanding of the hidden meanings of how an individual orients and questions life experiences (Kafle, 2011). A basic interpretative qualitative study would also use an inductive strategy, interview process, and document analysis to determine how participants make meaning out of a phenomenon, but may limit the complexity of understanding, meaning, and experience of the participants. A phenomenological approach helped to show how individuals with ID/DD perceive self-determination amid existing service systems and structures. The phenomenological approach allowed me to intuit and see phenomenon from the perspective of those who have experienced it (Englander, 2012). Using this method, data could be clustered into themes, examined from multiple perspectives, and the descriptions of the phenomena constructed.

Self-determination is the central phenomenon of this study, and billions of dollars have been spent to construct systems used for determining what techniques are most likely to succeed. Accordingly, the concept of self-determination tends to be measured by life quality outcomes.

## Research Questions

This study addressed the overall question: What are the self-determined experiences of individuals with ID/DD receiving services in the state of California, and how are those experiences actualized? There were three main sub-questions:

1. What are the perceived barriers to achieving independence through self-determination efforts in systems provided in California?
2. What are the perceived opportunities to achieving independence and self-determination by participating in California programs?
3. What are the perceived ways that service delivery in California can promote efforts to increase self-determined opportunities?

## Sampling Strategy and Participant Selection

The agency selected is a not-for-profit service provider vendor operating to serve adults with ID/DD, located in an urban area. Criteria for inclusion in the study included the following: (a) the agency should provide adult day care services, and (b) be vendorized as a licensed facility and funded through the local regional center.

An initial request was sent to the administrative head of the organization to determine interest for this study to take place. He served as the gatekeeper who had access to the Client Development Evaluation Report (CDER), which identifies individuals by number and diagnoses. The administrative head's involvement was limited to ensuring data supported the participant as being qualified to partake in the research, and eliminated inadvertent sharing of additional confidential information in the individual's file.

In total, eight individuals were selected to participate in interviews, with an additional three voluntary participants for backup. Interviews lasted for up to one hour per participant. The participants were men and women diagnosed with ID/DD as indicated by the CDER, a diagnostic tool used by the regional center. The CDER data is suitable for assessing placement, effectiveness of programming, planning and prevention, and resource development. It is comprehensive in its summary of the types, etiologies, and levels of severity of primary disabilities, as well as the impact the disabilities may have on programming (McCreary, Stanislaw, & Boucher, 2005). For operational purposes, data are used in coordination efforts by the regional center and the Interdisciplinary Team (IDT) to assess individual clients' capabilities, needs, and conditions that impede progress. For this study, participants were capable of communicating effectively, had attended the adult day care facility for at least one year, and ranged from 18 to 65 years of age (McCreary et al., 2005).

An initial individual meeting was conducted at the adult day care facility in order to meet with respondents, determine the extent of their involvement, and clarify the aim and goals of the study. Any member meeting the initial criteria who showed interest in the study was informed of the consent procedure.

The men and women who were involved in the study signed consents after they were deemed to be unconserved legal adults and had their understanding of the research and interview process assessed. During the consent process, further permission for audio recording was obtained.

The purposeful sampling method selected was utilized to obtain specific insights into phenomena explored by this interpretive study; it was necessary that the individuals selected, regardless of age, disability, and participation in the service delivery system, have experience or knowledge of the topic under study. Care was taken in the recruitment process to avoid statements that could be interpreted as coercive. The voluntary nature of participation was emphasized, including terminating the interview at any time for any reason.

## Materials and Instruments

Semi-structured interviews consisting of 14 questions I produced were used to recognize and understand the effectiveness of current practices on self-determination as interpreted via the experience of service recipients. These interviews provided feedback aspects of program inputs, activities, outputs, outcomes, and impacts, assisted with understanding the views of the participants and how the program was perceived to meet self-determination needs. Due to the semi-structured nature of the interview, participants received similar, but not identical, open-ended questions. A small digital audio recorder was used and those consenting to the audio recording were told they could listen to the recording after the completion of transcription. The digital audio recording was downloaded onto a laptop computer, which provided clarity in transcription.

After the completion of the consent process, including that for audio recording, I verified understanding of previously recorded points with the participants. A member-checking session was held immediately following each interview to address questions; this process involved the sharing of my interpretations. Upon approval of the research, study results were shared with participants and other relevant stakeholders. In order to preserve anonymity, all names of participants were altered when shared with those outside of the immediate research team.

## Data Collection Procedures

A priority of the research was to build trust at the outset of the interview process; this was accomplished via my understanding of the cultural contexts of the people and services being queried. Questions were designed to be clear, understandable, and inoffensive, with the ultimate goal being to gather the participant's unaltered description of their experience (Ulin, Robinson, & Tolley, 2005).

All interviews were transcribed by me. The semi-structured nature of the interview allowed for flexibility in interviewing, modifying or altering questions to accommodate barriers in verbal communication or cognitive understanding of respondents. These modifications included asking questions in differing order or reframing the questions in simpler statements. Upon completion, a structured member-checking procedure was utilized.

## Data Analysis Procedures

Information gathered and obtained from participants was focused on understanding the meaning of descriptions provided. Collective and individual themes were noted, as were emphases on particular words, areas where a speaker may pause or begin to speak rapidly, and the environment and conditions. Statements were arranged into groups in a preliminary manner, taking into account categories or groupings suggested by participants as well as set categories formed based on information obtained earlier.

Data aggregation included the development of subcategories to allow identification of key points that were not originally recognized during the primary coding process, such as subtle, nonverbal points, clarified ambiguities, and emerging themes. .

The data analysis process endeavored to recognize patterns, themes, and meaningful categories as communicated by the study's research questions. A systematic approach to data analysis included what was known, what needed to be known, and the overarching research question. Data was reviewed, analyzed and interpreted after interviews, and foundational themes were established to commence coding activities. Raw data were classified and formatted according to the conceptual framework to synthesize and interpret the information. A search for patterns, emerging themes and potential codes was conducted according to concepts gained from the literature (Babbie, 2010)

This process allowed continued investigation, questioning, and analyzing of participants' narrative responses of their experiences. For this study, data analysis included *NVivo* qualitative analysis software to evaluate transcripts. All information was typed into a Word document before being inputted into a standardized Excel worksheet. The analysis identified themes related to the participants' experiences and perspectives about the effectiveness of current practices as they relate to self-determination.

## Evidence of Quality

Validity and trustworthiness of data was ensured via monitoring potential effectiveness problems after ensuring that the methodology used within the study was the most appropriate to answer the  research questions. Careful administration of research as indicated in the design rendered extra compensation unnecessary, and ensured respondents were not demoralized by their participation (Babbie, 2010).

This phenomenological research endeavored to analyze a shared experience and problem in order to improve practices and policies (Creswell, 2007). Meaningful statements and themes were used to produce a description of the participants' experience. In order to ensure validity, a concept of measuring responses accurately, the participant's responses were interpreted at face value, regardless of my knowledge of issues. The use of a semi-structured interview and member-checking ensured reliability, that the same information or results would be obtained if the study was repeated (Babbie, 2010).

The design of this study recognized rigor and sophistication in its approach to the qualitative inquiry (Finlay, 2009). Rigor was also achieved through comprehensive data collection, multiple levels of coding analysis, and member checking (Finlay, 2009).

To improve transferability, authenticity, and responsibility of this study, a member-checking session, allowing for opportunities to address questions and process data, occurred immediately following interviews. Member-checking involved sharing interpretations with the participant and asking for feedback (Englander, 2012). This process endeavored to confirm exactness and validity of the concrete data and its interpretation.

Individual interviews were crucial to this phenomenological study. To get a clear view of the complex issues, in-depth analysis and understanding was required in order to link concepts and provide an exhaustive research. Distortion in research influence was counteracted by the self-selection of participants.

This study comprised a rich description of the question to better understand the meaning of self-determination in terms of norms, mores, values, attitudes, and concepts. An interpretive analysis to demonstrate theoretical assumptions was involved, and reliable external validity was encouraged in order to develop potential future policy and procedures. Despite the potential for conflicting themes and answers, reliability remains high. It is possible to imagine these data could be transferred to the community as a whole, as the study encapsulates the diversity of individuals with ID/DD in California, understanding multiple realities interplayed between personal interaction and perceptions.

## The Role of the Researcher

The qualitative research demonstrated that theory, methods, and analyses used could be applied to both scholarly information and the self. As such, my primary role was to remain unobtrusive and minimally involved in order to avoid undue influence, while asking questions such as when, why, how, and under what circumstances the query would impart positive outcomes for this vulnerable population. My experience, education, and professional background of allowed for understanding the agency's paradigm while collecting and interpreting data. I attempted to remain unbiased and open to multiple realities in order to increase awareness and understanding while offering value conclusions to the field of ID/DD in California.

My experience includes participation in interest groups related to legislative and other decisions made on behalf of the ID/DD population in California. Further, I currently serve as the California state director of a national organization serving individuals with cognitive and physical disabilities. I am interested in human integrity, equal opportunity, and individual rights, which could create biases in exploring systems that move away from problem-centered models of service delivery toward functional models where the individual chooses his or her daily life patterns.

I have provided services to individuals with ID/DD in California for more than 20 years, in the process developing professional relations with other leaders in the sector and industry. These bonds and commonality of visions will allow for further explorations of the field of industry. However, to avoid potential conflict of interest, I chose not to recruit individuals served by her current employer for this research.

My professional experience in the field, literature review, and collaboration and conference with other leaders in the field allowed for theoretical consideration, or the ability to provide insight and meaning, capacity for understanding, and the ability to separate pertinent and less-pertinent information. I endeavored to create a naturalistic inquiry, remaining responsive to cues to interact while simultaneously collecting data, providing immediate feedback, and requesting confirmation of information.

## Informed Consent and Ethical Considerations

Participants each reviewed and signed a consent form that included a complete overview of the research endeavor as part of IRB tradition. Informed consent disclosed to subjects the role, procedures, time commitment, risks, and benefits of the study, including confidentiality measures.

For this study, risk referred mainly to the potential for exploitation of this vulnerable population, including potential limitations to access of services, though there was a concern of physical exhaustion as well. This study preserved the confidentiality of the organization, as well as the participant's identity, and omitted details that could endanger the participant's safety. Consent documents that link participants to the research and remain locked in a cabinet for a period of five years (Ulin, Robinson, & Tolley, 2005). Participant risk was monitored, with each individual having the option to cease participation at any time. Respondents were advised of my requirement to report suspected abuse, neglect, or criminality to appropriate staff and administrators of the facility, as well as to state agencies and law enforcement as required by statutes and mandated reporting requirements. Qualified agency staff was available if any participant experienced undue stress before, during, or after the interview.

The benefits of the study for each participant depended on their personal experience, as well as assistance from the contributing organization; each respondent did receive a $10 gift card to one of a variety of local retailers. Members agreeing to share their experiences about the topic under review were further provided an explicit declaration of the privacy of their replies. Transcribed data remains on a password-protected device. Transcripts of audio-recordings, consent forms, and memoing will remain in a sealed envelope that is stored in the locked cabinet. Five years following the approval of the dissertation, transcripts and consent forms will be shredded to maintain participant and agency confidentiality.

Interview questions can be reviewed in Appendix A. My current contact information was provided to participants, and they were informed of their right to notify me at any time regarding issues or concerns with the study. Opportunities to withdraw from the study were available through advice that participation was voluntary; however, participants would not have been compensated for their participation if they chose to remove themselves from the study.

## Ethical Assurances and Confidentiality

Approval for this research was provided by the Walden University IRB, and after it was provided, the agency provided required consents and agreements for the research to be conducted. No fees were required to gain entry to the proposed agency or to conduct exploration.

After approval from IRB and the selected agency to conduct this study, I developed familiarity with the schedules of persons to be interviewed and made efforts to avoid disruption in services or operations. I understood the agency’s requirements regarding regulations and procedures for the protection of the population served, and a letter of request that remains on file was provided to the company.

Information usage took into account ethics and codes of practices for the agency and population served, including considerations regarding the vulnerability of the population. Besides the continued anonymity of the company and persons served, participants were not asked to specify identifying information outside of the consent forms.

The confidentiality of research data was maintained via the retention of interview transcripts, the original proposal, and codebooks in a locked file cabinet during transcription, where it will remain for approximately five years following the approval of the dissertation. It will remain protected from damage and tampering, loss or theft, with only key accessible to me.

Electronic data is maintained on password-protected external hard drive limited to administrative rights for access. The password will be changed quarterly. Computer-based information regarding human subjects has been identified. Upon the decision to terminate storage of data, deletion of computer based responses will be confirmed and documented by me.

In the event participant(s) required a personal assistant to aid in verbal expression, each assistant would have been asked to sign a participation form guaranteeing their agreement to ensure confidentiality of the interviews they provided assistance with.

## Methodological Assumptions, Limitations, and Delimitations

This research assumed that, given the historical complexities of systems and services afforded to individuals with ID/DD, barriers would persist between system-centered and person-centered methods. It was also assumed that participants would answer truthfully when provided anonymity, confidentiality, and the opportunity to leave the study at any time. The questions asked were considered to be easily understood even when modified, and the sampling was representative of the population for which inferences were made.

The research about individuals with ID/DD in California is limited by a potential lack of applicability to other geographic regions or other professions. The themes identified in this study could theoretically be generalized to (a) individuals in California; (b) individuals funded by any one of the 21 California Regional Centers, and (c) individuals who receive services through an adult program designed for individuals with intellectual disability.

A further limitation of the study involved the notion of information obtained as contingent on the conditions at that time in that setting, as well as the respondent's ability to comprehend the line of questioning presented to them. The individuals who participated in the study had a range of intellectual ability, with some participants diagnosed with intellectual disability and all participants having an IQ at least one standard deviation below the mean. Due to this, receptive and expressive language may have been impacted, causing negative implications for responses provided.

Delimiting factors in this study included the research questions, variables of interest, theoretical perspectives that were adopted, and the community chosen to explore. The question itself was also delimiting as it implied other related problems that could have been selected. Other delimitations included the geographic region covered in the study, the profession, and the agency involved.

## Summary

Chapter 3 included discussion of the chosen research methodological analysis, instrumentation, and the selection of the participants. In addition, data collection processes, limitations and delimitations, and assumptions were reviewed. A rationale for the use of qualitative phenomenological research was presented. Detailed explanations for the sample of participants were provided, and included a description of the survey instrument. Interview protocols were presented and included a brief discussion of ethical considerations, data analysis and trustworthiness. Chapter 4 will present data coding processes related to theme development and connect the results to the research questions.

# Chapter 4: Results

## Introduction

The purpose of this phenomenological study was to explore the manner in which self-determined outcomes are actualized in California's service delivery systems for adults with ID/DD. Disability policy requires recipients to be treated as independent individuals while simultaneously considering them dependent on the delivered services and lacking self-determination.

Previous research and literature did not explain this phenomenon and piqued an interest to examine the perspective of service members. By studying the supporting structures of how adults with ID/DD experience and understand the service system, the research discovered the value participants placed on outcomes within the service delivery system. A qualitative framework was used to design this study, while techniques common to phenomenological research influenced data assessment. The results are a culmination of the participants' voices and share an extended perspective into their existence. To study the self-determined experiences of adults with ID/DD, I established my research framework based on three primary questions:

1. What are the perceived barriers to achieving independence through self-determination efforts in systems provided in California?
2. What are the perceived opportunities to achieving independence and self-determination by participating in California programs?

3. What are the perceived ways that service delivery in California can promote efforts to increase self-determined opportunities?

Chapter 4 presents findings that developed gradually from the data collected through interviewing a total sample of eight involved participants selected from a Northern California adult day program. The interview protocol provided rich interpretations of how adults with ID/DD experience self-determinative opportunities. Careful analysis of the interview records allowed for the development of thoughts and patterns to establish the groundwork for later theme identification.

Through transcription of the audio-taped interviews, phenomenological abstraction and units of substance were discovered (Smith, Flowers & Larkin, 2013). Analysis was organized into whole units by noting patterns in the way participants described experiences. Agglomeration of the meanings validated the formation of themes (Smith, Flowers & Larkin, 2013).

Of the emergent themes, seven distinguished attributes developed. These characteristics are concepts associated with (a) community, (b) supports, (c) family, (d) advocacy, (e) friendships, (f) goals, and (g) self-determination. The selections of keywords were interrelated. Through further review of transcripts, characteristics were narrowed further to the following three themes: (a) community, (b) family, and (c) self-determination.

## Data Collection

The results of this phenomenological study developed through data collected from eight face-to-face semi-structured interviews with individuals with ID/DD, currently enrolled and participating in a designated California adult day program.

An integral part of this strategy included meeting with participants who: (a) voluntarily self-selected, (b) ranged in age between 22-65, (c) were enrolled in the organization as a recipient of services at the time of the interviews being conducted (d) have a medical diagnosis qualified of ID/DD, (e) were not self-identified as experiencing acute emotional or medical distress, (f) identified as either gender, (g) identified as being in satisfactory standing with the agency, (h) identified verbal as the primary mode of communication, and (i) identified as having the spoken language of English. The sampling proved to be a blend of both demographics and participant experience.

Phenomenological inquiry gave me the opportunity to explore and gather understanding from the experiences of individuals with ID/DD in order to identify perceived barriers to achieving positive life outcomes. This research method further allowed for me to understand how the program services and support systems have helped improve self-determination, and to recognize how the practical processes have developed the experience and understanding of self-determination. The overarching exploration was predicated on the universality of the desire for inclusion in decisions and choices impacting life quality for adults with ID/DD.

I used an interview protocol consisting of 14 interview questions (see Appendix A). In-depth interviews provided feedback on all aspects of program inputs, activities, outputs, outcomes, and impacts. These interviews assisted in understanding the views of the participants and how the program was perceived to meet self-determination needs. Interview data were then analyzed to determine themes.

Participants could speak to their experiences as recipients of services in the California disability service system. The following descriptions are intended to uncover the essence of their stories. Participants met the criteria for participation in this study and are listed below in the order they were interviewed (see Table 1). A brief introduction of each participant follows.

Table 1

Individuals Interviewed

| Respondents (names have been changed) |
|---|
| Dean |
| John |
| Sierra |
| Winston |
| Steve |
| Phillip |
| Andrea |
| Bethany |

**Dean.**

Dean receives services through the host organization. Services are coordinated through this organization from the North Bay Regional Center. Dean says he performs vocational tasks through the day program, specifically in a contract assignment negotiated between the vendor and wine distributors.

He feels his work is meaningful, though he asserts he aspires to keep the “legacy” of his parents alive. Both parents cared for him until their deaths, and both were in a field that “helped” others. He was frequently drawn to the concepts of “rights” and “choices” and believed he possessed an ability to help others identify with these concepts through participation in community outreach activities including Meals on Wheels, the teaching of American Sign Language, and participation on the Area IV Board. The Area IV Board specifically touches upon these interests, as it provides representation and advocacy for individuals with ID/DD and their families.

Dean shared an internalized message that he had learned, that individuals with differences had difficulty because of the community’s lack of understanding and awareness regarding their disabilities. He recalled frequent teasing in his past, but though the general community continues to show reservations, his recent experience was of increased sensitivity and less feeling of being “judged.”

He attributes his parents’ teachings as an integral part of shaping his perceptions of the public.  He is naturally drawn to others who have disabilities or special needs because he wants to be sure there is a universal language, and that in this universality is a commonality where people are heard and understood. He stated ,“It’s important to have universal languages and understand[ing] each other, [is] important.”

While California systems offer numerous services, Dean specifically mentioned the importance of the IPP to help with goals and future planning. He is challenged, however, by turnover in case management that limits his ability to connect with his service coordinator for development of his IPP, which is reviewed infrequently, only every three years. .

Much of Dean's support was identified as being from generic services, including his affiliation with the Church of Jesus Christ, Latter-Day Saints. Dean is in frequent contact with his extended family, which provides support, inspiration, and the skills necessary to find his purpose; however, his physical interaction with his family is limited by geography. Regardless, he stated, "Because [of] my mother and father, between the parents, [they] do everything they can for their son or daughter [to] progress in life.

Dean believes that his parents' actions increased his courage to pursue his dreams of helping others. He claimed a greater reliance on his family than on social services, indicating, "It's resources that I have, but it's family that helps."

He recalled that he receives services and supports through a coordinated effort funded by the regional center, but that "They have to deal with things differently; they do help. I'm very thankful because when they developed a lot of support systems that people have, younger or older depending [on] what they have."

As Dean referred to supports, his description suggested that since systems have changed, the person receiving the services has more say in their provision. While some service providers are used to the standard notion of caring for an individual, they now have to be willing to do things in a manner the recipient suggests or agrees to.

#### John.

John receives services through the host organization. Services are coordinated and funded by the regional center. Initially, John had some difficulty identifying services received. When discussing his IPP, he recalled, “Yeah, it’s to help you with your future, what you want to do with your life, to give visit, housing or help you with goals and your job or whatever.”

John indicated that he has done collating, filing, and office work.

> Well, I used to work at the regional center. So I was like an office assistant up there. I did a lot of, I got a lot of directions off the Internet and a lot of the CPC’s up there, they would email me and ask me for map directions.

Ultimately, he aspires to make more money and eventually to obtain a “better” job, utilizing skills learned at the host agency. Where systems of services and supports are concerned, he believes the regional center is the primary advocate for his needs. If he were to choose to do something differently at the program, he would notify either the facility supervisor or his regional center case manager. He recalls the manner in which services and supports have changed over time:

> You can get a lot more things and especially with the wheelchairs that I’m getting because I got my first lightweight when I was 15, and we didn’t know this but I go through the wheelchair place in Fairfield, and you can get it through Kaiser who pays the MediCal, but I always have gotten a lightweight chair because when I was growing up I had one of those that were heavy, it weighed like 50 points [pounds], so it helped.
>
> He added, “supports and services… help you, I would say, to help use, someone who’s disabled like me, help you with certain things like a

> wheelchair, or maybe like transportation things, staff, and if you can't feed yourself, they help you with that.

Where work is concerned, he said, "I am kind of, I am kind of looking, you know hopefully something will get better or whatever. So I'm like waiting."

However, his primary attention is focused on his relationship with Kingdom Hall as a Jehovah's Witness. Each Saturday and Monday, he and his mother go to the Kingdom Hall for religious meetings, and both frequently travel to San Francisco for Bible conventions.

He also communicates with his mother about the quality of services funded by the regional center and indicates his mother prompts him to ask his case manager many questions.

Overall, most of his time is spent with his mother. His sisters frequently visit, and he banters with them by asking them to assist him in making purchases and doing errands. He feels his greatest supporters are within his family, and remains cognizant that receiving support from the public requires a bit more effort. He said, "I find that when you're real nice to people they'll help you, yeah, when you're real nice, they'll help you or you let them know, 'Can you help me with this?'

#### Sierra.

Sierra is a participant in the host organization and is funded for services from the North Bay Regional Center. At the outset, she disclosed her role at the day program, as well as her employment status. Her focus at the day program included goal-setting; once she had established this, she quickly transitioned to why she enjoys her participation in the program:.

> They give us a place to go, get out the house from 9 to 3 and stuff, I got a lot of friends here. And we go on outings, and we have birthday outings…and stuff like that. And we do cooking, play games…

She credited services and supports including "Dental," Social Security, and MediCal. When asked about employment opportunities, she indicated that her father and aunt assist her in this area. When asked what plans are in place to support her choices and goals, she referred to the regional center representative as the focus person assisting her with finding a place to live. However, visits with her case manager are limited; her next is not expected to occur until her next birthday.

Overall, in her current program, she feels that she is making progress as it pertains to her ability to put more effort into her work. Sierra indicated that the purpose of the IPP process is:

> To talk about our goals and stuff, you know, like what we do here and stuff like that…and they ask us about moving out in the future and stuff like that. They help us like get our own places and stuff.

Sierra felt as though she had a great deal of input in choices she made, as well as how the IPP was developed. Her family was also involved in the process, with her parents attending all meetings with her. However, Sierra shared that even if she doesn't want something to go in a particular direction, if her parents do, then her case manager makes it part of the IPP.

### Winston.

Winston is a participant at the host agency and is funded for services through the North Bay Regional Center. When asked about setting goals, he described his primary interest as having an opportunity to learn English. In terms of the services currently received by the day program, he shared that he likes the vocational work he engages in, but stated a preference for meeting people and participating in art projects.

Winston went on to share that he receives supplemental services outside of the day program for supported living. He referred to himself as "complicated" when attempting to communicate what he does at the program. He believed he was making progress on his goals and would like to learn more:

> Because I'm to learn more, like doing more art, painting, and I'm to learn more art and I'm to learn more to speak English more with my friends. You know, sometimes my friend, he's half-Mexican and half-American. He talks to me in Spanish, and I ask him to repeat it in English and I learn more.

Winston was unable to identify the purpose of an IPP, but was able to indicate goals including increasing his abilities in English and returning to school. Winston's understanding of the changes in services and supports over time was encapsulated in an understanding of increased vocational opportunity, but he nevertheless did not feel as though community response toward him had improved. However, Winston's community integration is limited by a lack of interpretation services available for activities that he could potentially contribute to; he is constrained by the limited abilities of friends to teach him English, as well as the infrequent bilingual staff member to assist.

Winston described his leisure activities at home with clarity and precision, describing spending time with friends, playing PlayStation, watching TV, and "partying."

### Steve.

Steve is a participant in the host organization and is funded for services through the North Bay Regional Center. At the outset of the interview, Steve was very clear that he wants to have every job opportunity available through the day program.

Steve reported feeling "good" about services that he was receiving, and noted the purpose of the supports rendered was to assist him in securing meaningful and significant employment, as well as a home to meet his needs. In regards to vocational pursuits, he specifically mentioned dreaming of a full-time job at the day program, as well as being victorious in all sports through the Special Olympics. Steve further mentioned that the program supports were available to help him in "being happy, not depressed," and to make him a "better person."

Steve, who appeared shy and spoke minimally, shared that he keeps himself occupied with sports and creates his own schedule. He expressed a desire to return to school, but is hampered by a lack of knowledge regarding the financial aid system.

While Steve lives independently, he receives significant support from his grandparents and aunt, who attend all meetings regarding him; he self-identified his grandparents as being his foremost source of support, and feels that they are responsible for helping him to find housing of their social relationship with the landlord.

In order to assist Steve with living independently, the regional center provides funding for additional in-home support services, which he utilizes to assist him with shopping and money management.

**Phillip.**

Phillip is a participant at the host agency and receives funding from the North Bay Regional Center for services rendered by the day program. Although he receives coordinated services from the regional center, he indicated that he did not currently know his service provider due to frequent changes.

Philip was very interested in the interview process and was eager to discuss his goals, dreams, and activities that he has engaged in. A Stevie Wonder fan, Philip has successfully coordinated the purchasing of tickets to see him and other musical acts in concert, as well as to meet him backstage. He received support in this endeavor from a staff member, with whom he split costs for tickets, souvenirs, and transportation.

Philip regards the day program services as being positive, indicating his primary activities as artwork and contract work and his greatest pleasure as the friendships made. However, beyond the day program, Philip declines to reach out for additional supports despite being qualified.

Philip proudly reminisced about previous jobs, noting that despite his physical limitations, he pushed himself to be as independent as possible while performing duties.

Generally, Phillip presented with a positive outlook on his experience, which he attributed to the pride he takes in his family, including his siblings, children and grandchildren, and his mother:

> I have cerebral palsy, I was born with it and, um, I, uh, you know, she was amazed, she'd say, 'Boy, I'm so proud of you that you're in your own apartment, paying your bills, you're buying your groceries, you're buying your clothes, I'm so proud of you.'

Philip also maintained strong faith in religion, asserting that plans and outcomes rest in 'what God works out' for him. With that, he reportedly continues each day striving to do his best, knowing with satisfaction that he has achieved independent living.

In regards to vocational pursuits, Philip directs employee meetings with his peers where they collaboratively discuss issues or concerns that require attention and are then brought to the attention of the day program. His high expectations of himself seemed to have transferred to his peers, whom he expects to be committed to making changes:

> I'm the one trying to change, you know, you got to, you just can't sit there and say nothing you know, you got rights, and you need to use your rights. You know, because if you don't, ain't nothing gonna change. You know, you gotta be positive and in the choices that you make, you know? You can't be negative or nothing's gonna change.

Philip asserted that his biggest supporters include his family, the regional center, and his friends. He indicated that he is friendly and outgoing, making jokes to initiate interactions. This may be related to a recollection of time he was alone because of his visible disability. Sitting with his crutches on the lawn, he would watch his peers play. He shared:

> People that don’t have a disability and one’s that do, they don’t know what we go through day by day…you know, because your day may be a little bit different from my day… and they might think that we’re slow because we have a disability, no it isn’t our fault that we have this, you know…it’s just like, a gift from God…he was the one that made us, he was the one that [that] did what he needed to do you know, and I’m not shame for the disability that I have.

**Andrea.**

Andrea is a participant of the host agency and is funded through the North Bay Regional Center for Day Program services. While friendly and open, she appeared to have difficulty articulating her answers, as well as fully comprehending questions asked of her.

Andrea’s knowledge of advocacy services was limited to “receiving MediCal,” and she indicated that her choice-making is shown via her decision to go to the gym.

In regards to goals, Andrea’s knowledge of her progress was limited to them “telling her,” when she checks in with them. Her own interests included working and making money; she recalled asking for increased hours, which were granted.

Andrea appeared to have significant social support, speaking with ease and clarity about her relationship with her boyfriend and the support she receives from her family, who regularly attend meetings relating to her and express their satisfaction with her performance and progress at the day program.

**Bethany.**

Bethany is a participant in the host program and is funded through the regional center to receive day program services and supports. Bethany performs multiple contract jobs through the day program and is well-versed in the steps required to complete tasks.

Bethany was unable to identify her case manager at the regional center due to frequent changes, but remained unconcerned because she “doesn’t really need anything.” Bethany understands the regional center provides a number of coordinated services, but gains the majority of her support from generic resources. She receives primary support from her mother and grandmother, from whom she excitedly shared that she had gained many skills from and was aware of their pride in her.

Bethany self-identified as “antisocial,” and called herself “weird,” but indicated that she had learned to increase her social opportunities and make sufficient eye-contact while engaging in leisure activities such as going to the library and thrift stores, as well as creating craft projects.

Bethany prioritized her wants and needs confidently, making lists of pros and cons and regulating her tendency to be impulsive. She felt that her independence was at least partially prompted by being raised by “two smart women,” and that attending the day program had been an “eye-opener” in allowing her to intermingle with “different clients or supervisors.” In regards to the IPP process, Bethany stated:

> It’s to see if we’ve made progress or anything more that they can do to benefit our needs or wants here…I haven’t made any new goals because I’ve fulfilled my goals.

When asked about the frequency of meeting to discuss her goals, she indicated:

> Mine should be coming up pretty soon…normally, it happens right around the birthday, and they have it every 3-4 years roughly.

Bethany enjoys learning and gaining "real-world" knowledge, from peers and supervisors alike. She identified resources made available to her as the day program, SSI, and Section 8 housing assistance. She has been in various workability programs and through this experienced some challenges related to community treatment:

> Some places were more challenging than others, and other people were more, I guess, closed off, I guess to the idea of having a special needs person come in and then other people were warm and welcoming so it was also real eye- opening at ages 16-17.

When asked how services and supports have changed over time, Bethany stated that "I think people want change, but I also don't think they want change." When asked how the system can change, she explained:

> I think they just need to give people with disabilities chances, like really. To me, they're as normal as you or I…some people may be a little slower, and some people may not catch on as quickly so they may need more time or patience, but some people are great workers, and they can catch on like that but they may not have the social skills, they may lack the social skills, so they don't know how to communicate.

Bethany supported this explanation by sharing her experience working in a nail salon as part of her vocational training; there, she experienced confusion between the actions of her employer and the need to perform assigned tasks.

While Bethany stated that she was not currently working on IPP goals, she noted that she continues to dream of starting a book club. In the spirit of inclusion, she planned to have audio versions of books available for individuals who were unable to read. Inclusion, and making sure no one is “left out,” is important to Bethany, who described:

> A lot of people that I come across only see what they want to see and they don’t want to make changes or connections or go outside their bubble…, which in my opinion is sad.

When asked to clarify, she went on to say,

> They only want to see the normal, like how things used to be, they don’t want to face reality…I’ve noticed that a lot of people without disabilities don’t want to help…community is just a tricky thing in general.

Bethany was very clear with her assertion that developing meaningful relationships requires responsibility on the part of all involved. She further shared her view of the usage of “normal” as being a “safety word,” describing what is seen in magazines, TV shows, and tabloids. However, she regards normalcy as being a matter of “what you make it,” being who you are: “you can be either a loner or you can try and be in between or you can be out there. It doesn’t work for everyone. So those are the ones you have to try and help as much as you can.”

The following data analyses demonstrate the discovery of themes and their corresponding connection to the research questions.

## Data Analysis

### Emerging Themes

Three themes that stood out as meaningful from the participants were their relationship with social system services (later referred to as community), their relationship with their family as their strongest supporters, and their own internal motivation (later referred to as self-determination). These themes were supported by the literature and addressed the key concepts of self-determination as an external and internal motivation supported by theoretical constructs and experiences.

With this concept in mind, self-determination may reflect any of the characteristics or capacities that allow individuals to be involved in processes that involve them. Self-determination is defined in Chapter 1 as a wide range of actions that would allow persons with a disability to better manage their lives and destinies, including choosing and having control over individual activities. Respect and dignity to which all persons are entitled, including choice-making, self-assertion, self-management, autonomy, and independence are the salient features of individual self-determination (Wolfensberger & Nirje, 1972). Self-determination as a theme is consistent with the Social Construct Theory, which posits that individuals develop broad-based subjective value of their experience through varied and multiple meanings. These views tend to be complex in nature. The world of meaning is extensive with historical and cultural connotations; it is through this socially inductive and interactive process that reality is formed. Each of these themes directly relates to the research questions and the opportunities, strengths, and weaknesses in practical application in service delivery.

It seemed that for each individual, the purpose of the IPP was to set goals and plan for the future. However, this often appeared limited to assistance with locating housing and finding a program that offers employment opportunities. Frequently, the idea of having coordinated services through the regional center was noted as being helpful, but due to the frequent changes in case managers, many individuals were unaware of who their worker was or the last time they met.

For this study, analysis of the transcripts included memoing and analysis, identification of emergent patterns, development and interpretation of coded data, an exploration of relationships and themes, organization of comments, clustering, thematic development, and debriefing (Smith, Flowers & Larkin, 2013, p. 79-80).

Each method resulted in a different look at the data. Identifying patterns of themes linked back to reviewed memos, as well as related sentiments and reactions noted during interviews. Super-ordinate coding combined similarities in statements and helped me to think about and formulate the verbiage used for clustering the data. The final first cycle effort of coding enabled me to step back and review in entirety each participant's story to fully capture the essence of the data (Creswell, 2007).

Memoing helped me make sense of the input received and directed focus to the coding process. Various forms of coding were utilized, allowing for viewing of the larger theoretical perspective and examination and identification of patterns and relationships. These codings then led to the assignment of category clusters, succinct representations of data that captured the integrity of participants' experiences and understanding of self-determined outcomes (Groenewald, 2014).

## Data Coding

Through the process of analysis, I used QSR *NVivo* 10 qualitative data analysis software to identify 45 apparently repetitive statements as being significant to the individuals' experiences (see Table 2):

Table 2

*Theme Development*

| Word | Word length | # | Weighted percentage (%) | Similar words |
|---|---|---|---|---|
| Community | 9 | 41 | 11.61 | Communication, community, self-determination |
| Supports | 8 | 33 | 9.35 | Support, supports |
| Family | 6 | 30 | 8.50 | Family |
| Advocacy | 8 | 20 | 5.67 | Advocacy |
| Friendships | 11 | 20 | 5.67 | Friendships, self-determination |
| Goals | 5 | 18 | 5.10 | Goals, self-determination |
| Religion | 8 | 18 | 5.10 | Religion |
| IPP | 3 | 16 | 4.53 | IPP |
| Services | 8 | 16 | 4.53 | Services |
| Helping | 7 | 14 | 3.97 | Helping, self-determination |
| Resources | 9 | 14 | 3.97 | Resources |
| Housing | 7 | 12 | 3.40 | Housing |
| Learning | 8 | 12 | 3.40 | Learning, self-determination |
| Work | 4 | 10 | 2.83 | Work |
| Loss | 4 | 6 | 1.70 | Loss |
| Relationships | 13 | 6 | 1.70 | Relationships, self-determination |
| Choices | 7 | 4 | 1.13 | Choices, self- |

| | | | | |
|---|---|---|---|---|
| | | | | determination |
| CPC | 3 | 4 | 1.13 | CPC |
| Important | 9 | 4 | 1.13 | Important |
| Role | 4 | 4 | 1.13 | Role |
| Safety | 6 | 4 | 1.13 | Safety |
| Timeliness | 10 | 4 | 1.13 | Timeliness |
| Transition | 10 | 4 | 1.13 | Transition |
| Adaptation | 10 | 2 | 0.57 | Adaptation |
| Changes | 7 | 2 | 0.57 | Changes |
| Citizenship | 11 | 2 | 0.57 | Citizenship |
| Communication | 12 | 2 | 0.57 | Communication, self-determination |
| Environment | 11 | 2 | 0.57 | Environment |
| Equipment | 9 | 2 | 0.57 | Equipment |
| Health | 6 | 2 | 0.57 | Health |
| Helplessness | 12 | 2 | 0.57 | Helplessness |
| Independence | 12 | 2 | 0.57 | Independence |
| Interests | 9 | 2 | 0.57 | Interests, self-determination |
| Job | 3 | 2 | 0.57 | Job |
| Limitations | 11 | 2 | 0.57 | Limitations |
| Money | 5 | 2 | 0.57 | Money |
| Progress | 8 | 2 | 0.57 | Progress |
| Rights | 6 | 2 | 0.57 | Rights |
| Skills | 6 | 2 | 0.57 | Skills |
| Social | 6 | 2 | 0.57 | Social |
| Staff | 5 | 2 | 0.57 | Staff |
| Communication | 12 | 1 | 0.28 | Communication, self-determination |
| Scheduling | 10 | 1 | 0.28 | Scheduling |
| Scheduling, supports | 18 | 1 | 0.28 | Scheduling supports |

The initial groupings of meaning were reviewed through the context of the participants' complete response to each research question. This review indicated that a number of codes could be integrated under consistent concepts they represented, thereby supporting emerging themes. For example, "community" could convey elements of communication, perception, outcomes, and resources. Self-determination had elements of what emotionally moved the person, whether through an organization or self-awareness.

Using QSR *NVivo* 10 qualitative data analysis software, I placed the emerging themes into a query to determine word frequency, visually identifying the weight of repeated terms.

These groupings were then organized and negotiated into 11 coded clusters: Community, Supports, Family, Advocacy, Friendships, Goals, Self-determination, IPP, Services, Helping, and Resources. Continuing to use QSR *NVivo* 10 qualitative analysis software, I placed further refined coded data into a word frequency spreadsheet (see Table 3) to compare handwritten findings and transcript assessment, ensuring internal accuracy:

Table 3

*Clustered Response Frequencies*

| Word | Word length | Count | Weighted percentage (%) | Similar words |
|---|---|---|---|---|
| Community | 9 | 41 | 11.61 | Communication, community |
| Supports | 8 | 33 | 9.35 | Support, supports |
| Family | 6 | 30 | 8.50 | Family |
| Advocacy | 8 | 20 | 5.67 | Advocacy |
| Friendships | 11 | 20 | 5.67 | Friendships |
| Goals | 5 | 18 | 5.10 | Goals |
| Self-determination | 8 | 18 | 5.10 | Self-determination |
| IPP | 3 | 16 | 4.53 | IPP |
| Services | 8 | 16 | 4.53 | Services |
| Helping | 7 | 14 | 3.97 | Helping |
| Resources | 9 | 14 | 3.97 | Resources |

As suggested previously, the data was further refined through numerous first- and second-cycle coding efforts. The developing code clusters continued to change as data was refined through differing strategic lenses. The primary 11 coded clusters were further negotiated into seven data clusters (see Table 4):

Table 4

Clustered and Negotiated Response Frequencies

| Word | Word length | Count | Weighted percentage (%) | Similar words |
|---|---|---|---|---|
| Community | 9 | 41 | 11.61 | Communication, community |
| Supports | 8 | 33 | 9.35 | Support, supports |
| Family | 6 | 30 | 8.50 | Family |
| Advocacy | 8 | 20 | 5.67 | Advocacy |
| Friendships | 11 | 20 | 5.67 | Friendships |
| Goals | 5 | 18 | 5.10 | Goals |
| Self-determination | 8 | 18 | 5.10 | Self-determination |

Each data cluster represented a narrowing of concepts that frequently presented themselves in text. Those include Community, Supports, Family, Advocacy, Friendships, Goals and Self-determination. While the larger concepts were important, the outlier concepts also stood out. It became apparent through data reduction that the outliers often the most significant to the participants. Ultimately, analysis led to the emergence of three core themes describing the phenomenon of interest.

The three themes (see Table 5) included: Community (as it pertains to the transitional social systems and services the individual receives); Family (as it pertains to the individual’s principal social system) and; self-determination (as it pertains to the individual’s desire to navigate through social systems and services).

Table 5

*Main Themes*

| Word | Length | Count | Weighted percentage (%) | Similar words |
|---|---|---|---|---|
| Community | 9 | 41 | 11.61 | Communication, community |
| Family | 6 | 30 | 8.50 | Family |
| Self-determination | 8 | 18 | 5.10 | Self-determination |

The following discussion is designed to clarify and support the findings of this study. Direct quotes from interview transcripts are offered to best represent the experiences of respondents and to highlight how they experience and understand the phenomenon.

**Theme: Community**

The first theme, community, encompasses the significance participants place on the transitional social systems and services they received. The essence of this theme relates to how participants experience autonomy in their daily activities. Values are placed on attributes associated with normalization.

The consensus in the discussion of supports and services was consistently deflected away from the day program and back to external resources by the participants. Attention to the regional center (coordinated services) and generic resources (community-based services available to the general public) appeared to help the participants navigate toward goals and dreams. According to Bethany:

> I think it's a number. I think if, I think Regional has a big foothold and then like I said, we didn't know about SSI until I was about 4 and my doctor told us about it and got us on that so it helped us so I mean there's a lot of things where you can go and look it up. You could go to the local library and look it up on the web now or look it up in books if you need it so.

Consistent throughout were resources such as housing, housing assistance, social security and MediCal, which are beyond the scope of both the day program and the regional center. Participants were clear this is not a focus of their program, but they were supported in locating and identifying those resources through a variety of mannerisms. Commentary shared by Dean suggests that a connection with others increases potential belonging; whether advantageous or not, belonging allows opportunities to collaborate and contribute to the community:

> For people to be heard. It depends on what their choices are, what they are going to be, what their rights and choices…come from different families…to understand their language.

This focus is evident in the movement toward finding one's niche within a culture. All individuals interviewed conveyed that their disabilities are not a significant part of daily life, but rather are inherent to their lifestyle. Phillip shares:

> They might think that we're slow because we have a disability, no it isn't our fault that we have this…but I mainly because of the way I am and the way things go for me, my disability doesn't bother me at all, you know, it

> don’t. You know, I jump on my scooter after I leave here, and I go ridin’ I go ridin around Napa…and do what I need to do and watch me some movies and cook me something to eat.

For Bethany, the service system evolved based on the opportunities she has been presented:

> At the time when I was getting ready to graduate high school and going to a transition program, they had a lot of people like me, say 5-6 years ago, they didn’t have a lot…the good thing is you have places like Wal-Mart and other you know stores are trying to hire people with disabilities to give them a chance as well, so…that’s always a good thing as well.

Participants demonstrated several instances of determination and interest to succeed, responding that their disabilities have shaped how they manage interactions. For Phillip, much motivation came from a variety of sources:

> I’m the one trying to change, you know, you got to, you just can’t sit there and say nothing you know, you got rights and you need to use your rights you know, because if you don’t ain’t nothing gonna change. You know, you gotta be positive and in the choices that you make, you know? You can’t be negative or nothing’s gonna change.

This focus on self-initiated change was evident in the descriptions of the participants’ predispositions and upbringing, partly from interactions and experiences with the public and encountered through vocational training, and partly because they each drew from someone who believed in their potential.

Having opportunities to make choices in everyday living was evidenced by affiliation with coordinated services, and identification of ways in which experience can be transformed into strength. John describes the coordinated services he receives as:

> It's to help you with your future, what you want to do with your life, to give you housing or help you with goals and your job.

Bethany describes services as helpful:

> If there are people looking to move or if they're looking to transition, they're great…they look into what you are getting involved in you know what the deal is, so it's good to have a support system and connections as well.

The participants reported that they have gained significant confidence from the success attained through vocational pursuits. Each interview revealed a theme of independence in daily living and all members demonstrated positive esteem in terms of their abilities, what they can accomplish, will accomplish, or have accomplished.

On a personal level, Bethany revealed her progress is evidenced by her increased sociability:

> I used to be antisocial, I really didn't talk to people, so my goals were to try to get me to go on outings, cause' I didn't do a lot…we go on a lot of outings and I hang with my friends that I've made and I'm very social now. So, I can actually look people in the eye which I couldn't do before.

All the participants identified critical incidents that have helped them; this study clearly delineates the persisting effects in all domains of adult experiences. If those with disabilities are not demonstrating the kind of adaptive behavior desired by the public at large, the major part of the responsibility belongs to the public. The characteristic response of society to the existence of those with disabilities is to reject them.

Dean calls for a universal language; John seeks wages that promote gainful living; Sierra would like opportunities for socializing; Winston wants to learn to speak English better and to return to school; Steve desires increased work opportunities and to be a champion in sports; Phillip wants his home, and recognition for success; Andrea wishes to work more hours; and Bethany wants opportunities to continue to learn and to gain knowledge, and for people to be given a chance.

Therefore, it might be accurate to say that the adaptive behavior of the community and its inability to allocate its resources to those with disabilities does not reflect inherent inferiority of the disabled.

For Winston, ongoing learning and belonging to his community is important to him:

> How can I get more information to go to school to learn more English and when I go to school, it’s free? Or I need to pay?

Bethany shared in the sentiment:

> Learning is a big one, and knowledge. I think without those just in general, you can’t succeed.

According to John, his work history includes collating, filing and office tasks and subsequently:

> I'd like to make a little more money than eight dollars, nine dollars and hour…like I say; eventually I want to get a better job with all the skills that I'm learning.

The relationship between intellectual capability or functioning and psychological processes and development is complicated when referring to cultural variables regarding an individual's abilities or adaptive participation. When the cultural implications are shared widely, there runs a risk of the following experience shared by Phillip:

> I learned it from people that be talking' I be listening' to what they saying and um I would joke with them but, uh, back in the day when I was coming up, it was like "whoa, yeah." I was by myself, I wasn't really, I was by myself, because they see my disability, I was on crutches and, um, I would just sit on the lawn, stand on the lawn and watch people play.

Illustrating this, Bethany describes encounters experienced in the community through vocational training:

> I don't think that they want people to interrupt their business, I guess. I worked in a nail salon and they were not the nicest people. They pretended to have that air of niceness, but you knew that you weren't wanted there at the same time. So it was like you got mixed signals like they wanted you to do the job at hand but they don't want you asking too many questions.

These individuals displayed remarkable talent at synthesizing and actualizing. . This is particularly important considering diverse cultures, experiences, motivations and personality. Where services and supports are concerned, Dean articulated:

> It permits changes for people to make their own changes for themselves and helps people assist them with rights, choices, advocacy they would have for themselves or their families and providers that help them.

The essence of this theme relates to how participants experience everyday activities that are considered inclusive and support life quality. The second theme, family**,** will now demonstrate what members believed was the most significant and necessary characteristics to experiencing autonomy.

**Theme: Family**

Family describes participants' chief social systems for navigating toward self-determination. Parents or guardians were their children's advocates for each developmental and social task and presented relatively consistently in each transcript.

The role of the family works in conjunction with other variables to promote success in daily routines, personal lives, and ultimately identity development. This is illustrated in the experience of Bethany:

> My mom and my grandma give me a lot of support…they support me in whatever I decide, say if I don't, if I didn't want to work here anymore, they'd probably…so "okay, why don't you want to work there anymore? Are you unhappy? What's going on?" They always take a key interest in what I do and where I go which is great but they don't hold me back which is another great thing, so…"

ID/DD encompasses lifelong conditions that have assorted manifestations during the adult years. This can pose a challenge to the adult with ID/DD, particularly as key members of the family increase in age and decline in functioning. In the event this primary support is no longer available, individuals must rely on extended family. According to Dean:

> Well, I'll tell ya, they live far away. My mother's family live in Illinois and my father's family live in Oregon, so it's not easy when pulled apart from each other.

Vocational and societal concerns assume greater importance in adulthood. The supports shift to the efficiency of services. John notes:

> Mostly my mom or sister will be like, "Well, isn't there services you can do?"
>
> I'm the only one that's disabled, I have four sisters so they all live in their own houses and stuff, but, yeah, they are always asking, "Well can't you do this?"

The distinction between the effect of a person's particular disability and the daily impact of specific perceptual and cognitive deficits that are comorbid with it allowed this study to discover needs existing beyond the developmental stages. When families provide an encouraging milieu, they are facilitating adult adjustment that promotes the greatest likelihood of constructing self-confidence, overcoming challenges, and encouraging determination. Family involvement in later years of the participant's life is essential to long-term planning and satisfaction.

Each interview revealed a theme of self-determination in daily living, and all members demonstrated optimistic self-regard in terms of their ability; what they can or will do and accomplish. Involvement of family may be in the form of extended family or immediate, as in the description provided by Phillip:

> Well, my son…he's concerned about his dad's situation, you know, we talked and um, I'm kind of quiet about things that goin' on with me you know, I'll talk to him sometimes about it, sometimes I won't say anything. …I'm striving to do my best, I'm on my own and doing what I need to do but I'm glad he's concerned about his dad and understands you know, where I'm going and how I've been and how I'm doing it you know.

The viewpoints offered delineate the requirement of providing suitable and individualized services as a means for realizing a fulfilling adulthood.

The fundamental nature of this theme depicts how participants comprehend and navigate their experience. Participants distinguished their families as particularly important sources in their development, as well as in their comfort level in independently accessing resources. Bethany shared that her mother and grandmother are responsible for her increased independence:

> I'm very capable of verbalizing what I want and need and all without my mom being here, and I can tell her verbatim what went on at the meeting, which is good as well.

Participants suggest the support received from family is framed by an unbending certainty in their potential. This is further defined by the participants as their family's authentic concern and tendency to inspire their accomplishments. Participants remain motivated to become more engaged, and illustrate an essential connection to their families. Interactions between participants and family members can impact participants' ambitions. Most expressed feeling important, encouraged and inspired to connect to their communities, as a result.

Dean described his parents as supportive and encouraging. This experience has helped him to navigate systems and services as he ages:

> My mother and father, between the parents, do everything they can for their son or daughter progress in life. It helps with mine health as I decline in old age now, which is not easy to deal with.

These concepts were discussed in the 'community' theme and further implied in the 'family' theme. The third theme, self-determination, reflects characteristics or capacities that involve the individual in all aspects of their life. It describes the individual's desire to navigate through social systems and services.

### Theme: Self-determination

Self-determination describes the involvement of individuals with ID/DD in planning, decision-making, and life quality outcomes. Self-determination in the interpretative sense refers to internal characteristics or capacities that are inclusive and empowering. Helping others, teaching, and having compassion for community were common threads shared by participants, and served as the basis for many decisions each make. Examples involving the impact of helping and empathy are signified through participants indicating value in carrying out traditions that have left an impression on how they instinctively move through experiences. For Dean, helping others with their needs is important and for him, church and his parents' "helper work" shaped him:

> I had a friend that had Alzheimer's dementia and it's not an easy thing, but I'm helping him and his sister…it's a way to take care of people needs and that's more important.

John continues to want to promote fellowship through attendance at conventions and through Bible based talks.

Phillip facilitates employee meetings at his day program, indicating the importance and benefit of contributing to and advocating for change.

Bethany shared that she wants to lead groups that are diverse, collaborative and adapted to the needs of its members.

Challenges to self-determination occurred early in the lives of several respondents, ranging from ongoing teasing about visible disabilities, to being excluded from activities by peers, to having employers that were impatient with their inability to grasp concepts quickly.

Where the collective order of society is concerned, identity provides for the possibility of self-understanding and is synthesized into social transactions. However, determining the needed behavior for acceptance is challenging when met with groups that are inconsistent in what behavior is appropriate from the person deemed to be different.

Winston seeks opportunities to develop English as a second language so that he may communicate with his peers, and wants to continue to learn his "baby goals." Steve describes that outcomes acquired through goal development are to "make him a better person." John indicated that he will avoid conflict by 'doing what is asked and not asking questions.' Phillip succinctly stated,

> Well I think people that don't have a disability and ones that do, they don't know what we go through day by day… your day may be a little different from my day, you know?

A common thread suggested that coordinated services are in place, but the person either has to wait to meet with their service coordinator or doesn't know who it is because of caseload rotations and high turnover. When discussing goals, Sierra shared that she would like to live independently in the future, but has not shared this with her service coordinator due to infrequent visits. John has sporadic meetings with his service coordinator as well, and shared:

> I am kind of, I am kind of looking, you know, hopefully something will get better or whatever. So I'm like waiting.

The descriptions of experience provided by participants demonstrated that they were able to navigate the world despite adversity and the ambiguity of expectations of them. Removing an individual from the perceptions of who they are and what they do goes beyond freedom and living. As such, experiences are merely transitory. Such standards, which cannot be objectified or reduced, develop as part of the individual's life. The commitment to be themselves leads to the uncritical approval of role playing, acceptance of social roles and a freedom to choose. In her understanding of social roles, Bethany shared:

> They only want to see the normal, like how things used to be, they don't want to face reality, and it's like if you can't face this now, how are you going to face it in a year or two years from now with all the changes that

> go on in everyday life? It's like you can turn on the news and you can see the changes that are happening around you so why can't you as a person accept the changes. I've noticed a lot of people without disabilities don't want to help. I've met some people that do want to help but they don't know how. They don't know what that person has so they don't know how to help them so they try to help them but not help them, so it's just, community is just a tricky thing in general.

It is evident that each participant is not reduced to his or her social position, actions or attitudes, but is represented by their drive and initiative to take part in a continuously transformational process regarding their value instead. Actuality and self-reflection are phenomenon's reflected by their convictions. However, continuing to question one's role and placement in the social structure keeps alive the responsibility for maintaining them. In summary, the evolving themes and their supported foundations are displayed in *Table 6.*

Table 6

*Demonstrations of Themes*

| Emergent theme (s) | Supporting foundations |
|---|---|
| Community | Individuals' transitional services and supports. |
| Family | Individuals' primary social system. |
| Self-determination | Individuals' characteristics, capacities, and contributions to problem solving, decision-making and life quality. |

## Connection to the Research Question

California service systems are charged with leading complex integration opportunities for participants who are the central beneficiaries of community-based adult day facilities. People with ID/DD and systems should be, therefore, key groups within the community. Investigating the phenomenon relating to how individuals experience and understand autonomy is at the core of this research project. I set out to make meaning of this unexplored void in the scholarly literature. To accomplish this task, I posed three main questions designed to not only serve as a procedural map for the investigation, but also to structurally search for meaning through participants' experiences. The following relates to the findings to the research questions in an effort to describe the essence of phenomenology, weaving in the emergent themes from the study.

### RQ1

The first research question cut to the core of barriers to achieving independence: What are the perceived barriers for achieving independence through self-determination efforts in systems provided in California?

Answering this question was made possible by identifying a sample of involved participants who could demonstrate some connection to the systematic flaws in the delivery of services. I also bracketed out preconceived perceptions to promote accuracy in the emerging representation of the phenomenon. This process helped me to obtain, analyze, and describe data to accurately represent the first-person participant point of view. To this end, the participant voice in the preceding excerpts expressed how individuals experience and understand service delivery and resulting impact. Participants demonstrate community as a critical transition piece in their developmental progress.

### RQ2

The second research question delved into the meaning and impact associated with how participants perceive and experience opportunities for achievement of autonomy: What are the perceived opportunities to achieving independence and self-determination by participating in California programs?

As previously stated, several of the participants described encounters with their community as impactful. Participants viewed coordinated services as influential on their existence as integrated members of their community.

Respondents reflected on influential memories with their families, indicating the interactions left them feeling important and made a difference in their interpretation of their service experiences. Participants described being motivated by their families, and, as a result, have better understanding of how to navigate service systems. Family support was described as being a primary motivator for individuals to access services.

Lasting memories were formed by the participants who received family recognition for their effort and accomplishments. Participants indicate that cherished interactions and experiences with others were uniquely important occurrences. The experience and understanding participants have relating to the service outcomes enhances their connection to the community and, ultimately, the choices they make.

### RQ3

The third research question explored the meaning and impact associated with how participants understood how service delivery can promote independence: What are the perceived ways that service delivery in California can promote efforts to increase self-determined opportunities?

As previously represented, several participants described encounters with their community as impactful, yet further reflected on their thus-far unsatisfied quest to find challenging and inspiring opportunities that support peers and themselves to feel included in all aspects of their lives. Participants described a culmination of insights ranging from experiences encountered as children, within the service system; family supports, inspirational occurrences, and lessons and choices presented in their community.

Self-determination was described as the primary value participants placed on independently navigating through the service delivery system, their community, their role and ultimately through their identity development. Self-determination in the sense of interpretation relates to the instinctive satisfaction of choices made or desired on behalf of the individuals interviewed.

## Evidence of Trustworthiness

### Credibility

This phenomenological research endeavored to analyze a problem that is a shared experience, in order to improve practices and policies. Data were transcribed from individual statements regarding their experience of the phenomenon, gleaned from in-depth interviews with participants. Data was built upon, transcribed, and meaningful statements and themes were extracted to produce a description of the participants' experiences. The engagement with participants, researcher reflexivity, and member-checks enhanced the potential for merging analyses.

## Transferability

To improve transferability, authenticity, and responsibility of this study, a member-checking session immediately followed data collection to process the data experience and address any questions the participant had. Member-checking involved sharing interpretations with the respondent and asking for feedback on those interpretations. This process endeavored to confirm exactness and validity of the data and interpretation.

Individual interviews were crucial to this phenomenological study. To get a clear view of the complex issues, in-depth analysis and understanding of the issues were required, as opposed to a broad approach. This ensured the ability link concepts and provides relatively exhaustive research on the given subject.

## Dependability

To counter distortion over research influence, participants were self-selected. The study allowed for external validity that may have potential to develop policy and procedures. The reliability was high, given the potential for confounding themes.

It is possible to assume the discoveries from these data could be inferred to the similar populations in similar settings. A detailed chronology of research activities and processes, emerging themes and categories, and analytic memos were used during this study. The audit trail and transcripts were shared for review and discussion with a committee chair and will be available to future researchers as needed.

## Confirmability

The core issue represents the situation being researched rather than beliefs, personal theories, or biases. The integrity of findings confirms the adequacy of the data and the analytic processes. In particular, procedures used to accomplish dependability include the use of an audit trail, debriefing protocols, and data memos.

## Summary

In Chapter 4, findings were presented that describe how participants experienced and understood autonomy as a component of the service delivery system within California. Strategic determinations in design and analysis were reiterated, while a narrative of the participants was provided with frequencies of inclusionary representations. Data coding cycles and feedback loops were detailed, and the emergent process utilized for advancing idea clusters into developing themes was explored.

The experiences of the participants led the narrative for supporting the formation of three themes. The three themes that evolved from the data relating to how participants experience and understand autonomy are Community, Family, and Self-determination. Chapter 5 presents an interpretation of the findings, recommendations for further research, and implications for practice.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

This phenomenological study explored how participants experience and understand autonomy in the California disability services system. I was interested in discovering how participants described their interactions within the system, as indicated by the social model, as there is polarity between it and the medical model. This insight offers relevant input for researchers, the Department of Developmental Services, California advocacy agencies, vendor providers, and individuals with ID/DD.

The intent of this research was to augment the body of knowledge surrounding self-determination of individuals with ID/DD. The experiences of eight individuals from a California adult day program were captured through face-to-face semi-structured interviews. These interviews were categorized into 11 new combinations and then further condensed into three developing premises. This section will be a dialogue with the literature and the study results, as well as a discussion of implications for further study and dissemination of results.

## Interpretation of the Findings

In Chapter 2, a foundation of literature was presented to position the study within a framework of existing publications involving individuals with ID/DD. Empirical studies spanning service models, service needs, theories of normalization, self-determination and deviance, the historical underpinnings of pathology, and the evolving trends in current service delivery serve collectively as the lens for supporting my findings. Applicable literature was used to inform the significance of the premises evolving from this research. Previous studies had not investigated how participants experience and recognize self-determination from this perspective.

### Theme: Community

The first theme represented in the study, community, speaks to the way participants experience autonomy through the delivery of coordinated supports. Findings paralleled the research-based assertion that a dual approach remains in the implementation of systems (Fitch, 2002). To move beyond these contradictions of socially constructed problems of a biological status, an alternative discourse is to maintain systems promoting ability. This theme is related to theories of deviance, normalization, and social role valorization as it pertains to perceived barriers to and opportunities for achieving independence in the experiences of participants with ID/DD.

As suggested, self-actualization of participants, as demonstrated by self-determination within the service delivery systems in the community, was at the core of my research project. Many participants in my study attributed their participation and independence to interactions with a variety of sources. Perceptions of disability and environment are redefined under the social model by focusing on rights and responsibilities. However, the social model had demonstrated limitations, as viewed in the experience of participants' development of meaningful relationships.

As illustrated by participants' narratives, many challenges were encountered in their communities. Theoretical perspectives on ID/DD in this study are illustrated by two systems: medical and social. Participants, to varying degrees, remarked about the presence of a number of perceived policy impacts. The literature was in support of the described participant perspectives.

The medical perspective views disability as a condition that can be diagnosed and assessed, with the presence of observable pathology (Carey, 2009). To a degree, this assists with eligibility for funding requirements.

Biological concepts support the medical (or pathological) model definition of ID/DD as chronic impairment, whether anatomical, neurological, or biochemical, each of which represents an essential criterion of the traditional definition of ID/DD. Early definitions attributed “idiocy” to the central brain systems (Seguin, 1866). Psychological concepts introduced intelligence as a means to explain cognitive development, determined by the score obtained on a standardized intelligence test.

Social system perspectives were derived from sociological studies of deviance and labeling influenced by Becker (1963) and Mercer (1973). These views suggested ID/DD is characterized by achieved social statuses and the roles associated with each status. The social perspective focuses on norms, social desirability, and stigma. Consequences associated with labeling the individual are devaluation and segregation of the person. These views are incompatible, and, if considered from the perspective of the participants, it would seem the problem of disability is perhaps about social perceptions and norms rather than individual limitations.

The social model necessitates the provision of effective and meaningful services that are sensitive to individuals with disabilities (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004). Perspectives of participants, along with those gleaned from the literature, demonstrate the importance of education and skill acquisition, particularly where activities of daily living are concerned. Participants acknowledged that a number of sources contribute to life quality, and are not limited to services received within their existing adult day program. The coordinated services offered through the California North Bay Regional Center have been helpful in creating awareness that particular resources are available, including referrals to housing assistance and employment opportunities. However, participants described a sense of limitation with those resources that are actually available, especially where vocational opportunity is concerned.

Services are numerous in California. A brief overview of the literature demonstrated that to be eligible for services, a CDER is prepared by the regional center and used as a management tool for the coordination of services. CDER data determine the quantity of persons diagnosed with ID/DD, as well as specific type of disability. This tool establishes a foundation for staffing and caseload requirements, while identifying individual unmet needs and aggregating statistical reports. The data permit the IDT to assess the status of client capabilities and needs, as well as the conditions impeding their progress. In regard to independence, the CDER is useful for planning purposes and developing strategies and initiatives to promote quality of life.

The CDER is an important tool for the state in implementing requirements of the Lanterman Act (1977). As such, each eligible individual must have an IPP. This plan serves as a written agreement between the person and the regional center, and outlines goals, services, and supports needed to reach objectives. Once support needs are agreed upon, the service coordinator of the respective regional center is responsible for determining the services needed by the individual. When an agency is identified to provide support to the person, the staff is charged with following the directions outlined in the IPP.

Participants in this study indicated their experiences in the Day Program have been positive, because it provides opportunities for socialization, various activities, and work. These concepts discussed by participants touched on requirements established in the IPP. However, flaws were communicated in terms of delays in accessing service coordinators. This was further emphasized by unexpected changes in service coordinators resulting in a lack of awareness of who should be contacted to discuss goals and objectives. Either not knowing the service coordinator or not having frequent contact with a service coordinator negatively impacts oversight of the delivery of services outlined in the IPP.

In addition, not all participants were aware of the degree of support they may request. Self-determination (choice-making) in particular, did not appear to be an indicator within the IPP; but, rather, served as a concept to achieving outcomes. Movements supporting ontological and epistemological positions may continue to be challenged by disabling societal conditions, thereby necessitating both practical and social supports, as well as culturally relevant pursuits. Barriers associated with outdated linguistics in legislation further impede individuals with ID/DD. While some interviewees were explicit about slow progress in the cultural and social context, their experience suggests a larger impairment in the hierarchy of social class. This poses a barrier because it potentially reinforces exclusion within a community (Humphry, 1999).

One approach to encouraging self-determination in individuals diagnosed with ID/DD may be an extensive consciousness-raising campaign. Second, a continuation of identity-supported paths to integrated opportunities with individuals to experience convictions relevant to their journey is essential; however, it is imperative to note the difference between the opportunities for integration being provided with individuals rather than for them. Thirdly, consensus on the meaning of shared humanity and about experiences in roles, insights, and skills will provide necessary cross-collaboration (Wolfensberger, 1995). This process must be multidirectional and multidimensional.

While the social models of services purporting to promote self-determination are quite positive, a challenge remains to perceptions supporting concepts of identity. To combat this, continuing to redistribute resources and preventing dormancy are essential. Becker (1963) suggests perceptions of those who are not relegated full equality of access are neither accurate nor useful; rather, they are based on a set of different rules that are in disagreement about the individual, the situation, and the process of the judgment. The parallels in the findings suggest that service systems can maximize the facilitation of external encounters believed to be significant by participants. Developing positive impressions and encouraging a strengthened sense of belonging will be critical to the extent that choices are guided by the values individuals perceived and determined by their life project.

Earlier works by Sartre (1943) suggested it is through choice-making that value is learned and understood. Free will, therefore, is having the ability to rise above what is perceived to be a ‘determined' nature. It is perhaps suggested then that personal choice involves external care and concern.

Social interaction and social situations generate changes in diverse perceptions. The structure of interactions and perceptions may be impacted by standards established as norms of society, as well as pressures to "fit in" to a shift in the overall social construct (Bell, Eells, & Dodder, 2002). Understanding and changing perceptions in this area requires collaboration with families.

Emphasized by interviewees, trust and empowerment between the service model and the family are essential to effective programs. The voice of the participants repeatedly reflected the importance of having diverse backgrounds, involved families, and professionals seeking a common ground and partnership.

### Theme: Family

A secondary premise surfacing from the research data, family combined participant experiences of their understanding and perceived opportunities to achieve independence. My findings compared to some of the normalization and social role valorization principles that outlined the quality of collaborative partnerships and participant interpersonal relationships (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2008). Evidence in my study confirmed that receiving support of parents to integrate participants into the community and to acquire skills needed to participate was beneficial to respondents in their role as decision-makers. For example, Bethany perceived inconsistencies in the community as an indication of a dual nature of the label applied to her and an opportunity from which to draw upon for future decision-making.

John and Phillip believe their valued roles as members of their family promoted a determination for them to push perceived boundaries of their physical limitations or differences. Participants in the study did not appear to suffer image-impairment from the empowerment gleaned from significant relationships with parents. Consequently, it may be beneficial to alter practices to enhance collaboration with parents within curriculums.

Family collaboration can have an important impact on transitional supports and facilitating long-term decision-making from individuals with ID/DD. When choosing from or associating with concepts society aspires to, it will be beneficial to support social systems that reinforce valuation and acceptance. Participants in my study were able to speak to the function of the program plan in at least a basic manner; however, quality of life was consistently rich with description when referring to relationships between family members or those perceived as family. This suggests the quality of life is, further, a construct that can only be deliberated at an individual and subjective level informed by service users.

### Theme: Self-determination

These concepts lead to the third theme of this study, self-determination. For purposes of this study, self-determination is comprised of ideas emerging from transcripts and data reduction to refer to the experience of participants, and ways they make independent decisions or participate in the collaborative and strategic navigation of social systems and services. This composite of self-determination is a limited concept in the literature. Literature has not explained how these concepts are experienced by individuals with ID/DD, only how they are applied in practice.

Self-determination was described by interviewees as an innate ability to utilize and negotiate behaviors and activities that provide each with a sense of control over their life circumstances, or instigate desire for control over life events. Previous discussion touched on systems and services working for and with adults with ID/DD. This included challenges experienced in perception both from the outside and within the individual. Recommendations for a multidimensional approach were suggested. As a result of this study, distinct systems require further exploration as they pertain to self-determination. These include the external motivations (community and family collaboration) and internal motivations (the expression of one's sense of self-determination) while living with an ID/DD.

When social models were constructed by the community-based system, the focus of functional loss and impairment attempted to shift to external support networks, community, and government resources. However, it is not productive to focus solely on disability, nor medical or social frameworks. Both structures are essential considering the movements from institutional living to community and sheltered-workshops to employment, as well as the development of new communities (Rothman, 2010). A coordinated effort to maintain momentum in the areas of self-determination is required under all frameworks, but cannot neglect the manner in which it is experienced or required from the perspective of the individual with ID/DD.

Beyond the scope of this context, interviewees shared their experiences of lessons learned, communication, and capacity for recognition. This sense of connection and connectedness assisted them with their overall purpose (Sartre, 1943). Increased integration may increase life quality (Cummins & Lau, 2003). It is suggested that perceptions related to deviance are reinforced by observable disabilities, social norms and cultural standards that further impact disadvantage and distress for individuals with ID/DD (Goffman, 1963). Consequently, this may be attributed to lower self-images, rejection of the self, or fulfilling the role assigned to them. People who accept the label of others have a difficult time changing their opinion of the labeled person, even in light of the evidence to the contrary (Becker, 1963).

This suggests that at times, the participants in this study may have seen themselves in their physical form serving as an instrument that ultimately, and fundamentally, endeavors to discover value-based experiences. A program assuming the role of assisting one to actualize self-determined opportunities supports a transcendence beyond mere physicality (that historically may have supported the model of pathology) leading each toward an improved awareness. Through intellect and emotion, general senses of desire, reason, and decision-making can be developed.

It is recommended that reconciliation between the two models moves toward a holistic framework that embraces identity, personality, physical and mental abilities, families, and friends. The nature and perception of disability by those so labeled have tremendous impacts on identity. Transcripts share experiences of interviewees' perception of community attitudes and further encompass the biopsychosocial humanity of the person.

Bethany observed "people without disabilities don't want to help." Phillip observed "people might think that we are slow because we have a disability." It is recommended, therefore, that systems challenge perceptions to ensure they are encompassing perspectives that are inclusive of strengths, empowerment, and advocacy. Self-determination, therefore, calls for the system to embrace a personal and integrated system of services based on values, ethics and moral practice philosophies. These philosophies would be part of the overall understandings connected with caring and compassion.

As the transcripts demonstrate, giving back to the community is important to each of the participants. When presented with opportunities that they find important, they are likely to be motivated to draw from the value of familiar lessons learned. From this perspective, systems can move away from problems of the individual and adversities experienced in the environment and, instead, are grounded from the perspective of strengths, needs, and interests of the individual.

The dual nature of social policy and law are reflected in the literature and the transcripts that delineate experiences of adults with ID/DD. Resources, programs, and benefits are determined and further affect social perceptions associated. Self-determination from the experience of the individual is, therefore, a personal experience, and barriers, opportunities, and strengths in the application of services are contingent on understanding the needs of the individual receiving such services.

## Recommendations for Further Research

This qualitative phenomenological study reflects a perspective of the participants' experience and understanding of self-determination in the service delivery system.

Previous research had not explored this interaction as it pertains to receiving services through an adult day program.

While this research explored the experience of a particular group, other aspects of self-determination are not investigated. Facilitation of self-determination from the service agency to the participant impacts the ever-evolving experience. The construct of self-determination as defined by the agency is a limitation, especially given that many staff may not be familiar with the concept and therefore be limited in their ability to teach the ideology to individuals served. .

Participants in my study were involved clients with a variety of supports fostering self-determinative opportunities. This limits how well the findings apply to the general population of individuals enrolled in the adult day program. Limiting factors are also present in the representation of setting and sample and concept.

This research adds to gaining knowledge of how individuals with ID/DD experience and understand facilitated self-determination through participation in an adult day program in California. The findings are best explained in the context of the eight clients interviewed for this investigation. Transferability can be determined through consideration of the detailed descriptions specific to the participants' setting and situations.

The results of this study offer the foundation to build on as exploration into the concept of self-determination practices. The five areas I suggest for further research consideration are: (a) opportunities embedded in existing relationships and communities to include voluntary interests and personal advocacy; (b) pursuing supported arrangements and commitments that include valued roles in employment, volunteering, housing and recreational and leisure opportunities; (c) exploring concepts related to happiness and functional adaptation of integrated interests and increased opportunity; (d) studying how families serve as an essential communication conduits for service agencies to reach a larger population; and (e) conversely, investigating how service organizations experience and understand self-determination in their application of goals and objectives with participants.

I recommend future studies explore the opportunities that are embedded in existing relationships and communities, to include voluntary interests and personal advocacy. While service systems including adult day programs indicate numerous opportunities to integrate individuals into their communities, participants in my study showed a limited amount of individualized activities. Most reported that activities are pre-planned and scheduled. In fact, participant respondents from my study cited experiences of "doing what is asked" of them. Prospective exploration of this aspect of the phenomenon should be developed.

Of the eight interviews conducted, participants indicated interest supporting this recommendation. Bethany shared that she would like to start a reading club and Phillip shared that he would like to begin an employment advocacy group. For self-determinative opportunities to be successful, it is critical that individuals' interests and personal experiences are considered.

As disability systems continue to integrate the voice of their participants, it will be imperative to align with the diverse perspectives experienced by participants. The disability system by nature and vested authority compels leaders to think, act, connect, and respond sensitively. Discovering how this interaction is experienced and understood by participants would help further this investigation.

I recommend further research pursue supported arrangements and commitments to include valued roles in employment, volunteering, housing, and recreational and leisure opportunities. The involved participant population was intentionally targeted in this study because of increased likelihood that they had experienced some degree of self-determination in their services. While my research findings support both values in and positive impact associated with self-determinant opportunities between the service system and the participant, the uninvolved participant's voice is missing from the equation. Several of the participants spoke directly to their perception that services and supports have an active influence. Participants interviewed in this study described feelings of value after experiencing a self-determined opportunity.

Subsequent investigation should continue exploring the manner in which involved participants discover concepts related to happiness, adaptation, interests, and opportunity. Several of the participants spoke directly regarding desire to experience new endeavors, but felt limited by perceptions of others regarding their disability.

Finally, I recommend further research into the study of how families serve as the key communication conduit for service agencies. Many participants in this study indicated their degree of self-determination was influenced by family members. My research focused on the participant's voice as it investigated their experience.

This is one-half of the phenomenological equation. Collaboration is the center of this study, and, contrary to this research, experiential studies have not investigated the practitioner's perspective of self-determinant opportunities for their participants; future research should take the opportunity to do so. Themes evolving in data from studying self-determination could be compared and contrasted to my study's findings to further develop a framework for comprehending and describing this ever-changing phenomenon.

## Implications for Practice

A portrait of involved participants at an adult day program in California is presented. Participant experience was explained using a foundation of information pertaining to concepts of self-determination. Through the participant’s depictions and evolving stories of their experiences, recommendations for practice are encouraged.

Linking back to the primary development of this research, I speculated relevant implications for researchers, the Department of Developmental Services, California Advocacy agencies, vendor providers, and individuals with ID/DD. The participants communicated their personal experiences that remained the focus of the investigation and supported the experience described and interpreted. The interpretation of their stories serves as the foundation for future exploration.

This study has initiated a scholarly dialogue about the experience of individuals with ID/DD and the California service system. This research offers a preliminary step toward additional query into the subjective experience of such individuals.

California’s service providers are charged with promoting opportunities for inclusion. Participants are constituents of the state, and, according to my study's findings, experience meaningful impact from collaboration and coordinated services. The state can benefit from knowing their effort to coordinate and integrate services for participants are validated by this research. Recognition that members are positively impacted by increased communication standards encourages vendors, advocacy agents, researchers and the service system. This supports service systems investing time and strategy in creating methods that promote increased independence and exploration. The intentionality of shifting vocationally supported systems toward apprenticeships, unsupported employment, and unpaid valued roles may create valuable experiences where participants have ownership over their inclusion.

Shared governance structures in the management of day-to-day experiences can benefit members and the community, and ultimately achieve the mission and vision to create opportunities for self-directed decision-making.

Disability professionals are on the front line assisting participants in their journey. Great effort and extensive resources go into developing programs and services that encourage connectivity to aspects of life that people without disabilities experience. Recognizing that participants experience value from collaboration between their families and the service system enables industry professionals to strategically develop and foster interaction and collaboration with significant contacts in the individual's life. Leaders can help engage participants, organizations, and families in recognizing the importance associated with their circle of supports.

The respondents interviewed expressed appreciation for the lessons they learned developmentally, psychologically, and socially because a stable foundation of trust was established early on. Vendor agencies can help deliver self-determined systems through programming designed to encourage family involvement and communication exchanges that identify the family structure's cultural values. This may assist agencies to better understand the impact of integrated experience as it pertains to social trends and individual decision-making.

Individuals in my study communicated that they wanted independence but functional limitations in the system pose barriers of experience. Where collaboration with the family is concerned, the service system may benefit from supports that provide informal assistance rather than institutional or congregated living to increase reliance on family and friends.

Participants are at the center of the disability services equation. As recipients of the entitlement afforded them by California, individuals with ID/DD are promised opportunities for engaging with their community on important issues. While not all community-based systems demonstrate capacity or interest in interacting, participants should expect to have a voice in shared governance. Participants can advocate individually and collectively that they value opportunities that speak to their drive, determination, and desire. In settings where systems are perceived to offer opportunities for personal and meaningful choices, significant supports should promote engagement. Facilitation and coordination of collective skills between participants and their community may be available through vendor agencies.

The participants in my study expressed that inspiration was derived from connectivity. Locations that increase opportunity for engagement and interaction include participation in inclusive team sports or leagues, special interest groups, or church. Participants should have opportunities to take full advantage of meaningful interactions of their choosing.

## Conclusion

Previous studies had not investigated any connection between participants and self-determinant experiences within an adult day program. As a researcher and practitioner engaged in individualized planning, this defined absence of analysis compelled my interest. To address the void in the scholarly literature, my study explored how participants experience and understand self-determination. Using phenomenological methodology to structure explanatory premises, eight individuals self-identified as being enrolled in an adult day program were interviewed. Participants were selected from a Northern California adult day program. The semi-structured interviews with participants provided rich data.

The findings demonstrated that elements of the program support self-determination; however, ultimately, self-determinant opportunities occur within themselves, through the regional center, or through the family. These elements are neither in alignment nor in collaboration.

Findings further exposed three key themes in the examination of participant experience relating to concepts in support of self-determination: community, family, and self-determination. Participants experiencing self-determination acquired an enduring image of integration and choice-making while understanding the planning process as a balance between their needs and perceptions held by others. Respondents formed impactful memories from childhood and the supports received from their families. These memories became learning opportunities that have assisted them to continue to seek knowledge that not only promotes their happiness, but also helps others to achieve a greater sense of self-determination. Encouraging collaboration, enhancing connectivity with communities and generic resources, and inspiring individual aspirations benefit the person with ID/DD.

This research project has provided me with profound insight into how participants experience and understand self-determination. Interviewees shared valuable perspectives into the phenomenon, which may enhance the self-determination goals of service systems. Their stories demonstrate that meaningful experiences are a holistic process occurring at many levels. Evidence indicates that this is valued by participants and influences the way they perceive opportunities made available to them.

It was recommended that further research endeavor to understand the connectivity between these important groups of stakeholders in the California disability service system. It is also important to consider implications of social reaction, social role valorization, and social construction in the experience of individuals with ID/DD and agencies supporting self-determined opportunities.

Inferences that were developed from this phenomenological study provide expanded insight for me, the Department of Developmental Services, family and advocacy groups; and most importantly, the individual with ID/DD. Recommendations for further research include: (a) opportunities that are embedded in existing relationships and community to include voluntary commonalities and personal advocacy; (b) pursuing supported arrangements and commitments that include valued roles in employment, volunteering, housing and recreational and leisure; (c) exploring concepts related to happiness and functional adaptation of integrated interests and increased opportunity; (d) studying how families serve as an essential communication conduit for service agencies to reach a larger population; and (e) conversely, investigating how service organizations experience and understand self-determination in their application of goals and objectives with participants.

Current service systems in California remain steadfast in maintaining efforts to fully include individuals with ID/DD in their communities. However, efforts to optimize the quality of life and normalization principals are, at times, countered by social consequences. Self-determinant opportunities must have a benefit to the participant and demonstrate choice-making, input and increased community-integrated experiences.

The influence of social skills and skill acquisition are developed between individuals with disabilities and multiple communities. The person’s primary community tends to be noncoercive, with needs respected and interests encouraged; this is fundamental to the development of identity and belonging. Personal relationships are important for life quality and, as often is the case, the presence of these relationships serves to reduce adverse effects. The community provides an alternate setting for social integration and a sense of affiliation. If we wish to facilitate the actualization of self-determined opportunities, we have to increase collaboration with people who have similar life profiles.

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# Appendix A: Interview Questions

1. Describe the advocacy services you receive in terms of employment, housing, medical and dental support, day program, and recreation and leisure to help you meet your needs.
2. Describe how you make choices about your personal needs, wants, likes, and dislikes.
3. What plans are in place that supports your needs, wants, likes, and dislikes? What is the purpose of the Individualized Program Plan? What role did you take in the preparation of this plan?
4. Describe the progress you have made in your goals. Describe your relationships with members of the general public.
5. What is important to you?
6. What resources are available to you (volunteer, internships, work experience, interview support, department of rehabilitation, EDD, college campuses, Community living, housing plans)? Of those resources, which of those have you used? What was the outcome? Is there anything still pending?
7. How do you define supports and services?
8. How have supports and services changed over the years?
9. Describe what you remember about the last interdisciplinary meeting you had. What topics were covered? What was discussed?
10. How involved is your family in the IPP process?
11. What training materials have you used or have been a part of to achieve

individualized services?

12. Tell me about where and with whom you live, your relationships, the way they spend your time (including how you access education, business, and leisure activities)? Alternate: how do you pursue your future goals and decide upon services?

13. Tell me about your IPP. Do you understand it? Yes? No? Specify.

How do your services reflect understanding of and sensitivity to you, your family, and your culture?

14. Tell me about a time when a decision or choice you made resulted in new goals, objectives, and services and supports. Were they included in the IPP and were they received from the regional center or another source?